

# **EAST AFRICAN JOURNAL OF PEACE & HUMAN RIGHTS**

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# **EAST AFRICAN JOURNAL OF PEACE & HUMAN RIGHTS**

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## EDITOR'S INTRODUCTION

Patricia Atim\* & Damalie Naggita-Musoke\*\*

The School of Law under its Disability Law and Rights Project and with support from the Open Society Initiative of East Africa (OSIEA) has embarked on a journey to spearhead the protection and enjoyment of rights by persons with disabilities through the academia. Although Uganda has a legal regime for the protection of persons with disabilities, the actual enjoyment and realisation of their rights remains illusory. While Uganda's Persons with Disabilities Act, 2006 and the Convention on the Rights of Persons with Disabilities which was ratified by Uganda, have played an important role in helping people understand disability rights, the full enjoyment of these rights by persons with disabilities has not been achieved due to factors such as attitudinal and environmental barriers. The continuous perception of persons with disabilities as objects of charity as opposed to rights-holders, hinders the progress of the disability rights movement.

It is in the above context that the School of Law conceived the Disability Law and Rights Project. With the project theme of "Promoting Disability Rights through Legal Education", the School believes that the lens through which disability rights are viewed should be adjusted because the removal of attitudinal and environmental barriers is critical to the realization and enjoyment of disability rights. One way of doing this is through widening the curriculum to include and integrate disability issues and concerns in and within the syllabus. Due to the dearth of appropriate and relevant teaching materials in the area of disability, the Project has encouraged staff to undertake research in the different aspects impacting disability law and rights. This special issue is thus intended for publication of various papers from research on different aspects of disability rights authored by the academic staff at the School. The intended outcome of the papers is that they can be used as a tool for academic research, teaching and advocacy to enhance the protection of the rights of persons with disabilities in Uganda.

Contending that all models of disability are critical in understanding the challenges faced by women with disabilities in their struggle to access and utilise maternal health care, Prof Twinomugisha, in his article *'Maternal health Rights for women with Disabilities in Uganda'*, advocates for the protection of the maternal health rights of women with disabilities in Uganda. He recognizes the fact that women with

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disabilities are not a homogenous group, and notes that they face multiple forms of discrimination because of various variables like poverty, disability and gender. And yet, there exists a progressive international and domestic legal framework that guarantees their rights to life, health, equality and non-discrimination, privacy and freedom from cruel, inhumane and degrading treatment, among others. Despite these legal guarantees, women with disabilities still face discrimination in the enjoyment of maternal health rights. This is attributed to several barriers including physical barriers of infrastructure, unavailability of safe transport to attend health facilities, disability inaccessible medical equipment, communication barriers and negative societal attitudes that view women with disabilities as asexual, hypersexual and lacking control of their bodies. To combat these barriers, Prof. Twinomugisha calls for the need to adopt reasonable accommodation measures as well as break the physical and communication barriers to enhance access to the physical environment, information materials, and effective communication especially in health facilities. He observes that negative attitudes that also affect medical practitioners must not be left unabated, and massive sensitization to fight stigma, discrimination and marginalisation is also crucial. He urges state and non-state actors to embark on disability mainstreaming of all policies and programmes that relate to the maternal health rights of women with disabilities.

Related to Prof Twinomugisha's study, and the need to promote and protect the right to sexual and reproductive health for women with disabilities, Dr Zahara Nampewo, utilising the gender and human rights lens, interrogates the conundrum about the recognition and enjoyment of sexual rights of women with disabilities. In her article '*We have a Right to Love: The Right to Marry and Reproduce for Women with Disabilities in Uganda*', she contends that although various laws exist that recognise the sexual and reproductive rights of women with disabilities just like their non-disabled counterparts, there is glaring evidence of limited enjoyment of sexual rights by women with disabilities. This is attributed to several factors including the negative societal perception, which views women with disabilities as asexual and therefore unable to enjoy their sexual rights to marriage and reproduction. Historically, women with disabilities globally have had limited enjoyment of consensual marriage, often subjected to sterilisation in a bid to curtail the multiplication of disabled genes or birth of persons with disabilities. They also suffer multi forms and layers of discrimination as a result of the intersectionality of various factors like race, gender, class or nature of disability.

On a positive note, her empirical findings reveal that women with disabilities in Uganda take an active part in the community, as well as fewer cases of incest and sterilisation being reported. However, her findings show that there is lack of support from their husbands or partners who often desert them upon conception, thus leaving them to mainly rely on their older children or other family members for the much-

needed support. In addition, the often lower levels of education or unemployment status of women with disabilities leads to limited economic empowerment for them, which constrained their ability to enjoy their sexual rights and general living conditions. They are further disempowered from having the power of choice over sexual partners as well as when to have children due to limited access to family planning services. This is further compounded by the negative attitudes of health workers at health facilities pushing many women with disabilities to seek sexual and reproductive health services from traditional birth attendants or other less skilled providers.

In conclusion, Dr. Nampewo applauds the existing community initiatives and the overt resilience of women with disabilities in exercising their sexual rights amidst the various challenges they face. She advocates for the need to buttress initiatives towards empowering women with disabilities to enable them realise that they are rights-holders and must exercise and enjoy all their inherent rights, including their sexual rights.

Access to information is a fundamental human right and relevant in promoting empowerment, education and one's ability to make an informed decision pertaining to any matter. In the third article titled *'Deepening Access to Published works for Persons who are blind, visually impaired or otherwise print disabled in Uganda'*, Dr. Kakungulu makes a case for Uganda to ratify the Marrakesh Treaty in order to enhance access to print material for the blind, visually impaired and/or otherwise, print disabled in Uganda. He re-echoes the fact that Uganda has a robust legal framework that guarantees the rights of persons with disabilities to access information, to education and affirmative action, among others. In spite of this, persons with disabilities still face challenges in the area of access to published materials. Adopting the human rights model of disability, Dr. Kakungulu argues that it blends in well with the question of access to published works for Uganda's blind, visually impaired or otherwise print disabled since this model of disability conforms to most of the current human rights trends and standards in the global community. By ratifying the already signed Marrakesh treaty, Uganda will be able to take benefit of the copyright exceptions provided by the treaty, dismantle barriers of access to accessible formats and in effect enhance access to published works for Uganda's blind, visually impaired or otherwise print disabled.

Persons with disabilities often face economic marginalisation as a result of lower levels of education, unemployment or inaccessibility of credit facilities needed to engage in economic activity and combat poverty. Yet, disability is a key driver to poverty and poverty too can lead to disability. Ms. Ahumuza, in the fourth article titled *'The Efficacy of Disability Policies in Enabling Access to Employment for Persons with Disabilities in the Private Sector'*, contends that the perceptions of the capitalistic

economy and the dominant medical model of disability have perpetuated discrimination and marginalisation of persons with disabilities at the workplace. This is fuelled by the fact that employers focus on maximising profits and will shy away from employing persons with disabilities who may need additional supports or reasonable accommodations to facilitate their productivity at the workplace. And yet the cost of the supports or reasonable accommodation measures often deter employers from employing persons with disabilities. This situation is made worse by the negative societal stereotypes and prejudices that portray persons with disabilities as unproductive and objects of charity.

Furthermore, the often inaccessible physical environment that is void of universal designs compounds the situation. This deplorable state of affairs prevails amidst progressive international and domestic legal frameworks that guarantee the right to work for all persons, including persons with disabilities, and the call for equal opportunities for marginalised groups. The legal framework also places a duty on all state and non-state actors to respect and promote the rights of all persons, including persons with disabilities. This means that private entities must comply with the law and undertake measures to ensure the realisation of the right to work for persons with disabilities.

Drawing from her empirical findings, Ahumuza advocates for the development and adoption of disability policies at the workplace that are in harmony with the legal trellis and lay clear home grown solutions to the employment and economic empowerment of persons with disabilities. She recommends the passing of the National Action Plan on Human Rights to help propel business entities to adopt a human rights approach to business as well as effective regulation of the private sector to monitor their compliance with the law and availing actual equal opportunities to persons with disabilities.

We hope that these contributions will pave a way for stronger realisation and observance of rights of persons with disabilities in Uganda.

## MATERNAL HEALTH RIGHTS FOR WOMEN WITH DISABILITIES IN UGANDA

Ben K. Twinomugisha\*

### ABSTRACT

*The purpose of this article is two-fold: to examine the normative content of disability rights in maternal health and to interrogate key barriers that women with disabilities may encounter in their quest to access and utilise maternal health care. The article conceptualises maternal health within the broader concept of health and proceeds to locate the meaning of disability in the context of medical, social, human rights and critical studies models. Building on the understanding of maternal health and disability, the article teases out the nature, scope and content of disability rights that are critical for the realisation of maternal health rights. The article advances strategies for tackling barriers that inhibit women with disabilities from accessing and utilising maternal health care.*

### I. INTRODUCTION

Before examining disability rights in maternal health and the barriers women with disabilities face in their struggle to access and utilise maternal health care, it is necessary to commence with a lived experience of Sarah Ngobi as reported in the *New Vision* newspaper:

When Sarah discovered that she was pregnant, she was excited and terrified because she did not know what to expect. She did not know how she was going to carry the pregnancy to term and what would happen at the time of delivery. She was also worried how she would get to the nearest and only health facility, which was two kilometres away, for antenatal care. However, she never missed any antenatal clinic visit as she did not want to endanger her life. She did not want to wallow in self pity. She ‘crawled’ to the health facility for antenatal care. Birth waters had broken, yet there was neither an ambulance nor means of transport to the nearest hospital. The ambulance was several kilometres away. In such a condition, she could not sit on a bodaboda.

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Her sister negotiated for a wheel barrow, which her neighbour provided, and two gentlemen pushed her as her sister carried the bag containing her maternal essentials. As the labor progressed, she prayed to God to enable her reach hospital. She knew that delivering on the roadside would require them to hire a car to cover the remaining distance to hospital yet they did not have the money. She says it took them an hour to get to hospital and luckily the midwives were still on duty. However, the facility neither had a wheel chair nor a stretcher to push her to the labor ward. She was lifted from the wheel barrow to the labor ward. Without sympathy, the midwife told her to get onto the delivery bed, but she could not, as it was too high. The midwife scoffed at her, asking why, with such a kind of disability, she even bothered to become pregnant. On realizing she could not get herself onto the bed and there was no one to lift her, the midwife placed a black plastic bag on the floor and told her to lie on it. A sympathetic nursing sister examined her. She had already dilated. The nursing sister asked her to push. She gave birth on the floor. After that experience, Sarah shunned hospitals and resorted to traditional birth attendants, whom she says are respectful and besides, they live within the community.<sup>1</sup>

The World Health Organisation (WHO) estimates that persons with disabilities (PWDs) constitute 15% of the world's population.<sup>2</sup> Disabilities include visual and hearing impairments, physical disabilities, multiple disabilities, mental and psycho-social disabilities, intellectual disabilities, and albinism.<sup>3</sup> It is estimated that 12.5% of the population in Uganda has at least one form of disability.<sup>4</sup> According to the 2002 Uganda Population and Housing Census, 35.3% of PWDs had loss or limited use of limbs, 23.3% suffered from spinal injuries while 15.1% had hearing difficulties.<sup>5</sup>

PWDs, like other human beings, are entitled to the enjoyment of human rights in general and the right to health in particular. Disability rights are recognised in various human rights instruments, including the Convention on the Rights of Persons

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1. *Disabled, pregnant and scoffed at*, NEW VISION, 1 April 2013.

2. WORLD HEALTH ORGANIZATION (WHO), *DISABILITY AND HEALTH* (2016), available at <http://www.who.int/medicalcentre/factsheets/fs352/en/> (accessed on 24 March 2017).

3. *Id.*

4. UGANDA BUREAU OF STATISTICS (UBOS), *NATIONAL POPULATION AND HOUSING CENSUS 2014* (2016) at 6.

5. *Id.*

with Disabilities (CRPD).<sup>6</sup> The CRPD specifically obliges states parties to respect, protect and fulfill DRs, including the right to health, based on the principles of equality and non-discrimination, effective participation, inclusion in communities, respect for inherent dignity and autonomy.<sup>7</sup> At the national level, the constitution of Uganda,<sup>8</sup> the 2006 Persons with Disabilities Act, National Council for Disability Act, 2003 and Equal Opportunities Commission Act, 2007 also seek to protect disability rights.

The 2009/2010 National Health Policy, 2010 National Health Sector Strategic Plan and the National Policy on Disability all reiterate that the government should ensure that high quality services are available and accessible to all, including vulnerable and marginalised populations such as persons with disabilities. In spite of this recognition, health-related disability rights have not received adequate attention. PWDs have less access to health care services and therefore experience unmet health care needs. They are marginalised and excluded in society; their basic needs and rights are not fulfilled. They are subject to various forms of discrimination and marginalisation due to negative attitudes, norms and practices and lack of awareness of their rights.<sup>9</sup> Challenges to health care include prohibitive costs such as affordability of health services and transportation; limited availability of services; uneven access to buildings especially hospitals and healthcare centres; and inaccessible medical equipment.<sup>10</sup> Studies also indicate a link between poverty and disability.<sup>11</sup>

The CRPD has a specific provision on the rights of women with disabilities,<sup>12</sup> including MHRs which are also recognised in other human rights instruments.<sup>13</sup> Given

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6. Adopted 13 December 2006, A/RES/61/106 Annex 1. Entered into force 3 May 2008. Uganda signed and ratified the CRPD on 30 July 2007 and 25 September 2008 respectively.

7. For an outline of rights and freedoms under the CRPD, see Articles 4-32.

8. Article 35 of the Constitution.

9. S. E. Ahumuza et al, *Challenges in Accessing Sexual and Reproductive Health Services by Persons with Disabilities in Kampala, Uganda*, 11 REPRODUCTIVE HEALTH 59, available at <http://www.journals/plos.org/plosome/article?id=10.1371/journals> (accessed 24 April 2017).

10. WHO, *supra* note 2; T. Kroll et al, *Barriers and Strategies Affecting the Utilisation of Primary Preventive Services for People with Disabilities: A Qualitative Inquiry*, 1494 HEALTH CARE IN THE COMMUNITY (2006) 284-293; S. Wanjiku Ngugi, *The Challenges Women with Disabilities Face in Accessing Reproductive Health Services in Public Health Facilities in Nairobi* (Master of Arts (M.A) Dissertation, University of Nairobi, 2012).

11. M. Palmer, *Disability and Poverty: A Conceptual Review*, 21 JOURNAL OF DISABILITY POLICY STUDIES (2011), at 4.

12. Article 6 CRPD. See also, Committee on the Rights of Persons with Disabilities, General Comment No. 3 (2016), 'Article 6: Women with Disabilities', CRPD/C/GC/13.

13. See for example, article 23 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa. Uganda signed this Charter on 18 December 2003; ratified on 22 July 2010.

that women with disabilities are not a homogenous category, the majority suffer multiple forms of discrimination on account of variables such as disability, poverty and gender. Like the case of Sarah in the opening story, they are often portrayed by health workers and the community as asexual, infertile and incapable of being mothers. There are widely-held beliefs that the bodies of PWDs in general and women with disabilities in particular are ugly, shameful, and or unattractive. Studies that have explored the maternal healthcare experiences of women with disabilities have found that they face a myriad of challenges in accessing and receiving care.<sup>14</sup> Because of their disability, they may not receive information on critical components of maternal health such as contraception and other family planning methods. Health care workers, including doctors, midwives and nurses may even not know how to handle specific health care needs of women with disabilities.<sup>15</sup> Yet, the state has obligations to respect, protect and fulfill disability rights in maternal health by, *inter alia*, developing and implementing legal and policy frameworks and other interventions for protecting these rights.

Against this backdrop, the article seeks to address the following: What is the normative content of DRs in maternal health? What are the challenges faced by women with disabilities in accessing maternal health care? How can these challenges be overcome?

The article is divided into four sections. The next section revisits the meaning of maternal health and disability. The third section maps out the nexus between DRs and maternal health rights (MHR). Building largely on existing literature on the subject, the fourth section revisits key barriers to the realisation of these rights. In the final section, the article provides a conclusion and recommends modalities for the enhanced realization of DRs in maternal health.

## II. UNDERSTANDING MATERNAL HEALTH AND DISABILITY

In order to understand the nexus between DRs and MHRs, it is necessary to map out the meaning of maternal health and disability. It should be pointed out from the outset that there is no definition that can be both precise and sufficiently broad to encompass all aspects of maternal health. However, according to WHO, maternal health “refers to the

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14. M. Redshaw et al, Women with Disability; The Experience of Maternal Care during Pregnancy, Labor and Birth and the Postnatal Period, 13 BMC PREGNANCY AND CHILDBIRTH 174 (2013).

15. J.K. Ganle *et al*, Challenges Women with Disabilities face in Accessing and Using Maternal Health Care Services in Ghana: A Qualitative Study (2016), available at <<http://www.doci.org/10.1371/journalpone.015836>>, (accessed 23 April 2017).

health of women during pregnancy, childbirth and the post-partum period.”<sup>16</sup> This definition underlines the fact that for a woman to safely go through pregnancy, labour and delivery, she should be healthy. Maternal health is indeed a core component of health, which is defined by WHO as a “state of complete physical, mental and social well-being and not merely the absence of disease and infirmity.”<sup>17</sup> Thus, maternal health moves beyond maternal health care – antenatal care, labour and delivery care, and family planning – and encompasses all aspects of a woman’s physical and mental health and well-being during pregnancy, child birth and the post-natal period. Maternal health is protected in legal and policy frameworks because of women’s unique maternal functions in society. Thus, although men play a critical role in women’s lives, MHR are largely specific to women because of their unique reproductive functions.

The importance of maternal health was underlined by the Universal Declaration of Human Rights (UDHR), which declared that “[m]otherhood and childhood are entitled to special care and assistance.”<sup>18</sup> The constitution is also clear: in protection of women and their rights, the state shall take into account their “unique status and natural maternal functions in society.”<sup>19</sup> In any case, pregnancy and child-bearing increase the risk of mortality over and above the general population.

The World Health Organisation (WHO) has aptly captured the double-edged experience of motherhood: while it “is often a positive and fulfilling experience, for too many women, it is associated with suffering, ill-health and even death.”<sup>20</sup> Indeed, motherhood is critical for human survival and is granted recognition in human rights instruments. It may bring joy to the mother but can also be a source of pain. However, for women with disabilities, pregnancy and motherhood may bring ridicule, stigma and discrimination. Thus, for purposes of this article, maternal health care is that type of care that can enable a woman with disability to safely go through pregnancy, childbirth and the post-partum period without comprising her disability rights in maternal health.

The concept of disability may be understood through various models developed over the years. In the first half of the twentieth century, the English eugenics movement dominated views about PWDs. The term ‘eugenics’ was first used by a British scholar, Sir Francis Galton, who advocated for selective breeding of individuals who have

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16. WHO, MATERNAL HEALTH, available at [http://www.who.int/topics/maternal\\_health/en/](http://www.who.int/topics/maternal_health/en/) (accessed 9 January 2017).

17. Constitution of the World Health Organization 14 UNTS 185.

18. Art 25(2).

19. Article 33(3).

20. WHO, *supra* note 2.

desired or positive traits.<sup>21</sup> This led to increased institutionalised or sterilisation of PWDs in order to isolate them from other so-called 'normal' members of society. Some of the PWDs were even killed.<sup>22</sup> Over the years, the discourse on disability has been dominated by the medical and social models. The medical model views disability as a physical or mental impairment or biological condition of the individual that must be corrected through medical or surgical intervention.<sup>23</sup> This model regards disability as a deficiency that must be fixed by a rehabilitation or medical professional. It regards the limitations faced by PWDs as resulting primarily, or solely, from their impairments.<sup>24</sup> However, the disability rights movement fought for the rights of PWDs and pushed for the social model of disability.

In contrast to the medical model, the social model views disability as a product of social exclusionary practices. Advocates of the social model attribute disability to economic, environmental or cultural barriers, which are imposed on persons with disabilities by society. For example, the Union of the Physically Impaired against Segregation (UPIAS), a disabilities movement, has observed as follows:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation of society. To understand this, it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus, we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.<sup>25</sup>

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21. F. GALTON, *HEREDITARY GENIUS; AN INQUIRY INTO ITS LAWS AND CONSEQUENCES* (1869); B.F. Waxman, *Up against Eugenics: Disabled Women's Challenge to receive Reproductive Health Services*, 12 *SEXUALITY AND DISABILITY* 1 (1994); K. Norrgard, *Human Testing, the Eugenics Movement and IRBs*, 2 *NATURE EDUCATION* 1 (2008).

22. *Id.*

23. E.N. ZALTA, *STANFORD ENCYCLOPAEDIA OF PHILOSOPHY: DISABILITY, DEFINITIONS, MODELS, EXPERIENCE* (2011).

24. *Id.*

25. *UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION (UPIAS), FUNDAMENTAL PRINCIPLES OF DISABILITY* (1976), at 22.

Thus, according to the social model, disability is the result of social structures and not deficits in the body or brain. Systemic barriers, negative attitudes and exclusion by society are the main hindrances that disable people and not necessarily their impairments, albeit important. Social structures and norms disable people by devaluing and denying them access to social, economic and political opportunities and services. The social model views PWDs generally, and women with disabilities in particular, not simply as passive victims but as active agents that resist, challenge and subvert oppressive social structures that deny them their rights and opportunities to fully utilise their potential. The social model is based on how society organises its affairs and how the organisation discriminates and excludes PWDs from participation in the social, economic and political spheres.<sup>26</sup>

It is true that the social model provides a convincing approach to the understanding of disability. In fact, it has been argued that the social model of disability can greatly assist in understanding the challenges that women with disabilities face while accessing sexual and reproductive services such as maternal health care in public health facilities.<sup>27</sup> However, what is clear is that both individual impairment and the social environment play a critical role in defining disability. Although the CRPD does not explicitly define disability, it holistically defines persons with disabilities as including,

...those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.<sup>28</sup>

The 2006 Persons with Disabilities Act also defines disability as “a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environment barriers resulting in limited participation.”<sup>29</sup> Noting that both the medical and social models should be juxtaposed in order to respond adequately to disability related discrimination, Ngwena observed as follows:

[A] social construction of disability provides a meaningful paradigm in which to understand the definition of disability.... [D]isability is a

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26. B.K. TWINOMUGISHA, FUNDAMENTALS OF HEALTH LAW IN UGANDA (2015), at 120.

27. Ngugi, *supra* note 10.

28. Article 8.

29. Section 2.

fluid and highly contested construct. The medical model, with its focus on intrinsic pathology, is a limited, though not dispensable, paradigm for transacting disability. Disability is more than just the sum total of individual pathology and consequent mental and physical limitations. Extrinsic factors are extremely relevant to a meaningful interpretation of disability. The social model, with its overt political nuances, provides invaluable insights into the epistemology of disability and the formulation of normative responses that would otherwise be lost to the medical model operating on its own.<sup>30</sup>

Degner has also observed that the CRPD “goes beyond the social model and codifies the human rights model of disability,”<sup>31</sup> which places human rights of PWDs at the centre of all laws, policies, practices and interventions. The Critical Disability Studies (CDS) model, which builds on the critical studies movement, also views disability as a lived reality. Critical disability scholars such as Degner argue that “the experiences of persons with disabilities are central to interpreting their place of the world”<sup>32</sup> and should not be viewed as “pitiable, tragic victims who should adjust to the world around them.”<sup>33</sup> The CDS model is based on a social model of disability and its “objective is to support the transformation of society so that disabled people in all their diversity are equal participants and fully integrated into their communities.”<sup>34</sup>

What emerges from the literature on the subject points to one fact: disability is an evolving, fluid, complex and contested concept. Tackling disability-related stigma and discrimination requires a multi-faceted strategy involving bio-medical, juridical, political and socio-economic interventions. For women with disabilities, it is important to recognise their impairment and the social, attitudinal and environmental factors that inhibit the realisation of MHR. Thus, for the purposes of this article, disability is viewed as a multidisciplinary and multi-faceted concept where all models above are

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30. C. Ngwena, *Deconstructing the Definition of Disability Under the Employment Equity Act: Legal Deconstruction*, 23 SOUTH AFRICAN JOURNAL OF HUMAN RIGHTS 1 (2007) 116-156, at 117.

31. T. Degner, *A Human Rights Model of Disability* (2014) *Research Gate*, available at <<http://www.researchgate.net/publication/283713863>>, (accessed 9 March 2018) at 4. See also, G. Quinn et al, *Human Rights and Disability: The Current Use and Future of United Nations Human Rights Instruments in the Context of Disability*, available at <<http://www.ohchr.org/Documents/Programs.HRD>>, (accessed 9 March 2018).

32. Geoffrey Reaume, *Understanding Critical Disability Studies*, 4 CMAJ (2014) 186(16): 1248-1249.

33. *Id.*

34. D.L. HOSKING, *CRITICAL DISABILITY THEORY* (2008), available at <<http://www.lancaster.ac.uk/fass/events/disabilityconfr>>, (accessed 9 March 2018).

critical in understanding the challenges faced by women with disabilities in their struggle to access and utilise maternal health care.

### **III. EXPLORING THE NEXUS BETWEEN DISABILITY AND MATERNAL HEALTH**

It should be pointed out from the outset that both disability rights and MHR (MHRs) are human rights. They are interrelated, mutually reinforcing and are recognised in international, regional and domestic human rights instruments. The CRPD did not introduce new rights as such. It builds on existing rights in international human rights instruments, including the Universal Declaration of Human Rights (UDHR),<sup>35</sup> the International Covenant on Civil and Political Rights (ICCPR),<sup>36</sup> the International Covenant on Economic, Social and Cultural Rights (ICESCR),<sup>37</sup> the Convention on the Rights of the Child (CRC),<sup>38</sup> the Convention on the Elimination of all Forms of Racial Discrimination,<sup>39</sup> and the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW).<sup>40</sup>

However, the CRPD introduces a new paradigm shift: from a focus on a purely medical model to the more holistic social and human rights models of disability. It connotes a movement from viewing PWDs as simply objects of charity and medical treatment towards viewing them holistically as full and equal members of society with human rights, including access to socio-economic services such as maternal health care, participation in decisions that affect their lives and seeking redress for violation of their rights. It adopts the approach of the UDHR and the Vienna Declaration<sup>41</sup> and emphasizes the universality, indivisibility, interdependence and interrelatedness of human rights.

Disability rights are disability-specific: they apply to all PWDs. However, MHR apply to all women, including women with disabilities. MHR are cross-cutting in all civil, economic, political, and cultural human rights. Take the example of a pregnant woman with disability, who lacks the necessary labour and delivery care. She may neither vote nor actively participate in public affairs. She may even die. All these

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35. Adopted and proclaimed by the United Nations General Assembly in Resolution 217 A (III) 1948.

36. 999 UNTS 3. Uganda ratified it on 21 June 1995.

37. 993 UNTS 3. Uganda ratified it on 21 January 1987.

38. 1577 UNTS 3. Uganda ratified it on 17 August 1990.

39. UNGA Res 2106 (XX) of 21 December 1965.

40. 1249 UNTS 13. Uganda signed on 30 July 1980; ratified it on 22 July 1985.

41. Article 10.

are violations of her civil and political rights such as the right to vote and the right to life as well as socio-economic rights especially the right to health. Below I examine specific disability rights in maternal health.

#### A. *The Right to Life*

The right to life is a critical disability right in maternal health. It is specifically protected by the CRPD, which enjoins states parties to take all necessary measures to ensure that PWDs have the same right as others to the effective enjoyment of the right to life.<sup>42</sup> The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa<sup>43</sup> which, like the ACHPR, adopts the interdependence approach to human rights, also recognises the right to life and integrity.<sup>44</sup> It enjoins states parties to take effective and appropriate measures to ensure "respect for life, physical and mental integrity and the dignity of persons with disabilities on an equal basis with others."<sup>45</sup> States parties should also take measures to ensure that PWDs "have access to services, facilities and devices to enable them live with dignity and to realize fully their right to life."<sup>46</sup>

The right to life is fundamental to human living. Its ambit, horizon and scope have been actively expanded by judicial organs in a number of jurisdictions to incorporate all facets that are integral to life itself and those matters which form the quality of life. The courts and other tribunals have adopted direct and interdependent approaches in the application of the right to life.

In the Ugandan case of *Salvatori Abuki and Another v. Attorney General*,<sup>47</sup> the petitioner was sentenced to 22 months imprisonment under the Witchcraft Act, cap. 109 and an exclusion order banning him from his village was issued. He challenged the constitutionality of the order on grounds that it violated his fundamental human rights. The court held that the order violated his freedom from cruel, inhuman and degrading treatment, which is guaranteed under article 24 and 44 of the constitution.

In addition, Justice Egonda Ntende took judicial notice of the fact that the majority of Ugandans work the land for their livelihood, rendering an exclusion order an effective sentence to destitution. The learned judge held that the right to life

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42. Article 10.

43. Adopted at the 19<sup>th</sup> Extra-Ordinary Session of the African Commission on Human and Peoples' Rights, 16-25 February, 2015, Gambia.

44. Article (1).

45. Article 2(a).

46. Article 2(b).

47. Constitutional Petition No. 2 of 1997.

encompasses the right to a livelihood.

In India, the right to life has been expanded to include anything that is essential to live a life with dignity.<sup>48</sup> In *Paramanda Katra v. Union of India*,<sup>49</sup> the court correctly observed that preservation of life is of utmost importance, because if one's life is lost, the status quo ante cannot be restored as resurrection is beyond the capacity of man. In *Olliga Tellis v. Bombay Municipal Corporation*,<sup>50</sup> which is also known as *Pavement Dwellers' case*, a chief minister announced that all pavement and slum dwellers in the city of Bombay were to be forcefully evicted and deported to their respective places outside the city. The court held that Article 21 of the Indian constitution on the right to life had to be given a wide interpretation. It stated as follows:

It does not mean merely that life cannot be extinguished or taken away as, [for example] by imposition and execution of death sentence, except according to the procedure established by law. That is but one aspect of the right to life. An equally important facet of the right to life is the right to a livelihood because no person can live without the means of livelihood. If the right to livelihood is not treated as a part of the constitutional right to life, the easiest way of depriving a person of his right to life would be depriving him of his means of livelihood.<sup>51</sup>

There is no doubt that the right to life is the most precious right and goes to the heart of all fundamental rights; it is more than animal existence and should be lived with dignity.<sup>52</sup> In *Francis Coralie v. Union Territory of Delhi*,<sup>53</sup> the court held that the right to life,

includes the right to live with human dignity and all that goes along with it, namely the bare necessities of life such as adequate nutrition, clothing and shelter over the head and facilities for reading and

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48. See for example, *Olliga Tellis v. Bombay Corporation and Others*, AIR 1986 SC 180; *Corlie Mullin v. Administrator and Union Territory of Delhi* AIR 1981 SC 746.

49. AIR 1989 SC 2039.

50. AIR 1986 SC 180.

51. *Id.*

52. See, *Board of Trustees v. Dilip* AIR 1983 SC 109; *Unni Krishna v. State of Andhra Pradesh* AIR 1993 SC 2178.

53. SCC 608 (1981); *The State v. Makwanyane* (1995) 1 LRC 269. See also, A.R. Hannington, *The Expansion of the Right to Life under the Jurisprudence of the Inter-American Court of Human Rights*, 35 LOY. L. A. INT'L & COMP. L. REV. (2013) at 313-341.

expressing oneself in diverse forms freely moving about and mixing and commingling with fellow human beings'.<sup>54</sup>

Thus, without protecting the right to life of women with disabilities, all other human rights protections are meaningless. In *Sudan Human Rights Organization and another v. Sudan*,<sup>55</sup> the African Commission on Human and Peoples' Rights also observed that the right to life covers issues of livelihood and components of such rights as health and food. The Human Rights Committee<sup>56</sup> also noted that the right to life under article 6 of the ICCPR should not be interpreted narrowly and it is "desirable for States parties to take all positive measures to reduce infant mortality and to increase life expectancy, especially in adopting measures to eliminate malnutrition and epidemics."<sup>57</sup>

In its Draft General Comment on Article 6, the Human Rights Committee<sup>58</sup> has also observed that the right to life "concerns entitlements of individuals to be free from acts and omissions intended or expected to cause their unnatural or premature death, as well as their legitimate expectation to enjoy a dignified existence."<sup>59</sup> Under the General Comment, PWDs are entitled to special measures of protection against deprivation of their life.<sup>60</sup> The African Commission on Human and Peoples' Rights (African Commission)<sup>61</sup> has also observed that the right to life should not be narrowly interpreted<sup>62</sup> and in order to ensure a dignified life for all, the state has "a responsibility to address chronic and pervasive threats to life, for example with respect to preventable maternal mortality, by establishing functional health systems."<sup>63</sup>

It can be concluded from the above discussion that the right to life, which is protected by the constitution and international human rights instruments, is an inclusive and comprehensive tool that can be applied by an activist court in the protection of the rights of women with disabilities, including MHR. Where women, including women

54. *Id.*

55. (2009) AHRLR 153 (ACHPR 2009).

56. CCPR, General Comment No. 6 Article 6 (Right to Life) Adopted at the Sixteenth Session of the Human Rights Committee, 30 April 1982.

57. Para 5.

58. CCPR, Draft General Comment No. 36 Article 6 (Right to life) Human Rights Committee 115<sup>th</sup> Session, October 19-November 6, 2015, CCPR/C/GC/R.36/Rev. 2.

59. Para. 3.

60. Para. 22.

61. ACHPR, General Comment No. 3 on the African Charter on Human and Peoples' Rights, The Right to life (Article 4). Adopted during the 57<sup>th</sup> Ordinary Session of the African Commission on Human and Peoples' Rights, 4-18 November 2015, Banjul, The Gambia.

62. Para 6.

63. Paras 3 and 42.

with disabilities, are denied critical components of maternal health care such as emergency obstetric care, the chances of dying prematurely or suffering injury are high,<sup>64</sup> given the maternal mortality ratio (MMR) which stands at 336 deaths per 100,000 births,<sup>65</sup> roughly translating to approximately 16 women dying per day. Sarah in the opening story could have lost her life due to a glaring absence of disability-friendly maternal health services and she would have formed part of these statistics.

### *B. Equality and Non-discrimination*

All the relevant international and regional human rights instruments outlaw discrimination,<sup>66</sup> which refers to any distinction, exclusion, restriction or preference that has the intention or effect of nullifying or impairing the recognition or enjoyment of human rights.<sup>67</sup> According to the CRPD, states parties are obliged to prohibit “discrimination on basis of disability,”<sup>68</sup> which is defined as,

any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.<sup>69</sup>

The CRPD obliges states parties to “take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons living with disabilities.”<sup>70</sup> The constitution also guarantees equality and non-discrimination on given grounds including disability.<sup>71</sup>

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64. Twinomugisha, *supra* note 26.

65. UBOS, DEMOGRAPHIC AND HEALTH SURVEY (2016).

66. Article 2 UDHR; Article 2 ICESCR; Article 3 and 26 ICCPR; Article 2 CEDAW; Article 2 ACHPR; Article 2 Women’s Protocol to the ACHPR.

67. See for example, para 7 and 28 of CESCR, General Comment No. 20 ‘Non-Discrimination in Economic, Social and Cultural Rights (Article 2, para. 2), E/C.12/GC/20.

68. Article 5(2).

69. Article 2.

70. Article 4(b).

71. Article 21. There are cases where the Constitutional Court has impugned certain provisions of the law on grounds that they violate article 21 of the Constitution. See for example, *Uganda Association of Women Lawyers and 5 Others v. Attorney General*, Constitutional Petition No. 2 of 2003; *Law and Advocacy for Women in Uganda v. Attorney General*, Constitutional Petitions Nos. 3 of 2005 and 5 of

One of the objects of the 2006 Persons with Disabilities Act, which was enacted pursuant to Article 35 of the constitution that guarantees the rights of PWDs, is also to eliminate all forms of discrimination against PWDs on grounds of their disability.<sup>72</sup> The Act prohibits discrimination in all areas including education services,<sup>73</sup> employment,<sup>74</sup> and medical services.

Equality and non-discrimination are some of the norms and principles that guide the interpretation of the obligations under the CRPD.<sup>75</sup> In a number of General Comments, the CESCR has also emphasised that non-discrimination is an immediate and cross-cutting obligation under the ICESCR.<sup>76</sup> Although instruments such as the ICESCR do not explicitly provide for disability as one of the prohibited grounds of discrimination, the CESCR has observed that the list of such grounds “is not exhaustive and other grounds may be included,”<sup>77</sup> for example “where access to a social service is denied on the basis of sex and disability.”<sup>78</sup>

States parties must prohibit all forms of discrimination on the basis of disability<sup>79</sup> and PWDs are entitled to equal protection and equal benefits of the law.<sup>80</sup> The CRPD unequivocally emphasizes the fact that women and girls with disabilities are subject to all forms of discrimination and calls upon states parties to take all appropriate measures to ensure the development, advancement and empowerment of women and their full enjoyment of human rights and fundamental freedoms.<sup>81</sup> The Committee on the Rights of Persons with Disabilities stresses the point that gender equality is central to human rights<sup>82</sup> and women and girls with disabilities are more likely to be discriminated against than men and boys with disabilities.<sup>83</sup> Thus, states parties should take positive measures to ensure that women with disabilities are protected against multiple and intersectional discrimination and can enjoy human rights and fundamental

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2006.

72. Section 3(d).

73. Section 6.

74. Sections 12 and 15.

75. Article 3 (b) and (f).

76. See for example, CESCR, General Comment No. 20, Non-Discrimination in Economic, Social and Cultural Rights (art. 2, para. 2 of the International Covenant on Economic, Social and Cultural Rights, E/C.12/GC/20 (2009), para 7.

77. Para 15.

78. Para 27.

79. Article 5 (1).

80. *Id.*

81. Article 6.

82. Para 8.

83. Para 9.

freedoms on equal basis with others.<sup>84</sup>

In the Canadian case of *Eldridge v. British Columbia (Attorney General)*,<sup>85</sup> the appellants who were born deaf contended that the absence of interpreters impaired their ability to communicate with their doctors and other health care providers and thus increased the risk of misdiagnosis and ineffective treatment. One of the applicants testified that in the absence of an interpreter, the birth process was difficult to understand and frightening. The Supreme Court of Canada held that sign language interpreters must be provided in the delivery of medical services where doing so is necessary to ensure effective communication. The court observed that once a government undertakes to provide a benefit to the general population, it is required by section 15(1) of the Canadian Charter to ensure that the disadvantaged members of society listed in section 15(1) have the resources to take full advantage of that benefit. It was held that the equality rights had been violated. One of the questions before the court was whether the infringement was demonstrably justified in a free and democratic society. The court held that the infringement could not be justified under section 1 of the charter. On the standard to be met by the claimant, La Forest J stated:

A person claiming a violation of section 15(1) must first establish that, because of a distinction drawn between the claimant and others, the claimant has been denied “equal protection” or ‘equal benefit’ of the law. Secondly, the claimant must show that the denial constitutes discrimination on the basis of one of the enumerated grounds listed in section 15(1) or one analogous thereto.<sup>86</sup>

States parties are enjoined to take appropriate measures to ensure that reasonable accommodation is provided to PWDs. The CRPD defines reasonable accommodation as “necessary and appropriate accommodation and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on equal basis with others of all human rights and fundamental freedoms.”<sup>87</sup> According to the Committee on the Rights of Persons with Disabilities, the duty to promote reasonable accommodation is enforceable from the moment a person requests it in a given situation in order to enjoy

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84. *Id.*

85. [1977]3 SCR 624 (Supreme Court of Canada).

86. Para. 58.

87. Article 2.

their rights on equal basis in a particular context.<sup>88</sup> Failure to provide reasonable accommodation for women with disabilities may amount to discrimination under Article 5 and 6 of the CRPD.

In the American case of *Henrietta v. Bloomberg*,<sup>89</sup> which dealt with reasonable accommodation in the context of employment, the court held that the demonstration that a disability makes it difficult for a plaintiff to access benefits that are available to both those with and without disabilities is sufficient to sustain a claim for reasonable accommodation. In this case, the plaintiffs who were HIV positive brought a suit against New York City for failure to provide them with access to public benefits under Title II of the American Disabilities Act (ADA) and section 504 of the Rehabilitation Act. The court noted the “unique physical barriers” that persons living with HIV face with respect to accessing public benefits and services. The defendants also conceded that persons living with AIDS and other related diseases fell under the ambit of the ADA and the Rehabilitation Act. The court held that in order to bring a reasonable accommodation claim, it was not necessary for the plaintiffs to show that they were disparately affected. They had to show that they were unable to access the benefits or services because of their disability and they were denied reasonable accommodation.

### C. Right to Health: Availability and Access of Health Services

The fundamental right to health is recognised in international and regional human rights instruments to which Uganda is a party.<sup>90</sup> The constitution also enjoins the government to provide social services including health services to the population.<sup>91</sup> The Persons with Disabilities Act (PDA) also obliges government to provide access to user-friendly reproductive health services to women with disabilities.<sup>92</sup> The CRPD reaffirms the recognition of this right and provides as follows:

States parties recognise that persons with disabilities have the right to the enjoyment of the highest standard of health without discrimination on the basis of disability. States parties shall take all appropriate measures to ensure access for persons with disabilities to health

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88. Para.

89. 331 f. 3d 261, 264-6 (2<sup>nd</sup> Cir. 2003), 277.

90. See the WHO Constitution, Article 25; UDHR, Article 12; ICESCR, Article 14 of CEDAW; Article 24 CRC; Article 16 ACHPR; Article 14 Women’s Protocol to ACHPR. For an elaborate discussion of the right to health, see Twinomugisha, *supra* note 26, at 19-31.

91. NODPSP XX and XIV.

92. Sections 7 and 8.

services that are gender-sensitive, including health related rehabilitation.<sup>93</sup>

Thus, persons with disabilities, including women with disabilities, have the right of equal access to the same standard of health care and health-care services as others. Health care must be gender sensitive and should be provided on the basis of free and informed consent. The Committee on the Rights of persons with Disabilities has not yet elaborated on the normative content of Article 25 of the convention. However, the Committee on Economic, Social and Cultural Rights has attempted to explain the scope and content of the right to the highest attainable standard of physical and mental health under Article 12 of the ICESCR.<sup>94</sup> The CESCR recognises health as “a fundamental human right indispensable for the exercise of other human rights”<sup>95</sup> and states parties should ensure the availability, accessibility (physical access, affordability and information access), acceptability and quality of health care goods and services to all individuals without discrimination.<sup>96</sup>

Availability of care includes availability of facilities, goods and services as well as programmes that enable women with disabilities access maternal health services, including labour and delivery care. Deliveries should be by skilled birth attendants and pregnant women should be able to access pre- and post-natal services. There should be sufficient and well-equipped hospitals, clinics, and other health facilities including trained medical personnel. Accessibility includes physical access and this affects PWDs more due to a lack of disability-friendly physical facilities. Accessibility also includes access to family planning services and information and the right to control one’s fertility. In fact, the CRPD enjoins states parties to ensure that,

[t]he rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate education, reproductive and family education are recognized, and the means necessary to enable them to exercise these rights are provided.<sup>97</sup>

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93. Article 25.

94. CESCR, General Comment No. 14, The Right to the Highest Attainable Standard of Health, E/C.12/2000/14 (2000).

95. Para 1.

96. Para 12.

97. Article 23(1)(b). See also, paras 38 and 40 of General Comment No. 3.

Health care providers should therefore ensure that the availability, accessibility, acceptability and quality (AAAQ) of health services are taken into account in the provision of maternal health care to women with disabilities. Some of the important components of the AAAQ framework for provision of health services can be implied from the provisions of the CRPD and the PDA. For example, in order to enable PWDs, including women with disabilities, “live independently and participate fully in all aspects of life,” the CRPD obliges states parties to take appropriate measures to ensure PWDs access to the physical environment, transportation, information and communication technologies.<sup>98</sup> The Persons with Disabilities Act also enjoins government to provide access to the built environment.<sup>99</sup> Some of the access devices include ramps, stairs, elevators, urinals, toilets and bathrooms.<sup>100</sup>

According to the CRPD, states parties should ensure that communication and information services, transportation systems, buildings and other structures are designed and constructed so that they can be used, entered or reached by PWDs.<sup>101</sup> States parties must take effective measures to ensure personal mobility with the greatest personal independence for PWDs, and to facilitate access to assistive devices, technologies, mobility aids, forms of live assistance and training in mobility skills and making these available at affordable cost.<sup>102</sup> PWDs are entitled to receive and impart information.<sup>103</sup> The obligation to ensure access to information extends to providing information in accessible media and formats such as professional sign language interpreters, Braille and other forms of information and communication technologies.<sup>104</sup> The PDA also guarantees persons with disabilities access to information and enjoins the government to promote the development and use of sign language, tactile, and sign language interpreters.<sup>105</sup> The CRPD obliges states parties to “ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities.”<sup>106</sup>

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98. Article 9. For a discussion of accessibility as a precondition for persons with disabilities to live independently and participate fully and equally in society, see, CRPD, General Comment No. 2 (Accessibility) UN Doc. CRPD/C/GC/2, 11 April 2014.

99. Sections 19, 20 and 29(1).

100. Section 20.

101. Article 9(1).

102. Article 20.

103. Article 21.

104. *Id.*

105. Sections 21 and 29.

106. Article(9)(2)(b). See also, section 20 of the PDA.

Under the concept of reasonable accommodation, health facilities should make necessary adjustments in order to enable women with disabilities enjoy their MHR. As illustrated above, denial of reasonable accommodation amounts to discrimination under the CRPD.<sup>107</sup> For example, a pregnant woman with disability may be denied reasonable accommodation if she cannot undergo labour and delivery care at a health centre due to the inaccessibility of the labour suite. Although the PDA does not explicitly provide for reasonable accommodation, it provides that where PWDs have difficulties to access a building, “it shall be the duty of the provider of the facility to make adjustments or to provide an alternative method of making the facility available to persons with disabilities.”<sup>108</sup> However, such a provider is not required to do anything that “would fundamentally alter the nature of the service provided, trade, profession or business.”<sup>109</sup>

#### D. Right to privacy

Privacy is a complex and fluid concept. In *Griswold v. Connecticut*,<sup>110</sup> Justice Hugo Black correctly observed that privacy is a broad, abstract and ambiguous concept. The Webster Dictionary defines the right to privacy as “the right of a person to be free from intrusion into or publicity concerning matters of a personal nature.”<sup>111</sup> The right to privacy underlines the fact that private conduct should, as much as possible, be protected from intrusion by government and other actors. The law on privacy recognises the individual’s right to be left alone and to have his personal space inviolable. For example, in *Kennedy v. Ireland*,<sup>112</sup> the Irish Supreme Court, in addressing the right to privacy, held that phone tapping violated the right. Hamilton J stated that the right to privacy must ensure the preservation of the dignity and freedom of the individual in a sovereign, independent, democratic society. He observed as follows:

The dignity and freedom of an individual in a democratic society cannot be ensured if his communication of a private nature, be they

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107. See para. 17(d) of General Comment No. 3.

108. Section 26(1).

109. Section 26(2).

110. 381 U.S. 479 (1965).

111. See <<http://www.merriam.webster.com/legal/rightofprivacy>>, (accessed 25 July 2017).

For an elaborate discussion of the origins and contours of the right to privacy, see, L.R. Yankwich, *Right to Privacy: Its Development, Scope and Limitations* (1952) 27 NOTRE DAME LAW REVIEW 4 (2013) at 499-528.

112. (1987) I.R 587.

written or telephonic, are deliberately, consciously and unjustifiably intruded upon and interfered with.<sup>113</sup>

In the Ugandan case of *Mukasa and Another v. Attorney General*,<sup>114</sup> the judge also emphasised that the right to privacy of individuals must be honoured and protected. The right to privacy is critical in the health care setting and is recognised at international,<sup>115</sup> regional and national levels.<sup>116</sup> According to the CRPD, states parties are obliged to “protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.”<sup>117</sup> The right is aimed at protecting the personal interests of individuals and is an essential component of human well-being. Respecting privacy is recognition of the attributes that give human beings their uniqueness. Privacy promotes the ideals of personhood especially personal autonomy, individuality, respect, dignity and our worth as human beings. The right to privacy is central to protecting human dignity and supports and reinforces other human rights and freedoms such as expression, information and assembly.

Unauthorised disclosure of information may result in stigma, embarrassment and discrimination. Without assurance of privacy, a woman with disability may not visit a health facility. If she visits the facility, she may be reluctant to provide frank and complete disclosure of sensitive information even to a health worker. Ensuring privacy may thus promote more effective communication between the health worker and a woman with disability. Although it is in order for some women with disabilities to be accompanied to a health facility, this may, in certain circumstances, affect their right to privacy. A woman with disability may not be consulted by health workers who may decide to confide in the person who has accompanied her.

Medical procedures such as sterilisation may also be performed on a woman with disability without her informed consent. A woman with disability may also be taken through sensitive and intrusive medical examination without prior counseling and informed consent. Those accompanying a woman with disability may also be asked to give consent without consulting the patient. Yet, the right to make informed decisions about one’s health is a critical component of MHR.<sup>118</sup> The Special Rapporteur on the

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113. *Kennedy case*, *supra* note 112, at 590.

114. (2008) AHRLR 248.

115. See article 12 UDHR; article 17 ICCPR.

116. Article 27 of the Constitution; section 35 PDA.

117. Article 22(2).

118. Twinomugisha, *supra* note 26.

right to health<sup>119</sup> has correctly observed that informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision. Informed consent in a health care setting is at the core of a patient's autonomy, self-determination and human dignity.<sup>120</sup> Women with disabilities are particularly vulnerable to having their informed consent compromised given the power imbalance between health workers and patients, which is exacerbated by stigma and discrimination.

#### *E. Freedom from Torture, Cruel, Inhuman and Degrading Treatment*

This freedom is firmly enshrined in international, regional and national human rights instruments.<sup>121</sup> All medical or scientific experimentation without free informed consent of the individual is prohibited.<sup>122</sup> The constitution recognises this freedom<sup>123</sup> and renders it non-derogable.<sup>124</sup> According to the PDA, a person or institution shall not subject a person with disability to cruel, inhuman or degrading treatment.<sup>125</sup> Both the constitution and the PDA do not define what amounts to torture, cruel, inhuman or degrading treatment or punishment. The Convention against Torture and other Cruel, Inhuman or Degrading Treatment (CAT),<sup>126</sup> which was ratified and domesticated by Uganda,<sup>127</sup> defines torture to include both physical and mental suffering, which is purposefully inflicted.<sup>128</sup> The Prevention and Prohibition from Torture Act,<sup>129</sup> adopts the definition of torture in the CAT as,

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119. UNGA, Report of the Special Rapporteur on the Right to the Highest Attainable Standard of Physical and Mental Health, A.64/272 (2008), para 28. See also, CCPR, General Comment No. 20 Article 7 (Prohibition of Torture or Other Cruel, Inhuman or Degrading Treatment or Punishment), 10 March 1992. On the state's responsibility for actions of private actors, see for example, *da Silva Pimetel v. Brazil*, Committee on the Elimination of all Discrimination against Women, Communication No. 17/2008; *Ximenes Lopes v. Brazil*, Inter-American Court of Human Rights (Series C) No. 149 (2006), paras. 103 and 150; General Recommendation No. 19 (1992), para 9.

120. Article 7 ICCPR; article 15 (1) CRPD.

121. See for example, article 5 UDHR; article 7 and 10 ICESCR; article 5 ACHPR; article 15 CRPD.

122. *Id.*

123. Article 24.

124. Article 44(a).

125. Section 34(1).

126. UN Doc A/39/51 (1984); 1465 UNTS 85.

127. Ratified 3 November 1986; domesticated by the Prevention and Prohibition of Torture Act, No. 3 of 2012.

128. Article 1.

129. *Id.*

any act or omission, by which severe pain or suffering whether physical or mental, is intentionally inflicted on a person by or at the instigation of or with the consent or acquiescence of any person whether a public official or other person acting in an official capacity for such purposes as obtaining information or a confession from the person or any other person.<sup>130</sup>

The Act defines “severe pain or suffering” as the prolonged harm caused by or resulting from, among other things, “the intentional infliction or threatened infliction of physical pain or suffering,”<sup>131</sup> “the administration or application of mind-altering substances or other procedures calculated to disrupt profoundly the senses or personality.”<sup>132</sup> According to the Act, torture may be aggravated by certain circumstances, including, where at the time of torture, or immediately after the commission of torture, the victim was a PWD or the victim was pregnant or becomes pregnant.<sup>133</sup> Albeit the act does not define cruel, inhuman or degrading treatment or punishment, it provides that “[f]or the purposes of determining what amounts to cruel or degrading treatment or punishment, the court or any other body considering the matter shall have regard to the definition of torture as set out in section 2 and the circumstances of the case.”<sup>134</sup>

In the *Greek case*,<sup>135</sup> the European Court on Human Rights held that ‘torture’, ‘inhuman’, and ‘degrading’ treatment or punishment constitute distinct violations. Torture was singled out as carrying special stigma, which distinguishes it from other forms of treatment. The Court stated:

[A]ll torture must be inhuman and degrading treatment, and inhuman treatment also degrading. The notion of inhuman treatment covers at least such treatment as deliberately causes severe suffering, mental or physical, which, is unjustifiable. ... Torture ... has a purpose, such as the obtaining of information or confessions, or the infliction of punishment, and it is generally an aggravated form of inhuman treatment. Treatment or punishment of an individual may be said to be degrading if it grossly humiliates him before others or drives him

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130. Section 2(1).

131. Section 2(a).

132. Section 2(b).

133. Section 5.

134. Section 7(2).

135. YEARBOOK: EUROPEAN CONVENTION ON HUMAN RIGHTS, No. 12 (1969).

to act against his will or conscience.<sup>136</sup>

In *Ireland v. UK*,<sup>137</sup> the court held that in order to amount to torture, the treatment must cause serious and cruel suffering. In *Aydin v. Turkey*,<sup>138</sup> the court observed that in certain circumstances, rape causes physical and mental suffering sufficiently severe as to amount to torture. In *Salvatori Abuki v. Attorney General*,<sup>139</sup> the court held that banishment was a cruel, inhuman and degrading treatment. In *Simon Kyamanywa v. Attorney General*,<sup>140</sup> the Constitutional Court held that corporal punishment was a cruel, inhuman and degrading punishment. In *Susan Kigula and 417 Others v. Attorney General*,<sup>141</sup> a case where the petitioners challenged the constitutionality of the death penalty on grounds that it, among other things, contravenes Articles 24 and 44 of the constitution, the Supreme Court held that the penalty is constitutional since under Article 22(1) the right to life is not absolute and can be derogated from as a result of a judicially sanctioned sentence of death. However, the court observed that the freedoms under Article 24 are critical for the quality of living as a process. In *Bushoborozi v. Uganda*,<sup>142</sup> Justice Batema held that dumping persons with mental illness in prisons without resolution of their cases amounted to cruel, inhuman and degrading treatment.

The above cases illustrate the point that whether an act or omission amounts to torture, cruel, inhuman or degrading treatment depends on the degree of severity, which can be determined from the facts or circumstances of each case. As the court observed in the *Abuki* case above, the words in Article 24 should be given their ordinary plain meaning. Thus, in my view, if a medical procedure, for example, sterilisation is performed on a woman with disability without her free informed consent, or she is subjected to sexual violence such as rape by a health worker, this would be a violation of Article 24 of the constitution. There is no doubt that such an act, purposely or intentionally performed by a health worker, causes severe mental suffering to the woman with disability. With sterilisation, she will no longer have children – something that disrupts her personality. The act, which is performed against her ‘will or conscience’ will torment, grossly humiliate and stigmatise her forever among her peers and the community. There is special stigma attached to the act. It is cruel, inhuman and degrading and sufficiently severe to amount to torture.

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136. *Id.*

137. (1978) ECHR (Series A) No. 25.

138. 23178/94, Judgment on 23 September 1997.

139. Constitutional Case No. 2 of 1997.

140. Constitutional Reference No. 10 of 2000.

141. Constitutional Petition No. 6 of 2003.

142. HCT-01-CV-MC-011 of 2015; (2015) UGHCCRD 14.

Judicial officers handling cases of this nature need to administer justice in the name of the people, including women with disabilities, according to their aspirations.<sup>143</sup> Women with disabilities, like everybody else, aspire to live a life of dignity where they are treated well and their sexual and reproductive health rights respected. Judicial officers, as observed by Justice Batema in the *Bushoborozi* case above, should apply judicial activism in order to breathe life into the law. They should interpret and apply the freedoms under Articles 24 and 44 in order to meet the aspirations of PWDs in general and women with disabilities in particular.

A woman with disability has the right to be valued and respected by others including health workers. Inhuman and degrading treatment may include physical or psychological abuse of women with disabilities and may be extremely humiliating as happened to Sarah in the opening story. The Special Rapporteur on the Right to Health has observed that certain abusive practices in health care settings exceed the scope of violations of the right to health<sup>144</sup> and may amount to inhuman and degrading treatment. According to the Human Rights Committee, prohibition of torture or other cruel, inhuman or degrading treatment relates not only to acts that cause physical pain but also to those that cause mental suffering to the victim.<sup>145</sup> Such acts compromise the mental and physical integrity of women with disabilities.<sup>146</sup>

The obligation not to subject human beings to torture, cruel or other degrading treatment extends to private persons. The Special Rapporteur on Torture has also clarified that “the state’s obligation to prevent torture applies not only to public officials, such as law enforcement agents, but also to doctors, health care professionals, including those working in private hospitals.”<sup>147</sup> This position is supported by the constitution, which provides that all human rights and freedoms therein shall be respected and upheld by all persons.<sup>148</sup> According to the 2012 Prevention and Prohibition of Torture Act, persons acting in their private capacity may also commit torture.<sup>149</sup>

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143. Article 126 of the Constitution.

144. A/64/272.

145. Human Rights Committee, General Comment No. 20, Prohibition of Torture or Other Cruel, Inhuman or Degrading Treatment or Punishment (Art. 7) (1992) para. 5.

146. On protection of personal integrity of persons with disability, see Article 17.

147. UNGA Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, A/63/175, para 51.

148. Article 20.

149. Section 2.

*F. Equal Recognition of the Law: The Question of Legal Capacity*

There is a nexus between forced medical intervention based on discrimination and the deprivation of legal capacity. The capacity or competence to consent to treatment is determined by the ability to comprehend, retain, weigh, and believe information provided by a health worker in order to arrive at an informed decision. Under common law, legal capacity is presumed in adult persons and they have the right to consent to, refuse or choose an alternative medical intervention. It is only in a life-threatening emergency that a health provider may proceed without informed consent to perform a life-saving procedure.<sup>150</sup> The CRPD recognises the legal capacity of persons with disabilities “on an equal basis with others in all spheres of life”<sup>151</sup> and states parties should render them the necessary support to enable them enjoy their human rights.<sup>152</sup> According to the ICCPR, no derogation from the right to equal recognition of the law is permissible even in times of emergencies.<sup>153</sup> However, given the existing structural inequalities, especially the power imbalance inherent in the doctor-patient relationship – owing largely to the complexities of modern medicine – vulnerable individuals such as women with disabilities may not fully exercise their legal capacity.

The CRPD has clarified on the obligation of states parties to ensure that PWDs enjoy their right to legal capacity.<sup>154</sup> The committee emphasizes a movement from substitute decision making to supported decision making.<sup>155</sup> In *Abiru v. In Re Dradriga*,<sup>156</sup> the applicant sought an order appointing her as a manager of a mentally ill person. The judge observed that Article 12 of the CRPD favours a presumption of capacity and an order for substitute decision making can only be made if the respondent is incapable of managing his or her property. Substitute decision making is where the person with disability is assumed to have no will, preference and capacity to make decisions, which must be made by another person for example a relative, friend or health worker. Supported decision making views a person with disability as capable of making his or her own decisions: he or she enjoys full recognition and equality

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150. See, *Re C* [1944] 1 All ER 819; *Re T* [1992] 4 All ER 649.

151. Article 12(2).

152. Article 12(3).

153. Article 4(2). On the right to equal recognition before the law, see also article 15 CEDAW; Article 2 ACHPR.

154. Committee on Rights of Persons with Disabilities, General Comment No. 1 (Equal Protection Before the Law), UN Doc. CRPD/C/GC/1 (2014). For a discussion of the recommendations by the Committee, see Anna Arstein & Flynn (2016: 471-490).

155. Para 3.

156. Misc. Application No. 0031 of 2017.

before the law. PWDs can make fundamental decisions about their own lives. A disability or impairment should never be the basis for a denial of legal capacity.<sup>157</sup>

Support for PWDs takes various forms, for example, peer support, language aids, and decision making assistance in communication with health workers.<sup>158</sup> The purpose of support is to remove barriers and assist PWDs to exercise their legal capacity. It aims at building “the confidence and skills of persons with disabilities so that they can exercise their legal capacity in future if they wish.”<sup>159</sup>

However, support must not take a form of substitute decision making.<sup>160</sup> According to the CRPD, in order to protect the rights of PWDs to legal capacity, the ‘best interest’ standard should be replaced with the ‘best interpretation’ standard.<sup>161</sup> Decisions should be based on the supporter’s best interpretation of the will and preference of the individual, where necessary.<sup>162</sup> States parties are enjoined to abolish substitute decision making regimes that deny PWDs their legal capacity and should, with active participation of PWDs, design and implement legal and policy frameworks to protect the right to legal capacity for all persons.<sup>163</sup> According to the CRPD, there is a clear link between Articles 12 and 25 on the right to health:

States parties have an obligation not to permit substitute decision makers to provide consent on behalf of persons with disabilities. All health and medical personnel should ensure appropriate consultation that directly engages the persons with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over decisions of persons with disabilities.<sup>164</sup>

The CRPD has observed that choices of women with disabilities, especially women with psychosocial or intellectual disabilities, are often ignored, their decisions often substituted by third parties, including legal representatives, service providers, guardians

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157. Para 9.

158. Para 14-17.

159. Para. 20.

160. Para 15. On supported decision making and its implications for health law, see P. Gooding, *Supported Decision Making: A Rights Based Disability Concept and its Implications for Mental Health Law*, 20 *PSYCHIATRY, PSYCHOLOGY AND LAW*, 3 (2013) at 431-451.

161. *Id.*

162. Paras 21 and 25.

163. *Id.*

164. Para 37.

and family members, thus violating their rights under Article 12.<sup>165</sup> According to the CRPD, all women with disabilities must be able to exercise their legal capacity by taking their own decisions with support when desired with regard to medical and or therapeutic treatment, including decisions on retaining their sexuality, reproductive autonomy, their right to choose the number and spacing of children.<sup>166</sup>

Restricting or removing legal capacity can facilitate forced interventions such as sterilisation, abortion, contraception or surgery without their informed consent.<sup>167</sup> Yet, women with disabilities have the right to found a family and support it or be provided with appropriate assistance to raise their children. Like other women, a woman with disability also has a right to safe legal abortion especially where her life or health is in danger<sup>168</sup> or where the pregnancy is a result of sexual violence such as rape, incest or defilement.<sup>169</sup>

The sad opening story of Sarah clearly shows how women's disability rights in maternal health are violated. She was lucky she survived. She never sustained injuries in the course of giving birth. Otherwise she would be part of the alarming MMR in Uganda. The mental, emotional and psychological consequences of the degrading treatment she went through are a permanent reminder of the stigma and discrimination women with disabilities go through in the quest to realise their sexual and reproductive health rights, including MHR. Her rights to life, non-discrimination and dignity were violated. Her story illustrates the need to expand the conceptualisation of torture, cruel, inhuman and degrading treatment to include blatant and gross violations of the right to

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165. Committee on the Rights of Persons with Disabilities, General Comment No. 3, Article 6: Women with Disabilities, para 44, CRPD/C/GC/3 (2016).

166. General Comment No. 3, para. 44.

167. Para 45.

168. However, termination of pregnancy is prohibited in Uganda except where it is 'authorized by law' (Article 22 (2) of the Constitution). Sections 141-143 of the Penal Code Act, cap. 120 provide for abortion related offences. Under section 224, abortion is allowed for saving the life of the mother or foetus. Although Article 14(2)(c) of the Women's Protocol to the ACHPR allows medical abortion under circumstances such as 'sexual assault, rape, incest, and where the continued pregnancy endangers the mental and physical health of the mother or the life of the mother or foetus', Uganda entered a reservation in respect of this provision. However, it has been argued that the reservation does not absolve the state of the responsibility to reform or repeal its criminal laws to ensure that women and girls do not continue to die due to unsafe abortion thus violating their right to life. The Committee on Economic, Social and Cultural Rights (CESCR) has enjoined states parties to tackle the stigma and discrimination associated with unsafe abortion by reforming criminal laws on abortion. See, CESCR General Comment No. 22 of 2016 on The Right to Sexual and Reproductive Health, E/C.12/GC.22. See also, CESCR, *Concluding Observations on Uganda* (2015).

169. For a discussion of safe, legal abortion in a comparative context, see, Twinomugisha, *supra* note 26, at 48-56; 67-76.

health, which may lead to injury or loss of life. These violations are ‘intended’ by health workers who should be held personally accountable.

#### IV. BARRIERS TO REALISATION OF DISABILITY RIGHTS IN MATERNAL HEALTH

The discussion above has illustrated the point that disability rights in maternal health are recognised in international, regional and national human rights instruments, including the constitution. However, the realisation of these rights by women with disabilities is hampered by various barriers. Women with disabilities face major challenges in their quest to access and utilise maternal health care. According to Uganda Women’s Network (UWONET), accessing and receiving gender sensitive health care services remains a big challenge.<sup>170</sup> Women with disabilities face physical, medical equipment and communication barriers. There are also attitudinal barriers in the health care setting. Many health workers are ignorant of the specific issues relating to women with disabilities largely because they lack training in special health needs of PWDs. Most health providers view women with disabilities as incapable of making decisions affecting their health. As the Committee on the Rights of Persons with Disabilities observed,<sup>171</sup> these barriers create situations of multiple and intersecting forms of discrimination against women with disabilities. Physical barriers include inaccessible door entrances and staircases, and the absence of elevators, ramps and medical labels. Gipson observed that the ability of PWDs to access health services is influenced by architectural and transportation considerations among other factors.<sup>172</sup>

According to the Building Control Act,<sup>173</sup> building committees should “ensure that the design and construction of buildings and utilities to which the public is to have access cater for persons with disabilities.”<sup>174</sup> Most buildings in the country are inaccessible<sup>175</sup> and do not comply with the National Accessibility Standards 2010 that

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170. UGANDA WOMEN’S NETWORK (UWONET), MATERNAL HEALTH AS A HUMAN RIGHT FOR WOMEN WITH DISABILITIES, available at <http://www.uwonet.or.ug/2011/10/03/maternal-health-as-a-human-right-for-women-with-disabilities> (accessed 6 June 2017).

171. Para 2.

172. C.J. Gipson, *Access to Health Care for Disabled People: A Systemic Review*, 16 SOCIAL CARE AND DISABILITY (1998), at 2.

173. Act 10, 2013.

174. Section 29(1)(c).

175. E. Kasozi, *Most buildings not accessible to PWDs-report*, DAILY MONITOR, Monday, May 1, 2017, at 3.

are meant to promote accessibility to public facilities and services for PWDs.<sup>176</sup> The purpose of the Accessibility Standards is to guide architects, property managers and implementers. The standards are aimed at promoting better access for all people including elderly persons, the sick, pregnant women, and those carrying heavy loads. Accessibility is defined as “[t]he possibility to reach a place and maneuver within it; use a service, receive information; participate in activities provided in a public place; all these on equal basis with others, with dignity, independence and safety.”<sup>177</sup> In a report on physical accessibility to public and private institutions, the Equal Opportunities Commission (EOC) found that persons with disabilities face difficulty in accessing most buildings thereby marginalising them from service delivery.<sup>178</sup> At the Mulago National Referral Hospital based at Kiruddu in Makindye division, the EOC found that the hand rails were fixed at a high level in toilets for PWDs relative to the sitting position.<sup>179</sup> Poor hygiene in a health facility may even expose women with disabilities to several infections which may adversely affect their health.

Safe transport to attend health facilities or screening programmes may be unavailable, unaffordable or inaccessible for women with disabilities especially in rural areas. According to UWONET, PWDs, including women with disabilities, suffer discrimination in the transport sector.<sup>180</sup> The available modes of transport do not favour them and wheel chair users are almost completely excluded from most public transport. UWONET notes that the design of buses and taxis presents major obstacles to their use by PWDs as they lack sufficient grab rails at entrances and have narrow aisles and seat spacing, hindering maneuvering inside vehicles.<sup>181</sup> The available transport may also be inaccessible for women with disabilities as happened to Sarah in the opening story.

Barriers related to medical equipment include inaccessible beds, tables and chairs, and the lack of readable signs.<sup>182</sup> Processes in accessing services from registration to consultations and care are tedious, making it difficult for women with disabilities to easily get their way. Gynecological examination beds are often physically

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176. UGANDA NATIONAL ACTION ON PHYSICAL DISABILITY (UNAPD) & MINISTRY OF GENDER, LABOUR AND SOCIAL DEVELOPMENT, ACCESSIBILITY STANDARDS: A PRACTICAL GUIDE TO CREATE A BARRIER FREE ENVIRONMENT IN UGANDA (2010).

177. *Id.*

178. EQUAL OPPORTUNITIES COMMISSION (EOC), REPORT ON PHYSICAL ACCESSIBILITY TO SELECTED PUBLIC INSTITUTIONS BY PERSONS WITH DISABILITIES (2017).

179. *Id.*

180. UWONET, *supra* note 170.

181. *Id.*

182. E. Badu, *Access Barriers to Health Care among People with Disabilities in the Kumasi Metropolis of Ghana*, 5 CANADIAN JOURNAL OF DISABILITY STUDIES 2 (2016), available at <<http://cjds.uwaterloo.ca/index.php/cjds/article/view/275/505>>, (accessed 3 July 2017).

inaccessible for women with disabilities. Labour wards lack special facilities for women with disabilities such as adjustable delivery beds. Although a study of public health facilities in Uganda by Foundation for Human Rights Initiative (FHRI)<sup>183</sup> found that ramps had been put in place to ease the mobility of PWDs, it was observed that in the labour wards the beds are high, which hinders access for women with physical disabilities. The study found that health services are designed with no consideration for PWDs and that inaccessible medical equipment was cited as the major reason why many disabled women especially in rural areas prefer to deliver away from health centres.<sup>184</sup> Women who delay to seek and receive maternal health care may develop complications including obstructed labour that may lead to miscarriage or even death of the mother.

Communication barriers range from a lack of disability-friendly materials to health workers that do not have appropriate skills to communicate with women with disabilities. In most instances, materials are not available in adoptive technology such as Braille to enable visually impaired women with disabilities to read. Sign language interpreters who are able to communicate with the hearing impaired are usually not present. FHRI found that there are very few health centres that employ sign language interpreters and that some deaf and dumb people do not know the sign language.<sup>185</sup> The study found that at the end of 2009, Mulago, a public referral hospital, had only 29 nurses trained in sign language while Rubaga, a private hospital, had 30.<sup>186</sup> Because of these barriers, women with disabilities may have to rely on those who have accompanied them in order to communicate with health workers, which compromises the ethical principle of confidentiality thereby violating their right to privacy. The parliamentary committee on health has also decried the inaccessibility of maternal health facilities and services for women with disabilities, including maternity wards and delivery beds.<sup>187</sup>

Women with disabilities face multi-faceted challenges and stigma in accessing sexual and reproductive health services generally and maternal health care in particular. Like all other women, women with disabilities have the right to choose the number and

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183. FHRI (2009).

184. *Id.*, at 30.

185. *Id.*

186. *Id.*

187. REPUBLIC OF UGANDA/PARLIAMENT OF UGANDA, REPORT OF THE PARLIAMENTARY COMMITTEE ON HEALTH ON THE MINISTERIAL POLICY STATEMENT FOR THE HEALTH SECTOR FOR THE FINANCIAL YEAR 2012/2013, para 5.14. See also, *Disabled Maternal Patients Decry Mistreatment, Inadequate Facilities in Uganda Public Hospitals*, GLOBAL PRESS JOURNAL, retrieved from <<http://www.globalpressjournal.com/Africa/uganda/disabled-maternity>>, (accessed 5 June 2017).

spacing of their children, as well as the right to have control over their bodies and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of discrimination and violence. However, some health workers view women with disabilities as asexual or hypersexual, incapable, irrational, and lacking control over their bodies. Their ability to make independent judgments is questioned by society, including health workers.

Some health workers may treat women with disabilities as objects of treatment rather than rights holders and do not always seek their free and informed consent when it comes to treatment.<sup>188</sup> A health worker may ask a woman with disability: “how did you manage to climb on a bed to have sex and become pregnant if you are unable to climb onto our bed?” The negative perceptions, beliefs and myths about the sexual and reproductive abilities and roles of women with disabilities are largely influenced by superstition and a lack of training. These increase the risk of physical, emotional and sexual abuse and other forms of gender-based violence. As the CRPD has correctly observed, this stereotyping related to disability and gender is wrong and harmful and is a form of discrimination. It adversely affects the enjoyment of sexual and reproductive health and rights and the right to found a family.<sup>189</sup>

## V. CONCLUSION AND WAY FORWARD

A woman with disability, like any other person, has the right to full enjoyment of her human rights, including disability rights in maternal health. Uganda has a fairly disability-friendly legal framework that guarantees the rights of PWDs. Disability rights in maternal health are firmly established in international, regional and domestic human rights instruments. Both the state and non-state actors have obligations to ensure that women with disabilities access quality maternal health care. The state has an obligation to remove barriers that hinder women with disabilities from enjoying their MHR. Without losing sight of the fact that there is need to tackle the structural or root and systemic causes of non-realisation of MHR in the country,<sup>190</sup> the state should, using the existing legal and policy frameworks, urgently tackle the barriers outlined above. Most of the barriers to realisation of disability rights in maternal health are surmountable: what is required is the political will to tackle them.

There is need for an accessible barrier-free environment for all. The state should set up disability-friendly health facilities to enable women with disabilities

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188. UWONET, *supra* note 170.

189. Para 38.

190. *See*, B.K. TWINOMUGISHA, MATERNAL HEALTH RIGHTS, POLITICS AND THE LAW (2017).

access them. Architects, builders and engineers of public facilities should ensure that they comply with the access standards in order to enable women with disabilities access places and services with dignity. Local planning authorities should not compromise on the access standards. More is required beyond a ramp and an elevator to make a barrier-free environment. There is need to address door and passage width, floor surfaces, counter heights, door handles, signage, auditory signals and tactile guides. Labour wards should be equipped with adjustable beds and proper sanitation must be maintained. Women with disabilities should be provided with the necessary facilities including sign language interpreters and Braille, depending on the type of disability. The government should develop sign language and brailing of public information.

Materials in the health care setting should be available in Braille to enable visually impaired persons to read. It is necessary to ensure that sign language interpreters who are able to communicate with the hearing impaired are present at health facilities. All health facilities should have accessible tables, weighing scales, and machines. The Ministry of Health should regularly assess medical equipment and services at the various health facilities to ensure that they are accessible to women with disabilities. There should be reasonable accommodation of women with disabilities in the health care setting. There should be reasonable modifications to policies, practices, and procedures where necessary to ensure that health care services are fully available and accessible to women with disabilities, unless the modifications would fundamentally alter the nature of the services. Accessible examination and gynecological tables, wheel chair accessible scales and other disability and gender-friendly equipment may be costly. A tax incentive to private health providers could subsidise the expenses incurred in procuring accessible medical equipment and modifying premises.

There is need to tackle the negative attitude of health workers towards PWDs generally and women with disabilities in particular. Health workers should be sensitised about the fact that women with disabilities are human beings with sexual and reproductive health needs and desires like other women. Health workers need to know that women with disabilities are entitled to all human rights and freedoms, including disability rights in maternal health. The training of health workers on disability rights in maternal health should be covered in all medical schools and in continuing medical education and refresher courses. Health workers should ensure a gender-sensitive approach to the health service delivery system.

For the right to non-discriminatory access to maternal health care to be meaningful, it must be enforced. Litigation or the credible threat of litigation may help in demanding accountability from the state and non-state actors for non-realisation of disability rights in maternal health. Litigation can be utilised to address state

responsibility to ensure that MHR are accessible for women with disabilities. Litigation can be through the High Court for enforcement of human rights<sup>191</sup> or through the Constitutional Court for interpretation<sup>192</sup> or filing complaints through the Equal Opportunities Commission or the Human Rights Commission. These commissions have wide mandates that may be utilised in the protection of human rights of women with disabilities.<sup>193</sup> There is also a need to abolish laws, regulations, customs and practices that may constitute discrimination against women with disabilities. The proposed amendments to the PDA should be fast tracked in order to incorporate detailed components of disability rights in maternal health. Government should also ensure that the rights of women with disabilities are not infringed upon by third parties.

The rights and interests of women with disabilities should be mainstreamed across plans, strategies and policies concerning women. There should be active and genuine participation of women with disabilities in the design, implementation, monitoring and evaluation of legal and policy frameworks concerning disability rights. The capacity of women with disabilities to make their own decisions must be respected. Supported and not substituted decision making should be observed. Women with disabilities should be informed and have access to safe, effective, affordable and acceptable methods of family planning of their choice and the right of access to appropriate health care services that will enable them go safely through pregnancy and childbirth. A woman with disability who desires to terminate a pregnancy should be assisted to exercise her reproductive right to safe abortion.

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191. Article 50.

192. Article 137.

193. On the mandate of the Human Rights Commission, see article 52 (1) (a)-(i) of the Commission. For the Equal Opportunities Commission, see sections 14 and 15 of the Equal Opportunities Commission Act, 2007. One major drawback of this Act was section 15(6)(d), which prohibited the EOC from investigating 'a matter or behavior considered to be (i) immoral or socially harmful or (ii) unacceptable by the majority of the cultural and social communities in Uganda'. However, in *Adrian Jjuuko v. Attorney General* COA-00-CV-CPC-0001-2009, the Constitutional Court declared the section unconstitutional.

## ACCESS TO PUBLISHED WORKS FOR PERSONS WHO ARE BLIND, VISUALLY IMPAIRED OR OTHERWISE PRINT DISABLED IN UGANDA

R. Kakungulu-Mayambala\*

### ABSTRACT

*Over the years, there has been marginalisation of persons who are blind, visually impaired or otherwise print disabled in access to published works in Uganda and beyond. Despite numerous policy pronouncements as seen in both local and international legislations such as the Disability Act of Uganda, the Copyright and Neighboring Rights Act, and the regulations made thereunder, persons who are blind, visually impaired or otherwise print disabled continue to suffer and live in economic and literary exclusion in Uganda. The assumption is that poorly targeted policies and lack of focused programmes to address the question of access to published works for persons who are blind, visually impaired or otherwise print disabled has curtailed access to published works for this category of persons. There is therefore a need to review the policy prescriptions and explore further the circumstances that have perpetuated the inequity in access to published works for this category of people in Uganda.*

### I. INTRODUCTION

In 2006, the Parliament of Uganda passed the Persons with Disabilities (PWD) Act. The preamble to this Act states that the law aims to provide comprehensive legal protection for PWDs in accordance with Articles 32 and 35 of the Constitution of Uganda; to make provisions for the elimination of all forms of discrimination against persons with disability towards equalisation of opportunities and for related matters.” The Act also seeks to eliminate all forms of discrimination from educational services against PWDs.

The PWD Act comes against the backdrop of the constitution, which already bars all forms of discrimination against PWDs. This is a follow-up on Article 21, which prohibits discrimination in all forms against any persons, including PWDs. The constitution obliges the state “to take affirmative action in favour of groups marginalised on the basis of gender, disability or any other reason created by history,

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tradition or custom, for the purpose of redressing imbalances which exist against them.”<sup>1</sup>

Article 35(1) of the Act provides for the rights of PWDs and thus states: “Persons with disabilities have a right to respect and human dignity, and the State and society shall take appropriate measures to ensure that they realise their full mental and physical potential.” Similarly, the Act enjoins the state “to enact laws appropriate for the protection of persons with disabilities.”<sup>2</sup>

Section 6(1) of the PWD Act prohibits the denial or refusal to give educational services to PWDs on the ground of disability. It is however interesting to note that despite this provision, many PWDs are still facing challenges in accessing education especially in the area of access to published materials. This article seeks to examine how to ease access for PWDs in Uganda to published materials in line with the Marrakesh Treaty of 2013.

Access to published works for PWDs is at the intersection of human rights and intellectual property but is often treated as separate. Yet, connections that exist between access to published works and human rights are historical, conceptual and political, and can be evident through academic research and teaching. As scholars in the human rights and intellectual property fields, we are able to generate meaningful research to impact on policy discourse in Uganda and beyond. It is important to analyse the intellectual property regime in Uganda on access to published works for PWDs. On a positive note, it is important to note that the intellectual property regime has sought to ‘vindicate’ itself when the World Intellectual Property Organization (WIPO) adopted the Treaty of Marrakesh.

On 28 June 2013, the Marrakesh Treaty to Facilitate Access to Published Works by Visually Impaired Persons and Persons with Print Disabilities (Marrakesh Treaty) was signed by 51 countries. The treaty focuses on copyright exceptions to facilitate the creation of accessible versions of books and other copyrighted works. The treaty requires ratification by 20 states for it to enter into force.<sup>3</sup>

The intersection of intellectual property and human rights, and in particular disability rights, is receiving increasing scrutiny from the international community. As already noted, the Treaty of Marrakesh is one important development. Since it concerns itself with access to published works by PWDs, it is very important to interrogate this

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1. Article 32(1).

2. Article 35(2).

3. P. Jaszi, M. Remington, O. Ivins and S. Dyas-Correia, *Copyright and Intellectual Property: What you Need to Know*, 70(1-4) THE SERIALS LIBRARIAN (2016), at 41.

question further especially in the context of a country, which is least developed and is yet to ratify the Treaty of Marrakesh.

The research component of this study examined recent and current intellectual property reform processes that can be used to deepen access to published works by PWDs. It is expected that the research will yield insights into the current dynamics and discourse of intellectual property policy making while suggesting where human rights might develop policy traction in line with access to published works for PWDs. The objectives of this investigation are:

- (i) To analyse recent and current Intellectual property reform processes in Uganda and investigate if and to what extent human rights were considered in these processes;
- (ii) To analyse the intersection the impact of intellectual property rights regimes on access to published works for Uganda's PWDs;
- (iii) To provide research-based evidence that can empower scholars, activists, and policy makers in policy development processes for PWDs; and
- (iv) To contribute to the integration of human rights analysis into mainstream intellectual property teaching and research in Uganda and beyond.

The research aspect of the study was based primarily on doctrinal analysis of the legal principles and concepts relating to access to published works for PWDs using desk research and literature review. Primary and secondary documents were consulted and, where possible, stakeholder interviews conducted.

## **II. UGANDA'S OBLIGATIONS UNDER INTERNATIONAL LAW**

Uganda is a signatory to a host of treaties and agreements in both the human rights and international copyright arenas. At the international level, on 27 June 2013, the World Intellectual Property Organization (WIPO) adopted a Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired or Otherwise Print Disabled in Marrakesh.<sup>4</sup> The treaty is also referred to as the "Marrakesh Treaty." Uganda is a member of the WIPO and the World Trade Organization (WTO) and the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS Agreement) (1994), all of which focus on access to copyright materials for copyright users.

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4. Accessible at [http://www.wipo.int/wipolex/en/treaties/text.jsp?file\\_id=301016](http://www.wipo.int/wipolex/en/treaties/text.jsp?file_id=301016) (Accessed April 7, 2017 at 1853 Hours).

The “Treaty mandates its signatories to create provisions for making of accessible format copies of published works, and for these copies to be shared, within and across borders, without seeking permission from copyright holders. It gives a specific role to ‘authorized entities’, often libraries or organizations for the blind, in copying and sharing works.”<sup>5</sup>

Currently, 22 countries have ratified the Treaty of Marrakesh and an additional two countries have already submitted their ratifications to the Secretariat.<sup>6</sup> Unfortunately, Uganda is yet to ratify the treaty. This article urges Uganda to ratify and domesticate this very important treaty. This comes hot on the heels of the East African Community (EAC) Persons with Disability Act which was passed in 2015. Uganda is a founding partner state of the EAC. In line with its operational principles, the EAC “Partner States undertake to abide by the principles of good governance, including adherence to the principles of democracy, the rule of law, social justice and the maintenance of universally accepted standards of human rights.”<sup>7</sup>

Similarly, the EAC recognises the need to empower PWDs in line with the provisions of Article 120(c) of the treaty that urges partner states to cooperate amongst themselves in the field of social welfare with respect to, among others, the development and adoption of a common approach towards disadvantaged and marginalised groups, including children, the youth, the elderly and persons with disabilities through rehabilitation and provision of, among others, foster homes, healthcare, education, and training.<sup>8</sup>

The EAC PWD Act enjoins partner states, including Uganda, to take appropriate and effective measures including policy, legislative, and administrative and budgetary steps to ensure and protect the rights and dignity of PWDs; to recognise that disability is not inability and to provide safety nets for PWDs; to ensure and improve access to rehabilitation, education, training and community sports and more importantly, to guide, coordinate and harmonise interventions for PWDs by stakeholders.

Thus, it is clear that even though Uganda is yet to ratify the Treaty of Marrakesh, her obligations under international law, as seen and manifested by its signing and domestication of both the TRIPS Agreement and the UN Convention on

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5. D. Kawooya, *et al*, *The Treaty Of Marrakesh: From Good Law to Good Implementation*, OPEN JOURNAL SYSTEMS (2016), 1.

6. *Id.*

7. Article 7(2) of the Treaty for the Establishment of the East African Community, 1999.

8. Accessed at <http://www.eac.int/sectors/gender-community-development-and-civil-society/pwds> on August 4, 2017 at 1545 Hours.

the Rights of Persons with Disabilities (CRPD) and other international instruments, enjoins the country to respect, observe and promote the rights of persons who are blind, visually impaired or otherwise print disabled to access published works, so as to facilitate their right to information and education as well as freedom of expression.<sup>9</sup>

### III. EXAMINING EXISTING LAWS IN UGANDA ON ACCESS TO COPYRIGHT FOR PRINT DISABLED PERSONS

Uganda has a number of laws in the field of intellectual property, particularly the Copyright and Neighbouring Rights Act (CNRA),<sup>10</sup> and the Copyright and Neighbouring Rights Regulations of 2010. These provide for the protection of literary, scientific and artistic intellectual works and their neighbouring rights and provide for other related matters. It is notable that “Uganda signed the Marrakesh Treaty to Facilitate Access to Published Works by Visually Impaired Persons (VIPs) and Persons with Print Disabilities (Marrakesh VIP Treaty) on 28 June 2013 but is yet to ratify it.”<sup>11</sup> Since Uganda has signed the treaty,<sup>12</sup> it is hoped that she will demonstrate political will on promoting the rights of PWDs by finally ratifying and implementing the treaty.

According to Nicholson, “Uganda has made provision for both groups, i.e. transcription of Braille for blind persons and sign language for Deaf persons in its Copyright legislation.”<sup>13</sup> The CNRA defines “braille” as “writing of the blind consisting of raised dots which are read by touching.”<sup>14</sup> Although not expressly mentioned, since the CNRA has defined braille, it is clear that (works of) braille are part and parcel of the works eligible for copyright protection.<sup>15</sup> Similarly, the Uganda constitution enjoins the state to “promote the development of a sign language for the deaf...”<sup>16</sup> However, the fact that the “Uganda Constitution (1995) places Sign language

9. See Articles 5, 12, 19, 21, 24, 27, 28, 29 & 30 of the CRPD.

10. Act No. 19 of 2006.

11. Submission of the National Union of Disabled Persons of Uganda (NUDIPU) in response to the List of issues of the Committee on the Rights of Persons with Disabilities for the initial review of the Republic of Uganda on the implementation of the Convention on the Rights of Persons with Disabilities, at p. 24, Accessed on 28<sup>th</sup> May 2017.

12. See [http://www.wipo.int/treaties/en/ShowResults.jsp?Treaty id=843](http://www.wipo.int/treaties/en/ShowResults.jsp?Treaty%20id=843) (accessed on August 4, 2017).

13. D.R. Nicholson, *Accommodating Persons with Sensory Disabilities in South Africa Copyright Law* (Master’s degree Dissertation, University of the Witwatersrand, Johannesburg, 2012), at 48, available at: <<http://wiredspace.wits.ac.za/handle/10539/12525>>, (accessed on August 6, 2017).

14. CNRA, Section 2.

15. *Id.*, Section 5.

16. National Objective XXIV of the 1995 Constitution.

under national objectives rather than the substantive Articles affects its legal enforcement.”<sup>17</sup> The ideal and most appropriate approach is that Uganda should “take steps to ensure recognition of Ugandan Sign Language as a legally enforceable right.”<sup>18</sup>

The CNRA does not provide for the protection of technological protection measures. Besides, the Marrakesh Treaty prohibits the use of technological protection measures that inhibit access to published works for persons who are blind, visually impaired or otherwise print disabled.

Uganda does not standard copyright limitations and exceptions addressing persons with sensory disabilities or persons who are blind, visually impaired or otherwise print disabled. As Nicholson notes:

For blind persons, even ‘fair use’ or ‘fair dealing’ provisions cannot be exercised, because of other restrictions that create access barriers, such as the making of adaptations, format-shifting, technological protection measures and licensing. Also, cross-border sharing of accessible material from one country to another is not permitted due to the territorial nature of copyright law.<sup>19</sup>

Uganda provides for copyright limitations and exceptions broadly through its fair use provision.<sup>20</sup> The biggest window for access to published works and access to education and information in Uganda for persons who are blind, visually impaired or otherwise print disabled lies in the *fair use* provision as enunciated in section 15 of the CNRA. This section details the instances and circumstances under which use of a copyright work will not amount to infringement. Thus,

- (i) The fair use of a protected work in its original language or in a translation shall not be an infringement of the right of the author and shall not require the consent of the owner of the copyright where:
- (ii) any work is transcribed into braille or sign language for educational purpose of persons with disabilities.

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17. NUDIPU, *supra* note 11, at 24.

18. *Id.*

19. D.R. Nicholson, *Treaty for Visually Impaired Persons (TVI) and treaty proposal on Copyright Limitations and Exceptions for Libraries and Archives (Tlib): implications for the Developing World*, IFLA WLIC (2013), at 4, available at: <<http://creativecommons.org/licenses/by/3.0/>>, (accessed on August 6, 2017).

20. CNRA, Section 15.

Braille is one of the accessible formats for visually impaired persons (VIPs). However, sign language is largely a preserve of the deaf and may not be of much help to VIPs.

Section 15(1) paragraphs (a) – (k) lists situations when use of a work may not be tantamount to infringement whereas section 15(2) paragraphs (a) – (d) gives the factors to consider in determining what amounts to *fair use*. The fair use provision is wide enough to accommodate access to knowledge and access to education materials. However, herein lies its own ‘undoing’, for section 15(2) narrows down this window of hope by creating several conditions that have to be met in order to qualify for benefit under section 15(1). It should, however, be noted that although this provision provides for fair use, it has only a closed list of uses unlike fair use in the United States. It is thus more akin to the fair dealing in the United Kingdom than fair use as it is generally understood.

The fair use doctrine is a shield for use of copyright work by non-owners. Four key factors under section 15(2) of the CNRA (copied from Sec. 107(2) of the USA Copyright Act) analysed on a case-by-case basis are: (a) the purpose of the use; (b) the nature of the copyrighted work; (c) the amount and substantiality of the portion taken; and (d) the effect of the use upon the potential market. Such is the scope and nature of the fair use doctrine and its application in Uganda.

Copying of copyright protected works is generally prohibited in Uganda, unless done within the confines of ‘fair use’. “Copy” means ‘a production of a work in a written, recorded or fixation form or in any other material form, but an object shall not be taken to be a copy of an architectural work unless the object is a building or a model.’<sup>21</sup> The only way for which copies of works can be made available for persons who are blind, visually impaired or otherwise print disabled is by complying with the requirements of section 15 of the CNRA.

The *fair use* provision in the CNRA needs to be amended to include more exemptions to copyright so as to enhance access to published works for persons who are blind, visually impaired or otherwise print disabled as provided for in the Marrakesh Treaty. Only and until then shall Uganda be able to fully benefit from the provisions of the Marrakesh Treaty which she has signed but is yet to ratify. As Nicholson notes:

The Marrakesh Treaty specifically calls on Member States to establish exceptions and limitations to copyright holders’ exclusive rights in their national laws to allow for the unauthorized creation of accessible formats (e.g. Braille, audio and large print). It does not, however, exclude the possibility of individual States requiring the payment of

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21. *Id.*, Section 2.

reasonable royalties to copyright holders for conversion of their works to accessible formats.

The treaty provides for the free flow of accessible copies for use by persons with visual disabilities domestically, regionally and/or internationally, i.e. countries are obliged to allow the cross-border export of works to persons with visual disabilities in accessible formats.<sup>22</sup> For the above reasons advanced by Nicholson, it is imperative that Uganda moves to ratify the Marrakesh Treaty.

#### IV. THE ROLE OF LIBRARIES IN AIDING ACCESS TO PUBLISHED WORKS FOR PRINT DISABLED PERSONS

Libraries and the human resource therein (librarians) play a pivotal role in aiding persons who are blind, visually impaired or otherwise print disabled. Globally, university libraries play the crucial role of ‘distributing,’ ‘storing’ and ‘retrieving’ key information for learners including PWDs.

As Martinez-Calvo notes, “the Marrakesh Treaty is not only a treaty by and for persons with print disabilities – it is also a treaty for libraries, for societies, to help them become more inclusive and fair; it is the first international legal instrument, sanctioned by a UN agency, that can help the UN Convention on the Rights of Persons with Disabilities to carry out part of its purpose, to promote respect for the inherent dignity of persons with a print disability.”<sup>23</sup>

At the international level, the International Federation of Library Associations (IFLA) has played a key role in ensuring access to published works for print disabled persons, with Makerere University library playing a key role at the national level.<sup>24</sup> As Naluwoza notes,

Makerere University Library’s vision is to meet the study, teaching, research and outreach information needs for sustainable development. It serves as a National Reference Centre in addition to its primary role

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22. Nicholson, *supra* note 19, at 5.

23. F.J. Martinez-Calvo, *The Role of Libraries in the Implementation of the Marrakesh Treaty for Persons with Print Disability*, IFLA (2014), at 8, retrieved from: <<http://creativecommons.org/licenses/by/3.0/>>, (accessed on August 6, 2017).

24. See generally, Musoke G.N. Maria, *Reconstruction @Maklib with minimal resources* (Paper presented at IFLA conference on meeting, Academic and Research Libraries with Management and marketing, Gothenburg, Sweden, 2010).

of serving the institution (Makerere University). Due to the increasing numbers of students at the university, the library has tremendously expanded to cater for its users. It has a seating capacity of over 2,800 users and serves a population of approximately 40,000 users.<sup>25</sup>

Makerere University Library's efforts in aiding access to published materials for print disabled persons comes at a time when, "according to the World Health Organization (WHO), there are '285 million people (who) are visually impaired worldwide: 39 million are blind and 246 have low vision. About 90% of the world's visually impaired live in developing countries.'"<sup>26</sup> Similarly, "the World Blind Union (WBU) estimates that of the million or so books published worldwide every year, less than five per cent are made available in formats accessible to visually impaired persons, and less than one percent in the developing world."<sup>27</sup> It is for this reason that a developing country should ratify the Marrakesh Treaty so as to be able to access accessible format copy through its authorised entity.

An "Accessible format copy" is 'a copy of a work in an alternative manner or form which gives a beneficiary person access to the work, including to permit the person to have access as feasibly and comfortably as a person without visual impairment or other print disability. The accessible format copy is used exclusively by beneficiary persons and it must respect the integrity of the original work, taking due consideration of the changes needed to make the work accessible in the alternative format and of the accessibility needs of the beneficiary persons.'<sup>28</sup>

In respect of beneficiary persons, and the fears of rights-holders of the likelihood of their works being abused by the unintended beneficiaries, "the treaty (also) ensures right owners that 'the system will not expose their published works to misuse or discrimination to anyone other than the intended beneficiaries.'"<sup>29</sup>

The "authorised entity" means an 'entity that is authorised or recognised by the government to provide education, instructional training, adaptive reading or information access to beneficiary persons on a non-profit basis. It also includes a government institution or non-profit organization that provides the same services to beneficiary

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25. M. Naluwoza, Inclusion: The Provision of Information Services to Persons with Disabilities at Makerere University Library, QQML 2014 conference paper on Persons With Disabilities, 1.

26. Nicholson, *supra* note 19, at 3, quoting the World Health Organization Report (2012), at para. 1.

27. *Id.*, at 3-4.

28. Marrakesh Treaty, Article 2.

29. Nicholson, *supra* note 19, at 5, quoting UN News Centre (2013), para. 3.

persons as one of its primary activities or institutional obligations.”<sup>30</sup> The authorised entity is given power to establish and follow its own practices in respect to determining who the beneficiary person(s) shall be,<sup>31</sup> but which in any case shall be in line with the definition below of a beneficiary person. A beneficiary person is a person who:

- (i) is blind;
- (ii) has a visual impairment or a perpetual or reading disability which cannot be improved to give visual function substantially equivalent to that of a person who has no such impairment or disability and so is unable to read printed works to substantially the same degree as a person without impairment or disability; or
- (iii) is otherwise unable, through physical disability, to hold or manipulate a book or to focus or move the eyes to the extent that would be normally acceptable for reading; regardless of any other disability.<sup>32</sup>

The libraries serve as a vehicle for access of accessible format copy as the authorised entity (entities) for the beneficiary persons. Whether dealing with traditional libraries or specialised libraries such as libraries for the blind, devoted to the welfare of blind and VIPs, all libraries play a leading role in enabling access to published works for print disabled persons.<sup>33</sup>

Libraries also offer assistive technologies for print disabled persons. According to Tripathi and Shukla:

Assistive technologies (ATs) is a rubric term that refers to assistive, adaptive rehabilitative devices, products, or equipment for helping people with disabilities. These improve, increase and maintain the functional capabilities of persons with disabilities. ATs assist individuals in communication, education, work, and recreation; help them achieve greater independence; and enhance quality of life. Assistive technologies offer independence by enabling people with disabilities to perform tasks which they were formerly unable to accomplish. ATs can immensely improve the quality of life of

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30. Marrakesh Treaty, Article 2.

31. *Id.*

32. *Id.*, Article 3.

33. Martinez-Calvo, *supra* note 23, at 6-7.

individuals with disabilities by providing better access to information, knowledge, education, healthcare, and employment.<sup>34</sup>

Libraries must have “ATs for visually challenged people such as braille embossers, screen magnifiers, screen readers, speech recognition programs, text-to-speech synthesizers, talking and large print processors.”<sup>35</sup> Equally, workstations in the libraries, traditional or for the blind, should have “special software and hardware including Tiger Pro Braille embosser, Basic Index DV4, Braille typewriter, Zoom X instant reader, JAWS for Windows, Kurzweil 1000, Talking typing teacher, Spell Well.”<sup>36</sup>

Makerere University Library recently acquired the JAWS for Windows programme for her print disabled students but is yet to acquire the entire set of ATs as listed above.<sup>37</sup> The challenge has been the cost involved in procuring both the software and hardware required for these ATs.<sup>38</sup> These challenges notwithstanding, it remains clear that:

ATs enable persons with disabilities to productively use information technology resources. Through ATs, tasks such as reading an assignment, listening to a textbook, enlarging a syllabus, or printing a braille copy of a page or computer file can be easily accomplished. The use of technology can diminish or even eliminate barriers to learning, enable people with visual disabilities to reach their full potential.<sup>39</sup>

The use of ATs is in line with Article 7 of the Marrakesh Treaty on taking appropriate measures concerning technological measures to help print disabled persons access the works.

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34. M. Tripathi & A. Shukla, *Use of Assistive Technologies in Academic Libraries: A Survey*, 26(2) ASSISTIVE TECHNOLOGY (2014), DOI:10.1080/10400435.2013.853329, retrieved at <<http://dx.doi.org/10.1080/10400435.2013.853329>>, (accessed August 5, 2017).

35. *Id.*

36. *Id.*

37. Naluwoza, *supra* note 25, at 7.

38. Interview with Mr. Mathias Mazinga Luyaya, Library Assistant in charge of the Visually Impaired/disabled persons library/laboratory at Makerere University Main Library, on 13<sup>th</sup> September 2017 at the Main Library.

39. Tripathi & Shukla, *supra* note 34, at 1.

“Works” means literary and artistic works within the meaning of Article 2(1) of the Berne Convention for the Protection of Literary and Artistic Works, in the form of text, notation and/or related illustrations, whether published or otherwise made publicly available in any media.<sup>40</sup>

Libraries can also be very useful through their “loan scheme” by way of cross-border exchange and importation of accessible format copies.<sup>41</sup> Libraries should also develop policies in favour of disabled students. Makerere University, for example, “gives a point to the disabled students during the admission process to enable them get university qualifications. It further provides a guide for each student in that category while at the university.”<sup>42</sup> All these are very good policies. However, Makerere University needs to implement its “policy in favour of persons with disabilities at the University.”<sup>43</sup> Such a step will certainly go a long way in streamlining the operations and rights of persons with disabilities at Makerere University.<sup>44</sup> Section 6.6 of the Makerere University Policy on Students with Disabilities deals with physical infrastructure and obliges the University to “endeavor to make suitable adaptations existing infrastructure, and to ensure that newly created buildings in the University including sanitation facilities have access for people with disabilities.”<sup>45</sup>

However, owing to the costs involved in making suitable adaptations to existing infrastructure to make it accessible for PWDs, the University has been slow in implementing its policy. This scenario (historically) in turn gave rise to the case of, *LAPD v. Attorney General, Makerere University and KCCA*,<sup>46</sup> in which the petitioners, acting on behalf of PWDs, sued the three defendants alleging *inter alia* discrimination and failure to access key university facilities including buildings. It was held that:

Utilising its scarce resources on the existing structures may substantially increase the cost of education making it impossible for all citizens to attain the highest educational standards and that the challenges faced by PWDs in accessing structures (at Makerere

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40. Marrakesh Treaty, Article 2.

41. *Id.*, Articles 5 & 6 respectively.

42. Naluwooza, *supra* note 25, at 2.

43. *Id.*

44. Luyaya interview, *supra* note 38.

45. The Policy was passed by Makerere University Council in February 2014.

46. Misc. Cause No. 146 of 2011).

University) should be attributed to the old structures which never made sufficient provisions for such people.

Based on this, the court declined to order the respondents to make suitable adaptations to existing infrastructure so as to accommodate PWDs.

Equally, Ahuja cautions thus:

The educational institutions and libraries must make efforts to achieve access for VIPs. A greater responsibility also lies on the NGOs, particularly those working for the welfare of disabled persons. It is, however, important for the States to ensure that the provisions meant for the benefits of beneficiaries in their national copyright laws are not misused and the work so converted does not enter into ordinary channels of business, causing serious harm to the copyright owner.<sup>47</sup>

Uganda should, therefore, ensure that its librarians and NGOs drum up support for accessible formats for published works for the country's VIPs. When Uganda finally ratifies the Marrakesh Treaty, it should as a "contracting party provide for other limitations in its national copyright law pursuant to Articles 10 and 11 of the Marrakesh Treaty."<sup>48</sup>

The business model works against access to published works for the world's VIPs since its preoccupation is profit. However, digitalisation enables access to e-books for persons who are unable to read traditional printed books currently available to sighted people.<sup>49</sup> Largely blamed on the absence of a strict adherence to human rights in all spheres of the social life and interactions, "equality is a dream that is confounded by how society is structured. The social model identifies institutions and structures in society as the primary cause of disablement."<sup>50</sup> The libraries may make some losses as they seek to implement the Marrakesh Treaty, but ultimately the main

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47. V.K. Ahuja, *Marrakesh Treaty to Facility Access to Published Works for Visually Disabled: Putting an End to Global Book Famine*, in COPYRIGHT LAW IN THE DIGITAL WORLD (M.K. Sinha & V. Mahalwar, eds., 2017).

48. *Id.*

49. P. Harpur & N. Suzor, *The paradigm shift in realizing the right to read: how ebook libraries are enabling in the university sector*, 29(10) DISABILITY & SOCIETY (2014), at 1669-1670, retrieved from DOI: 10.1080/096887599.2014.973476 (accessed on September 8, 2017).

50. *Id.*, at 1658-1659.

role of the library is access to materials.<sup>51</sup>

Equally important is the early use of technologies for accessible formats for PWDs. As Christensen and Stevens observe, “proper use of authority technology such as word processors, editors in content management systems and similar facilities should be a mandatory part of any curriculum beyond primary education, ensuring that mainstream technology is used properly and that published documents comply with the basic principle of digital accessibility.”<sup>52</sup> This will go a long way in helping entrench a culture of accessible formats across the entire population, thereby even benefitting those sighted people who may become visually impaired or go blind later in life.<sup>53</sup>

Ficsor opines further that “...by avoiding duplication of investments in the making of accessible format copies of the same works in the same language in various countries, the objective to be served by the Treaty – facilitating availability of copies in such formats – may be more effectively achieved.”<sup>54</sup> Libraries are the main custodians of access format copies, which is very important.

## V. COPYRIGHT, THE ACCESS QUESTION FOR PRINT DISABLED PERSONS AND THE DEVELOPING WORLD

This section examines the challenges faced by print disabled persons in accessing published works and how those challenges may be overcome.

### A. Challenges faced by Print Disabled Persons in Accessing Published Works in Uganda

The territorial nature of intellectual property presents a major challenge when it comes to the sharing of accessible format works. As Martinez-Calvo notes, “intellectual property legislation is, by nature, territorial. This means that whatever rights, obligations, and limitations are expressed in your copyright law, these apply exclusively

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51. J. Charlton, *Marrakesh Treaty Goes Forward, World Libraries Take Cuts*, INFORMATION TODAY, July/August 2016, at 9.

52. B.L. Christensen and S. Tanja, *Universal Access to Alternate Media*, in UNIVERSAL ACCESS IN HUMAN-COMPUTER INTERACTION: ACCESS TO TODAY'S TECHNOLOGIES (M. Antona & C. Stephanidis, eds., 2015), at 413, accessed at DOI: 10.1007/978-3-319-20678-3\_39.

53. M.J. Ficsor, *Commentary on the Marrakesh Treaty on Accessible Format Copies for the Visually Impaired*, Copyright See-Saw of 11 October 2013, available at [http://www.copyrightseesaw.net/archives/?sw\\_10\\_item=50](http://www.copyrightseesaw.net/archives/?sw_10_item=50) (accessed 19 September 2017).

54. *Id.*

to the country where this law was enacted.”<sup>55</sup> As Band notes, “because it is so costly to produce accessible-format copies of copyright works, the ability to share such copies across borders would benefit print-disabled people everywhere”<sup>56</sup> including in developing countries such as Uganda.

Materials in accessible format for VIPs are as important as the tools used in helping their access via the hardware and the software. In this respect, Lewis notes:

accessible hardware, software, and non-computer formatting methods for persons with print disabilities have developed rapidly. Using specifically-designed or mainstream digital players, smartphones, tape players, large print copies, text-to-speech, text-to-Braille, audiobooks, and scanning equipment and conversion software, many blind or vision-impaired can now more easily make their own contributions to community-based or worldwide communications platforms.<sup>57</sup>

Whereas this may be the case in the developed world, developing countries such as Uganda are lagging behind in respect of the use of ATs due to limited capacity. Despite the rhetoric on promotion and protection of human rights at the international level, none has been used to resolve these conflicts between private and public rights, as is the case with access to published works for VIPs, especially those in the developing world. According to Helfer, “the primacy of human rights obligations, over economic policies, laws and treaties such as TRIPS...for its proponents, this resolution (of the conflict) flows from the fact that human rights are fundamental and by definition of higher importance than private economic rights.”<sup>58</sup>

### *B. From Disdain and Despair to Hope and Victory*

The bid to overcome the challenges faced by print disabled persons in accessing published works has been captured by Wechsler thus:

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55. Martinez-Calvo, *supra* note 23, at 2.

56. J. Band, *How the Marrakesh Treaty Opens Vistas for Print-Disabled Readers*, TRENDS, PERSPECTIVES, (2013), at 14.

57. H. Lewis, *Introductory note on Marrakesh Treaty to Facilitate Access to Published Works for Persons who are Blind, Visually Impaired, or otherwise Print Disabled*, 52 ILM 1309 (2013) at 1.

58. Helfer, R. Laurence, *Mapping the interface between Human Rights and Intellectual Property*, Handbook HR and IP, Chapter 1, based on an expanded version of the keynote address delivered on April 5, 2013 to the Conference on Human Rights and Intellectual Property: From Concepts to Practice, held at the European Court of Human Rights in Strasbourg, France.

...the establishment of the *Accessible Books Consortium (ABC)* by WIPO in late June 2013...ABC was created to support implementation of the Marrakesh Treaty on a practical level. It focuses, in particular, on the provision of technical skills, on the promotion of inclusive publishing and on building an international database of accessible books. ABC is also responsible for TIGAR book exchange, a database of titles of over 238,000 accessible format books in 55 languages from libraries all around the globe.<sup>59</sup>

The limited access is because “national laws were indeed once geared towards (such) public policy objectives.”<sup>60</sup> The close relationship between law and technology needs to be examined, in light of accessible formats for Uganda’s VIPs. Fundamental steps can be taken to help harness the benefits of technology and copyright.

Copyright changes are needed in light of developments in the digital networks era. For, example, Uganda’s Copyright and Neighbouring Rights Act (CNRA) is silent on technological protection measures and how these can be lessened so as to aid access to published works for the country’s VIPs. In this regard, Hua notes:

There is always a close relationship between technology development and law reforms. When advancement of technology brings about new changes to social lives and challenges existing legal relationships, the laws will often be amended and reformed to adapt to the new environment and address new problems. Such an inter-relationship is especially reflected in the area of copyright laws.<sup>61</sup>

However, technical inhibitions still limit Uganda’s ability to use ATs for its VIPs to access the accessible formats. ATs are a key component to access to published works

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59. A. Wechsler, *WIPO’s Global copyright Policy Priorities: The Marrakesh Treaty to Facilitate Access to Published Works for Persons Who are Blind, Visually Impaired, or Otherwise Print Disabled*, in *EUROPEAN YEARBOOK OF INTERNATIONAL ECONOMIC LAW* (C. Hermann *et al.* eds., 2015), at 401.

60. S. Hall, *An Entirely New Angle, A Commentary on International Copyright Law and Access to Education in Developing Countries*, 8(12) *JOURNAL OF INTELLECTUAL PROPERTY LAW & PRACTICE* (2013), at 966.

61. J.J. HUA, *TOWARD A MORE BALANCED APPROACH: RETHINKING AND READJUSTING COPYRIGHT SYSTEMS IN THE DIGITAL NETWORK ERA* (2014), accessible at DOI 10.1007/978-3-662-43517-5\_1, (accessed on September 10, 2017).

for VIPs, such as the zoom text services. Uganda had services of lay braille at the Uganda National Institute for Special Education (UNISE), but upon UNISE's merger with other institutions to form the current Kyambogo University, these services have not been forthcoming, and at least not with the ease with which UNISE used to provide them.

In addition to the law, the services needed to create or use accessible formats need to be in place. Access to the internet, which is key in using accessible formats, remains constrained in Uganda, besides the expensive software and hardware needed to operationalise the use of most ATs in Uganda. There is also a need to recognise the paradigm shift in international copyright law, which indicates a shift from "personal" copyright to a "new three-way balance in the public interest that is required for copyright going forward. This includes a balance between (1) economic rights holders, (2) authors, and (3) users."<sup>62</sup>

As Kur notes, "the seriousness of 'book famine' among blind and visually impaired people to which the Marrakesh Treaty is meant to respond is not doubted by anyone."<sup>63</sup> Addressing the insurmountable challenges faced in enabling access to published works is historical, as is the term "book famine," an expression which was reportedly coined by William Rowland, former president of the WBU."<sup>64</sup> A ray of hope is galvanising in favor of an international copyright regime that facilitates access to published works for VIPs. In this vein, Fitzpatrick notes:

The globally debilitating effects of the book famine demand international cooperation to address the scarcity of copyrighted works available to persons with print disabilities. The WIPO Member States have shifted in favor of a more balanced international copyright regime. Now, the Marrakesh Treaty helps achieve that balance.<sup>65</sup>

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62. M.A. Wilkinson, *International Copyright: Marrakesh and the Future of Users' Rights Exceptions*, in GLOBAL GOVERNANCE OF INTELLECTUAL PROPERTY IN THE 21<sup>ST</sup> CENTURY (M. Perry ed., 2016), accessible at DOI 10.1007/978-3-319-31177-7\_7 (accessed on September 10, 2017).

63. A. Kur, *From Minimum Standards to maximum Rules*, in TRIPS PLUS 20, MPI Studies on Intellectual Property and Competition Law 25 (Springer-Verlag Berlin Heidelberg, 2016), accessed at DOI 10.1007/978-3-662-48107-3\_4 (accessed on September 5, 2017).

64. *Id.*, quoting A. Scheinwald, *Who Could Possibly Be Against a Treaty for the Blind*, 22 FORDHAM INTELL. PROP. MEDIA & ENT. L.J. (2012), 448.

65. S. Fitzpatrick, *Setting Its Sights on the Marrakesh Treaty: The U.S. Role in Alleviating the Book Famine for Persons with Print Disabilities*, 37 B.C. INT'L & COMP. L. REV. (2014), at 161.

The Marrakesh Treaty was formulated purposely to handle the question of book famine and its ratification by Uganda is one step towards ending the book famine for her visually impaired persons.

## VI. EXAMINING ACTIONS FOR UGANDA'S PRINT DISABLED PERSONS

This section deals with the question of affirmative action for Uganda's print disabled persons. Relying on the four popularly acclaimed models in the disability discourse, vide the charity, medical, social and human rights models. A critical analysis of the four models gives credence to the human rights model as being the most ideal in addressing the question of access to published works for print disabled persons in Uganda. In analysing Uganda's constitution and other laws including those on intellectual property, the human rights model helps to view these laws using the human rights perspective and of the disability rights discourse.

As a strong advocacy mechanism, "organisations for the blind (in Uganda and beyond) should call for an international legal regime that, at least from (a) copyright perspective, facilitates access to knowledge and (a) culture for facilitating blind and visually impaired persons."<sup>66</sup> There is also need for "licensing and mass digitisation"<sup>67</sup> in order to take advantage of the library exception and possible revisions to Uganda's CNRA section 15(1)(k), to include other accessible formats for VIPs aside from braille and of course sign language which is only for the deaf.

There is also a need to adopt a judicious adjustment and approach to interpretation of limitations on copyright, with a view of striking a balance between the rights of rights holders and copyright users.<sup>68</sup> A judicial system of copyright protection, which is more aligned to copyright users, is very much needed in Uganda so as to enable the country's VIPs access published works.

Uganda ratified the Marrakesh Treaty as the 38<sup>th</sup> Member State on 4<sup>th</sup> May 2018 and the 9<sup>th</sup> African country alongside Botswana, Burkina Faso, Kenya, Liberia, Malawi,

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66. K. Koklu, *The Marrakesh Treaty – Time to End the Book Famine for Visually Impaired Persons Worldwide*, Max Planck Institute for Innovations and Competition, Munich, Springer, Germany (14 October 2014).

67. Jaszi, *et al*, *supra* note 3, at 38, 40.

68. T. Dreier, *Thoughts on Revising the Limitations on Copyright under Directive 2001/29*, 11(2) JOURNAL OF INTELLECTUAL PROPERTY LAW & PRACTICE (2015), at 138.

Mali, Nigeria and Tunisia.<sup>69</sup> Uganda will “promote the participation of the country’s VIPs in the civil, political, economic, social and cultural spheres with equal opportunities.”<sup>70</sup> All the major strides that need to be taken in order to fully embrace disability and the rights discourse have been given in both the UNCRPD and the Marrakesh Treaty. Indeed, what is needed for a country such as Uganda, which has already ratified the UNCRPD, is to domesticate the complimentary Marrakesh Treaty. The two treaties have a close bonding as explained below by Sganga:

... the Marrakesh Treaty represents, today, the closest point of contact between the UNCRPD and international copyright law, and the best result achieved through their dialogue. If, and when, it is implemented at a national and/or regional level, its provisions will help to ensure more uniformity in the (broad) definition of disability and rights covered by the exception, introducing a technologically neutral and open-ended conceptualisation of accessible works, and creating an international network of authorised entities to facilitate the cross-border exchange of accessible materials, so as to avoid duplications in efforts and investments.<sup>71</sup>

Court action or litigation is another avenue through which VIPs can exploit limitations on copyright. The four cases below help to illustrate this point.

First, in 2009, Colombia adopted the Convention on the Rights of Persons with Disabilities (Law 1346 of 2009, C-293/2010). Article 30 of the Convention states:

States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

On 20 November 2013, the Colombian Congress enacted Law 1680, which aims to ensure that VIPs have access to information, knowledge and digital technologies (ICT).

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69. See, Ratification by the Republic of Uganda (Marrakesh Notification No. 38) published on 4<sup>th</sup> May 2018.

70. C. Sganga, *Disability, right to culture and copyright: which regulatory option?*, 29(2) INTERNATIONAL REVIEW OF LAW, COMPUTERS & TECHNOLOGY (2015), 88-115, accessible at DOI: 10.1080/13600869.2015.1055658 (accessed on September 10, 2017).

71. *Id.*

The principles underlying this law are based on Articles 3 and 9 of the Convention on the Rights of Persons with Disabilities (Law 1680 of 2013, Art 3). The objective of the law included fostering the social inclusion of vulnerable and disadvantaged groups, allowing access to information and digital technologies especially the internet.

In June 2014, two Colombian citizens, through a public constitutional action, challenged Law 1680 of 2013 on a number of grounds, in particular its Article 12. The main argument of the plaintiffs was that the exception of Article 12 violated intellectual property rights that were guaranteed under Article 61 of the constitution, which enjoined the state to protect intellectual property for the period and through the formalities prescribed by law.<sup>72</sup>

In responding to the above petition, “the Colombian Constitutional Court held that a copyright exception for the benefit of visually impaired persons is an affirmative action to protect their fundamental rights.”<sup>73</sup> This case illustrates how the Colombian Constitutional Court ably resolved the matter when “faced (with) the tension between rights of persons with disabilities and intellectual property rights”.<sup>74</sup> Three other cases, two from the United States and one from Israel, also help to underscore the role of national courts and public interest litigation in bridging the gap between in access to accessible formats by VIPs.

Second, in the landmark decision of *Sony Corp v. Universal City Studios*,<sup>75</sup> the court confirmed that making a copy of a copyrighted work for the convenience of a blind person is expressly identified by the House Committee Report as an example of fair use, with no suggestion that anything more than a purpose to entertain or to inform need motivate the copying.<sup>76</sup> Although this case predates the Marrakesh Treaty by far, it was a major impetus and precursor to the emergency of the treaty. The court’s decision was phenomenal.

Third, in 2014, in the case of *Authors’ Guild v. HarthiTrust*<sup>77</sup> on Google books, Google had engaged in scanning of millions of books for its search results. The Authors’ Guild contended that this infringed on publishers’ copyrights although Google

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72. Pabon Cadavid Antonio Jhonny, “Current Intelligence”, *Journal of Intellectual Property Law & Practice*, Vol. 10, No. 6 (2015), at 407-408.

73. *Id.*, Colombian Constitutional Court, Decision C-035/15, 28 January 2015.

74. *Id.*

75. 464 US 417, 455 (1984).

76. Zemer, Lior & Gaon, Aviv, “Copyright, disability and social inclusion: the Marrakesh Treaty and the role of non-signatories”, *Journal of Intellectual Property Law & Practice*, Vol. 10, No. 11 (2015), 841.

77. 755 F 3d 87 (2014).

was showing only snippets of the work. In June 2015, the 2<sup>nd</sup> US Circuit Court of Appeal held that it was legal for Google to scan books without owning copyright under the fair use doctrine. Dissatisfied with the ruling by the Court of Appeal, Author's Guild appealed to the US Supreme Court which in April 2016 declined to grant the appeal. The Supreme Court ruling meant that Google is free to continue scanning books, and this can serve as a vehicle of access for the world's VIPs.<sup>78</sup> This ruling is likely to inspire more large scale digitisation of published works under fair use in the United States and beyond, thereby enabling print-disabled people access to digital copies of universities' collections using the HathiTrust Digital Library (HDL) in Google's Mass Digitalization Project.<sup>79</sup>

The fourth example worth quoting is based on Israel's copyright law. In 2013, the Human Rights Centre for People with Disabilities—Bizchut—demanded that the Israel Ministry of Education provide textbooks accessible to blind and visually impaired children, an accessible examination form for Israeli matriculation exams and examination sessions at the same time as those of other students. Both parties agreed on the importance of providing the necessary educational resources and adapting the existing materials to meet the needs of VIP students. The Supreme Court instructed the parties to meet and reach a mutual agreement for the court's eventual approval. While all of Bizchut's main demands were met, two matters remained unsettled: setting a date for the conversion of textbooks and for the provision of the materials in digital format adapted for the visually impaired.

Regarding the former, the ministry argued that such a conversion takes time and that the requirements for teaching staff will not come into force immediately. Concerning the latter, the ministry claimed that due to copyright issues, the possibility to provide digital adaptations depends on publishers and the timeline would have to be mutually resolved with them. Nevertheless, the ministry agreed that digital versions were necessary, and it made the approval of new school books conditional upon the supply of digital versions.

This case could have been easier to resolve if Israel had embedded in its local copyright law, as in other countries, a specific exception recognising the access right of disabled persons to materials protected by copyright. Indeed, even before the adoption of the Marrakesh Treaty, it was possible for countries to enact copyright exceptions for their disabled populations and carry them forward into the digital era, as long as they were drafted in line with the stipulations of the Berne Convention three-step test.

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78. Zemer & Gaon, *supra* note 76, at 841.

79. *Id.*

The above four cases from Colombia, USA and Israel underscore the fact that a human rights approach to access for accessible formats for Uganda's VIPs can serve as a useful model.<sup>80</sup> Uganda should take similar approaches while dealing with such situations.

## VII. WHY UGANDA RATIFIED THE TREATY OF MARRAKESH

Uganda signed but did not ratify the Marrakesh Treaty until 4 May 2018. As a developing country, it will benefit significantly by domesticating the Marrakesh Treaty as discussed below. The treaty will greatly help the country to dismantle barriers of access to accessible format copies. As Band notes:

The Marrakesh Treaty addresses these problems by requiring contracting parties to adopt copyright exceptions that allow accessible format copies, under certain conditions to be: (1) created; (2) distributed domestically; (3) exported outside their country of origin; and (4) imported. Further, contracting parties are given great flexibility in implementing their obligations through "exceptions specifically for the benefit of beneficiary persons, other limitations or exceptions, or a combination therefore," as noted in Article 10(3). The Treaty creates minimum standards for exceptions, with a ceiling presented by existing obligations under the Berne three-step test.<sup>81</sup>

A contracting party to the Marrakesh Treaty enjoys the benefits outlined above in addition to textbooks. The treaty also bridges the information gap between print disabled persons and their counterparts who are not print disabled. This goes a long way in building social inclusion and cohesion in access to knowledge and education for print disabled persons. The humanitarian nature of the treaty makes it possible to harness copyright limitations and exceptions for the benefit of print disabled persons in Uganda and beyond. The treaty is one of its kind and an almost once-in-a-lifetime opportunity to end what has been referred to as the "book famine" for print disabled persons. According to Zemer and Goan:

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80. Interview with Lawyer Kasule, as visually impaired advocate practicing with Kasule and Company Advocates in Wandegaya. The interview was held on September 27, 2017 at 3.00 pm at his office.

81. Band (2013), at 14.

The Marrakesh Treaty was introduced at a time when the IP community became more aware of the needs of people with disabilities. The access dilemma confronting disabled persons involves copyright law, technology, market conditions and an understanding that existing formats, like braille, large print and audio are no longer efficient. The Marrakesh Treaty aimed to overcome some of the challenges with which disabled persons had to deal when laws and policies prohibited their access and use of materials protected by copyright. In the short time since its adoption, the treaty has achieved much, both ideologically and in practical terms.<sup>82</sup>

About 90% of the world's visually impaired people live in developing countries.<sup>83</sup> Even countries which have ratified the Marrakesh Treaty need to do more to take full charge of the benefits of the treaty.<sup>84</sup> Equally, it is important that in promoting access to accessible formats by VIPs, all the major stakeholders actually do participate.<sup>85</sup> As a country that has recently ratified the Marrakesh Treaty, Uganda should avoid making mistakes made by other countries like Malawi in the ratification process.<sup>86</sup> The following observations can be made about the Malawi case.

Malawi embraced the spirit of the Marrakesh Treaty in 2017. However, an analysis of Malawi's copyright law, adopted in September 2016, shows that while the new law permits a range of library activities and services, complex conditions limit in practice what libraries in the country are permitted to do. This was not considered during the ratification and it still impedes access. It is still very difficult for authorised entities or beneficiary persons and persons acting on their behalf to ascertain whether or not accessible format copies are "obtainable commercially and reasonably in the market" (no emphasis on this). For work published outside Malawi, it is still impossible to ascertain with certainty whether it is available in the format needed. For

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82. Zemer, Lior & Aviv Goan, Copyright, disability and social inclusion: the Marrakesh Treaty and the role of non-signatories, *Journal of Intellectual Property Law & Practice*, Vol. 10, No. 11 (2015), 836-849, at 836.

83. *Id.*, at 839.

84. A. Ramalho, *Signed, Sealed, but no Delivered: The EU and the Ratification of the Marrakesh Treaty*, 6(4) *EUROPEAN JOURNAL OF RISK REGULATION* (2015), at 629.

85. D. Ferri and Giannoumis G. Anthony, *A Revaluation of the Cultural Dimension of Disability Policy in the European Union: The Impact of Digitization and Web Accessibility*, Wiley Online Library (16 February 2014), at 34.

86. Interview with Eric Nelson Haumba, Head Librarian, YMCA, Wandegeya, held on September 25, 2017 at his office at 4.00 pm.

Malawi's community of more than 10,000 people who are blind or visually impaired, it will inevitably result in information requests that are delayed or denied. The introduction of a commercial availability test would also put Malawi's law out of step with other countries ratifying the Marrakesh Treaty in Africa and around the world. The diversion of limited resources available for accessibility work to commercial availability research is an unacceptable waste of philanthropic and public resources. Consequently, Malawi, which joined the Marrakesh Treaty on 14 July 2017, is in a strong position to provide leadership in Africa on a domestic implementation that respects both the spirit and the letter of the treaty. However, to achieve this, restrictions such as a commercial availability test must be removed. There is therefore need to work with other associations such as the Consortium of Uganda University Libraries (CUUL) which is the official mouthpiece of electronic libraries in Uganda.<sup>87</sup> Similarly, the National Association of Blind People (NABP) can play a pivotal role in<sup>88</sup> ensuring that key needs of VIPs are taken care of. As Mulumba notes:

The negative attitudes and insensitivity to disability issues reduce persons with disabilities' opportunities to participate and benefit under the development programs as the same level as their non-disabled counterparts. This is contrary to the rights based approach to development, which demands that policies, programmes and practices should not, intentionally or unintentionally, reinforce social, political or economic inequalities. Therefore the nature of the design and requirements of the PRSP programmes, which automatically exclude Persons with disabilities, violate this principle.<sup>89</sup>

The human rights model blends in well with the question of access to published works for Uganda's VIPs. This is so because "the human rights model of disability conforms most to the current human rights' trends and standards in the global community. The model deals with 'power relations and reorients the focus away from need to right', from exclusion to inclusion, from discrimination to equality and from marginalization

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87. *Id.*

88. *Id.*

89. M. Mulumba, *Facilitating Disability Inclusion in the National Development Agenda in Uganda: What Role Can the Human Rights-Based Approach Play?*, 18(2) EAST AFRICAN JOURNAL OF PEACE & HUMAN RIGHTS (2012), at 497.

to equalization of opportunities.”<sup>90</sup> The human rights model is key in aligning itself even with the constitutional dispensation in Uganda. For example, the constitution deals with the right to education,<sup>91</sup> non-discrimination and equality<sup>92</sup> and participation in civil activities.<sup>93</sup> This is more so the case because “under the framework of International Law, the human rights model has been identified and well received by social model advocates since it shares the goal of overcoming all barriers to participation and inclusion of PWDs in society.”<sup>94</sup>

Deepening access to published works for Uganda’s VIPs can also be achieved through the lens of access to information as provided for under Article 41 albeit with challenges to information, which is in the possession of private entities. Access to information is also a key governance question especially in light of citizens demanding for accountability from their government(s).<sup>95</sup> Although guaranteed under Article 41 and the Access to Information Act,<sup>96</sup> the implementation of the right to information remains largely ‘haunted’ by both the pre-1995 constitution laws and a culture of secrecy and officialdom.<sup>97</sup> Yet, there is no doubt that access to information is key in ensuring access to justice,<sup>98</sup> including for marginalised groups. Disability rights have developed under international law from mere social or humane considerations premised on charity to human rights.<sup>99</sup> The new developments in international law acted as a big boost for Uganda to ratify the Marrakesh Treaty.<sup>100</sup> The human rights approach to

90. B.R. Akinbola, *Paradigm Shifts in Disability Models and Human Rights*, 18(2) EAST AFRICAN JOURNAL OF PEACE & HUMAN RIGHTS (2012), at 311.

91. Article 30.

92. Article 21.

93. Article 38.

94. L. Nyirinkindi, *A Critical Analysis of Paradigms and Rights in Disability Discourse*, 12(1) EAST AFRICAN JOURNAL OF PEACE & HUMAN RIGHTS (2006), at 56.

95. Asiimwe D. Katebire, *Access to Information, Gender Participation and Good Governance in Uganda*, 14(1) EAST AFRICAN JOURNAL OF HUMAN RIGHTS & PEACE (2008), at 44-66.

96. Act No. 6 of 2005.

97. H. Onoria, *Realization and Enforcement of the Right of Access to Information in Uganda, 1995-2005*, MAKERERE LAW JOURNAL (2004-5), at 39-56.

98. J. Oloka-Onyango & J. Tumusiime, *How Much do we Really Know? Decentralisation, Access to Information and Improving Accountability in Uganda*, HURIPEC WORKING PAPER No. 28 (June 2010), at vi.

99. KANTER S. ARLENE, *THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW: FROM CHARITY TO HUMAN RIGHTS* (2015).

100. F. ARMSTRONG AND L. BARTON (EDS.), *DISABILITY, HUMAN RIGHTS AND EDUCATION: CROSS-CULTURAL PERSPECTIVES* (1999).

accessible materials helps VIPs in enjoying their right to education.<sup>101</sup>

### VIII. CONCLUSION

The article has examined the marginalisation of persons who are blind, visually impaired or otherwise print disabled in accessing published works in Uganda and beyond.<sup>102</sup> Consequently, Uganda has ratified the Marrakesh Treaty, which it signed on 28 June 2013. This will enable the country's PWDs to benefit from the many copyright limitations and exceptions as given in the treaty.<sup>103</sup> It was not enough for Uganda to have ratified the CRPD and also passed the Persons with Disability Act. It also needed to ratify the Marrakesh Treaty so as to complement its obligations at both the international and national levels. The country also needs to amend its intellectual property and copyright laws so as to aid access to published works for her print disabled persons.

Lastly, all key institutions in Uganda should have a policy in favour of persons with disabilities. Since the country is now a member state of the Marrakesh Treaty, what is left is for her to domesticate the treaty and to amend her copyright laws.

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101. M. COLE (ED.), EDUCATION, EQUALITY AND HUMAN RIGHTS: ISSUES OF GENDER, 'RACE', SEXUALITY, DISABILITY AND SOCIAL CLASS (2012).

102. Leblois Alex, "Implementing the Digital Accessibility Agenda of the UN Convention on the Rights of Persons with Disabilities: Challenges and Opportunities", in Quinn Gerald & Washington Lisa (eds), *European Yearbook of Disability Law*, Intersentia, Vol. 1.

103. UN Division for Social Policy Development (DSPD) and Department. of Economic and Social Affairs (DESA), Toolkit on Disability and Communication Technology (ICT) and Disability.

## **WE HAVE A RIGHT TO LOVE: THE RIGHT TO MARRY AND REPRODUCE FOR WOMEN WITH DISABILITIES IN UGANDA**

Zahara Nampewo\*

### **ABSTRACT**

*This article interrogates the enjoyment of sexual and reproductive rights by women with disabilities in Uganda in two capacities: the right to marry and enjoy sexual and/or romantic relationships; and their experiences of parenthood. Despite the strong legal and human rights framework guaranteeing these rights for all persons, it is commonly and yet incorrectly assumed that women with disabilities are asexual and therefore unable to enjoy the sexual rights of marriage and reproduction. As a result, the experiences and enjoyment of these rights for these women have largely been ignored and negated by society, including family members. The article highlights challenges faced by women in this regard, including discrimination and stigma suffered from the onset of pregnancy right through to motherhood, being ignored and mistreated during antenatal visits, to actual verbal abuse during delivery. The article also lists the lack of social support especially from partners, as well as the effects of intersectionality and multiple layers of discrimination faced, which restrict the enjoyment of fulfilling romantic relationships. Most of the respondents interviewed were economically destitute with limited means for their own socio-economic welfare and had to rely on parents for their livelihood, even when involved in romantic relationships. However, it was found that there are many interventions happening at different levels within the communities sampled, that facilitate an enabling environment for women with disabilities to enjoy their sexual rights just as any other, giving a ray of hope that all is not lost.*

### **I. INTRODUCTION**

One of the most important fronts in the struggle for women's human rights is around sexual and reproductive autonomy, and the coercive and often violent ways in which that autonomy is suppressed. The process of ensuring that women enjoy their sexual and reproductive human rights is slower and more uneven for women with disabilities.

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In most ways, women with disabilities have the same sexual and reproductive health-related needs and rights as anyone else. For example, they have the right to decide if and when to choose a partner, whether and when to have children and to be directly involved in raising these children. It should be recognised, however, that there is a powerful interplay between sexuality and social marginalisation. Many persons such as those with disabilities are sexually marginalised because of their inabilities. The prejudice and silence surrounding sex has serious effects, particularly among marginalised groups and the fear of sexuality amongst women with disabilities represents a social barrier that prevents them from enjoying their sexual and reproductive human rights.

This article focuses on the situation of women with disabilities in Uganda in two aspects: right to marriage and reproductive choice. The selection of these two aspects was stirred by the author's interest when observing women with disabilities on the streets of Uganda's capital, Kampala. Many of these women often have young children with them on the streets, braving the daily hot sun as they peddle small items for sale. When confronted with this picture, questions repeatedly barraged the author as to how these women, who were supposedly vulnerable due to their disabilities, managed to balance making a living whilst tending to young children at the same time. Through a rights-based and legalistic approach, this article interrogates the ability of women with disabilities in Uganda to enjoy sexual and/or romantic relationships and their experiences of parenthood.

Because of the focus on women as a subject of the study, a gendered approach is favoured in guiding the key areas of discussion since it analyses the inequalities, discriminatory practices and unjust power relations which are often at the heart of women's welfare. Similarly, a human rights-based approach is employed because it recognises women with disabilities as rights-holders striving to secure the freedom, choice, dignity and wellbeing related to sexual relationships and parenthood within a human rights framework.

## **II. UNDERSTANDING DISABILITY**

Disability is not an illness, although some disabilities are caused by illness. Rather, disability is a chronic or long-term condition which substantially limits an individual in performing one or more activities of daily living. The World Health Organisation (WHO) defines "disability" as a condition with significant and long lasting effect on an individual's daily life and activities, and which affects their physical, intellectual,

sensory or mental health functionality.<sup>1</sup> This is similar to the definition laid out in the Persons with Disabilities (PWD) Act of 2006 which defines disability as “a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation.”<sup>2</sup>

The definition given by the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) 2006 builds onto the social model introduced in the other instruments. The social model of disability is a reaction to the dominant medical model of disability which argues that society is the main contributory factor in disabling people due to stigma and discrimination, much more than the physical, sensory, intellectual, or psychological variations of the person with disability.<sup>3</sup> In line with its overall purpose of promotion of full and equal enjoyment of human rights and freedoms by persons with disabilities, the CRPD recognises that there are various barriers that may hinder their full and effective participation in society on an equal basis with others.

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. In Uganda, previous surveys have indicated that 12.5% of the population have at least one form of a disability.<sup>4</sup> Applying this estimate to Uganda’s population (approximately 34.6 million as at the most recent census) indicates that there are some 4.3 million people with disabilities in the country.<sup>5</sup>

Whereas one might argue that the population of persons with disabilities in Uganda is small, researching disability is important because of the fundamental rights and welfare issues that it brings along. Additionally, the social model of disability responds to every experience, and no individual’s experience is negligible. It should also be noted that the number of persons with disabilities globally is increasing, particularly in developing countries due to conflicts,<sup>6</sup> natural disasters, malnutrition, aging, accidents, violence, and communicable and non-communicable diseases.<sup>7</sup> It therefore makes the area a credible and significant one for study.

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1. WHO Guidelines, retrieved from <<http://www.who.int/topics/disabilities/en/>>, (accessed on 12 July 2017).

2. Persons with Disabilities Act 2006, Article 2.

3. G. Kangaude, *Disability, the Stigma of Asexuality and Sexual Health: A Sexual Rights Perspective*, 5(4) REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL (2009).

4. UGANDA BUREAU OF STATISTICS, NATIONAL POPULATION AND HOUSING CENSUS 2014 (2015).

5. *Id.*

6. Delight S. Moyo, *Ensuring Sexual and Reproductive Health Rights of Women with Disabilities: A Study of Policies, Actions and Commitments in Uganda and Zimbabwe* (Dissertation, University of Reading, 2010), at 14.

7. For instance, medical ailments such as HIV may cause suppression of immunity and lead to physical as well as mental disabilities.

### A. A Shift in Disability Approaches: From Charity to Rights

There has been a dramatic shift in perspective that has taken place over the past decades from an approach motivated by charity towards those with disabilities, to a scientific explanation and thereafter to one based on rights. As Kangaude avers, the charity model constructed persons with disabilities as unfortunate victims of nature gone awry and therefore deserving society's pity and charity. The location of the problem was therefore in the individual, who by virtue of some physiological or psychological characteristic was labelled handicapped.<sup>8</sup>

The medical model conceived disability as impairment of an individual, and focused on disability as an abnormality subsisting in the individual. A person with a disability was therefore measured against a certain standard of normalcy.<sup>9</sup> Locating disability in the person and conceiving disability as an objective condition subsisting in the person also justified discriminatory treatment.<sup>10</sup> This explains the use of exclusion or elimination of persons having disabilities through processes such as institutionalisation, segregation of schools, asylums and sheltered workshops. The stigma surrounding the sexuality of persons with disabilities was therefore legitimised by science.<sup>11</sup>

A rights-based approach to disability was conceived in the period following World War II which spurred civil rights movements, including the disability movement, to frame their concerns in terms of human rights. They criticised the policies and laws that were based on the medical model, which perpetuated negative stereotypes. In essence, the human rights perspective on disability means viewing people with disabilities as subjects and not as objects. It entails moving away from viewing people with disabilities as problems towards viewing them as rights holders. Thus, the disability rights debate is not so much about the enjoyment of specific rights as it is about recognising persons with disabilities as equals and ensuring the equal effective enjoyment of all human rights without discrimination. Importantly therefore, 'non-discrimination' and 'equality' principles as part of the human rights framework help to make human rights relevant in the specific context of disability.

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8. Kangaude, *supra* note 3.

9. T. Shakespeare, *The Social Model of Disability: An outdated Ideology*, 2 RESEARCH IN SOCIAL SCIENCE AND DISABILITY JOURNAL (2002), at 14.

10. Kangaude, *supra* note 3.

11. *Id.*

Two resolutions adopted in the 1970s were the first signs of a shift from a “caring” to a “rights-based” approach.<sup>12</sup> Other major international developments include the United Nations Standard Rules on the Equalisation of Opportunities for People with Disabilities<sup>13</sup> and the Vienna Declaration and Programme of Action,<sup>14</sup> which allays lingering doubts about the “universality” of human rights and the strength of the international community’s commitment to them.

More importantly is the CRPD, ratified by Uganda in September 2008 without reservations. The CRPD was made in recognition of protection of the rights of persons with disabilities as people who need more intensive support to overcome barriers to participation in mainstream development. The CRPD is commendable for its innovative components with regard to human rights law. It recognises that women and girls with disabilities are often at greater risk of violence, injury or abuse, neglect, or negligent treatment, maltreatment or exploitation both within and outside the home.<sup>15</sup> The treaty obliges states parties to ensure that the sexual and reproductive rights of women with disabilities are respected, and that they can decide freely and responsibly on the number and spacing of their children while retaining their fertility on an equal basis with others.<sup>16</sup>

At a national level, human rights of persons with disabilities are reinforced in the country’s constitution. This, together with the Persons with Disabilities Act of 2006 and the National Policy on Disability in Uganda of 2006, adopt a rights-based approach to disability and ensure legal protection and equal opportunities for people with disabilities (PWDs).<sup>17</sup>

Despite an impressive legal framework, Uganda shows limited progress in observation of the rights of PWDs. In fact, PWDs and women in particular are known to be one of the most marginalised groups.<sup>18</sup> The purpose of this article is not to delve into the detail of human rights shortcomings of PWDs. However, these shortcomings are important to note in order to better appreciate the areas of focus in this article.

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12. Declaration on the Rights of Mentally Retarded Persons, 1971 and the Declaration on the Rights of Disabled Persons, 1975.

13. Adopted by the General Assembly in resolution 48/96 of 20 December 1993.

14. Adopted by the World Conference on Human Rights on 25 June 1993.

15. Preamble CRPD, (q) and Art. 6(1).

16. Article 23.

17. Article 1 of the Person with Disabilities Act obliges the elimination of all forms of discriminations against PWDs. There are also provisions requiring equal opportunities such as for education and employment.

18. UN Convention on the Rights of Persons with Disabilities. Uganda Periodic Report, 2010, CRPD/C/UGA/1.

### III. WOMEN'S SEXUALITY AND SEXUAL RIGHTS

Women's sexuality has become part of the international human rights discourse, falling within the realm of sexual and reproductive health and rights. In order to attain a better understanding of sexuality, it is important to contextualise it within the more general and better understood framework of rights.

Sexuality and sexual rights are guaranteed under a number of international human rights instruments and reference documents. Firstly, mention is made of the WHO Technical Report series released in 1975 which integrates sexual health as part of the right to health. It defines sexual health as "the integration of the somatic, emotional, intellectual and social aspects of sexual being, in ways that are positively enriching and that enhance personality, communication and love."<sup>19</sup>

Following in these footsteps, leading human rights and sexual health organisations have made the necessary link between sexuality and sexual rights by embracing certain human rights that are already recognised in national laws, international human rights documents, and other consensus documents. According to the International Women's Health Coalition (IWHC), for example, the working definition of sexuality links sexual rights to existing human rights that are critical to the realisation of sexual health. These include the right to equality and non-discrimination; the right to be free from torture or to cruel, inhumane or degrading treatment or punishment; the right to privacy; the right to the highest attainable standard of health (including sexual health); the right to marry and to found a family and enter into marriage with free and full consent of the intending spouses, and to equality in and at the dissolution of marriage; and the right to decide the number and spacing of one's children, among others.<sup>20</sup>

The UN made a first attempt to apply a human rights perspective to sexuality with the Convention on Elimination of All Forms of Discrimination Against Women (CEDAW) in 1979. The CEDAW specifies the right to reproductive choice, rights to family and minimum age for marriage.<sup>21</sup> However, the CEDAW makes no explicit mention of PWDs, and therefore has been criticised for its failure to ensure that these women realise their full human rights, including sexual rights, just as all other women.

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19. A. Jablensky, R. Schwarz, T. Tomov, *WHO Collaborative Study on Impairments and Disabilities associated with schizophrenic Disorders*, 62(S285) *ACTAPSYCHIATRICA SCANDINAVIA* (1980), retrieved online at [onlinelibrary.wiley.com](http://onlinelibrary.wiley.com) (accessed on 17 September 2017).

20. International Women's Health Coalition (IWHC), *Sexual Rights Are Human Rights*, retrieved at <https://iwhc.org/articles/sexual-rights-human-rights/>, (accessed 27 February 2018).

21. See, Articles 12 and 16, UN Convention on Elimination of all Forms of Discrimination against Women (CEDAW).

Major progress in this area was seen almost 20 years later at two world conferences which pioneered the agenda for sexual rights: the International Conference on Population and Development (ICPD) of 1994 and the Fourth World Conference on Women of 1995. The ICPD included sexual health under the definition of reproductive health, indicating that its purpose “is the enhancement of life and personal relations, and not merely counselling and care related to reproduction and sexually transmitted diseases.”<sup>22</sup> Additionally, the programme of action agreed at the ICPD put forward the ground breaking notion that women have the right to control their sexuality through, among others, reproductive choice and sexual health.<sup>23</sup>

This position was reinforced a year later in Beijing when the main elements in the sexual rights category were spelled out.<sup>24</sup> The Beijing Platform for Action defined sexual rights in the following terms:

The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence.<sup>25</sup>

Although a great achievement for the recognition of sexual rights, this definition was not a complete victory because it lumped sexual rights together with reproductive rights.<sup>26</sup> The Beijing Platform, however, is crucial because it gave further recognition to the aspect of disability when it stated:

We are determined to intensify efforts to ensure equal enjoyment of all human rights and fundamental freedoms for all women and girls who

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22. Report of the ICPD, A/CONF.171/13, para 4.6.

23. A/CONF.171/13. The International Conference on Population and Development (ICPD) was held in Cairo, Egypt in September 1994. It finalized a program of action which endorsed a new strategy emphasizing the numerous linkages between population, development and the empowerment of women (see principles 4 and 8 of the Plan of Action). The international conference gave focus to women’s freedom to control reproduction.

24. Para 96 of the Beijing Declaration and Platform for Action provided that the human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. It also extends to equal relationships between women and men in matters of sexual relations and reproduction, including full respect for the integrity of the person, and requires mutual respect, consent and shared responsibility for sexual behavior and its consequences.

25. Para. 96, Beijing Platform.

26. Petchesky 2006, in Kangaude, *supra* note 3.

face multiple barriers to their empowerment and advancement because of such factors as their . . . disability.<sup>27</sup>

These international instruments are evidence of acknowledgement by states parties that they must take specific measures to ensure that sexual and reproductive rights are protected, respected, and fulfilled. However, it was not until 2004 that attempts were made to define sexual rights. The then UN Special Rapporteur on the right to health, Paul Hunt, wrote:

...no doubt that the correct understanding of fundamental human rights principles, as well as existing human rights norms, leads ineluctably to the recognition of sexual rights as human rights. Sexual rights include the right of all persons to express their sexual orientation, with due regard for the well-being and rights of others, without fear of persecution, denial of liberty or social interference.... The contents of sexual rights, the right to sexual health and the right to reproductive health need further attention, as do the relationships between them.<sup>28</sup>

Hunt's definition attempts to develop the term 'sexual' from a mere biological or physical understanding to embrace other aspects that enrich human living. Yet again, the WHO explicated the term further, resulting in the most commonly cited definition of sexual rights:

Sexual rights embrace human rights that are already recognised in national laws, international human rights documents and other consensus statements. They include the right of all persons, free of coercion, discrimination and violence, to:

- i. the highest attainable standard of sexual health, including access to sexual and reproductive health care services;
- ii. seek, receive and impart information related to sexuality;
- iii. sexuality education;
- iv. respect for bodily integrity;
- v. choose their partner;
- vi. decide to be sexually active or not;

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27. Para. 232

28. INTERNATIONAL COUNCIL FOR HUMAN RIGHTS, *SEXUALITY AND HUMAN RIGHTS* (2009).

- vii. consensual sexual relations;
- viii. consensual marriage;
- ix. decide whether or not, and when, to have children; and
- x. pursue a satisfying, safe and pleasurable sexual life.<sup>29</sup>

In light of the above definition, it is clear that sexual rights embrace a wide range of aspects, some of which are related to stand-alone rights under international law. In other words, sexual rights are not new rights, but rather the existing rights applied to sexuality and they are gaining ever-increasing recognition internationally.<sup>30</sup>

Even so, respect and observance of sexual rights is not without contention and there is still great debate at the international level about whether or how to define sexual rights. For example, at the 58th Commission on the Status of Women in March 2014, country after country, including from the Global South, expressed disappointment in their inability to agree on sexual rights and committed to keep fighting for them. At the 47th Commission on Population and Development in April 2014, 59 countries voiced support for sexual rights during negotiations, and 58 governments signed onto a statement calling for sexual rights to be included in the post-2015 Sustainable Development Goals.<sup>31</sup>

Notably, even though there is undeniable momentum for the global sexual rights movement, this is countered by considerable backlash. Conservative forces at the United Nations, often led by Iran and the Vatican, have worked to obstruct global recognition of sexual rights as human rights. Thus, advancement of the agenda on sexual rights is not without its challenges.

This article focuses on two aspects of sexual rights: right to marriage and right to reproductive choice.

### *C. Sexuality and Sexual Rights of Women with Disabilities*

PWDs face the stigma of asexuality. Following from the definition of sexual rights given in the preceding section, asexuality could mean lack or deficiency to express or experience any one or more of the elements constituting sexuality. The stereotype that ascribes asexuality to PWDs is a general phenomenon in society. To most, PWDs are asexual beings.

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29. *Id.*

30. Klugman 2000, in Kangaude, *supra* note 3.

31. IWHC, *supra* note 20.

The assumption of asexuality for PWDs emanates from the roles that society ascribes to sexuality. At the socio-cultural level, sexuality is constructed to serve a variety of needs, the major one being a means of procreation.<sup>32</sup> PWDs are often viewed as ‘*abnormal*’ and therefore carrying the capacity to produce other ‘*abnormal*’ beings, which explains the fear of allowing them to enjoy their full sexuality in this regard. There are also issues raised regarding capacity to consent to sexual relations, especially for persons with mental challenges.

The stigma of asexuality has adverse effects on the sexual wellbeing of PWDs especially in relation to marriage and reproduction. Shakespeare, in his groundbreaking book, has given an insightful account of the impact of this denial of sexuality on PWDs. This includes lack of sexual self-esteem, failure to enjoy pleasurable sex, and failure to get sexual partners.<sup>33</sup> Their access to sexual expression may be limited or excluded.<sup>34</sup> They are thought of as incapable of consenting to sexual relationships so that they are on one hand protected by the law from sexual abuse, but on the other denied sexual relationships.<sup>35</sup>

From the foregoing literature, therefore, sexuality is generally perceived as a problem for PWDs. Neither are intimate partnership nor motherhood perceived as realistic perspectives in disabled women’s lives since society does not think that they are capable of fulfilling these roles. This position is not helped by the approach adopted in the CRPD, which shies away from portraying PWDs as sexual subjects. The CRPD does not explicitly mention sexuality and sexual relationships. The term “sexual” is mentioned in Article 25(a) in the context of health and only in conflation with reproductive health. Otherwise, it mentions the right of PWDs to marry and have a family, which *prima facie* is a narrower context than sexual relationships.

All in all, the impact of the existing literature which majorly negates the enjoyment of key aspects of sexuality and sexual rights of women with disabilities, together with the timidity of the CRPD in guaranteeing the same, justify asking questions surrounding the ability and ways in which women with disabilities in Uganda initiate and maintain sexual and/or romantic relationships, and their ability to make informed choices on reproduction. The section below outlines the legal position on marriage and reproduction for women with disabilities.

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32. See *supra* note 3.

33. Tepper 2000, in Kangaude, *supra* note 3.

34. Shuttleworth & Mona, 2002; Wade, 2002, in Kangaude, *id.*

35. Evans & Rodgers, 2000, in Kangaude, *id.*

### A. Consensual Marriage

The positive right of all people to marry is acknowledged and upheld under human rights law, both internationally as well as nationally. The Universal Declaration of Human Rights (UDHR) establishes that consent to marriage should be freely given and that there should be equal rights for men and women: at marriage, in marriage, and at its dissolution.<sup>36</sup> Similarly, the International Covenant on Civil and Political Rights (ICCPR) as well the International Covenant on Economic and Social Rights (ICESCR) recognise the right of men and woman of marriageable age to marry and found a family.<sup>37</sup> In Uganda, the constitution entitles a man and woman of 18 years to marry and start a family.<sup>38</sup>

More specifically to disability, the Committee on Social, Economic and Cultural Rights in its General Comment No. 5 states that laws and social policies and practices should not impede the realisation of the rights of PWDs to marry and form a family.<sup>39</sup> Comment No. 5 reiterates Rule 9(2) of the Standard Rules, stating that ‘persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood.’ It then stresses that ‘the needs and desires in question should be recognised and addressed in both the recreational and the procreational contexts’.<sup>40</sup> Additionally, General Recommendation 18 of the UN CEDAW Committee on Disabled Women, basing on article 3 of the CEDAW, observed that women with disabilities “*can participate in a social and cultural life.*” Ideally, this includes the right to marry or associate intimately.

At the national level, the Persons with Disabilities Act 2006 recognises the right of PWDs to marry and found a family and to decide the number of and spacing of children.<sup>41</sup>

Despite these legal guarantees, the enjoyment of consensual marriage for women with disabilities is not automatic. Rannveig Traustadottir states that compared to both men with disabilities and non-disabled women, women with disabilities are

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36. Art. 16 UDHR.

37. Art. 23 ICCPR, Art.10, ICESCR. This right is elaborated upon by the Human Rights Committee in General Comment No. 19, HRI/GEN/1/Rev.9 (Vol.I), which emphasizes the fact that no marriage shall be entered into without the free and full consent of the intending spouses.

38. Article 31.

39. Paras. 30 & 31.

40. Section 5.3.4.

41. Section 36.

more likely to never marry, marry later, and to be divorced if they do get married.<sup>42</sup> Also, comparison of divorce rates of women and men with disabilities seems to suggest that women with disabilities are more likely to be left alone than are men.<sup>43</sup> When disability occurs during marriage, men are much more likely to divorce their wives who become disabled, while the marriage rarely breaks down if it is the man who becomes disabled.<sup>44</sup>

Moreover, the legal right for PWDs to marry is not always practically possible. In one case before the European Court of Human Rights, *Lashin v. Russia*,<sup>45</sup> the applicant challenged the position of the Russian Family Code which prohibited persons from marrying if they were legally incapacitated due to a mental disorder. In this case, the applicant suffered from schizophrenia and had been prevented from registering his marriage. The court found a violation of article 8 on the right to respect for private and family life. This decision was premised on the maintenance of the applicant's status as an incapacitated person despite several efforts by him and his family to have it reviewed for two consecutive years.

However, while the European Court went ahead to find a violation of the applicant's Article 8 rights, due to the deficiencies in the justice system which denied him a reclamation of his capacity, the court did not pronounce itself on the legality or otherwise of the denial of marital status to a couple where one of the parties has a mental disability. In this regard, even a court such as the European Court of Human Rights, regarded as fairly progressive and which has decided many relatively progressive judgments on human rights on contentious aspects such as sexual rights for lesbians and gay persons, was not confident to secure the right to marry for persons with mental impairments. Instead, it endorsed the traditional view that inability to marry is a legal consequence of incapacity status. In conclusion, therefore, the reality is that legal guarantees exist for most of the rights, but it is rather the politics and goodwill that determine what is done in realising the rights of PWDs.

### *B. Reproductive Rights*

The WHO states that reproductive rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and

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42. R. Traustadottir. *Obstacles to Equality: The Double Discrimination of Women with Disabilities: Overview Article* (1990).

43. *Id.*

44. *Id.*

45. *22 January 2013 (ECHR)*.

timing of their children and to have the information and means to do so. They also include the right to make decisions concerning reproduction free of discrimination, coercion and violence.

Relatedly, the UDHR guarantees the right of men and women of full age, without any limitation, the right to found a family.<sup>46</sup> This position is complemented by Article 23 of the ICCPR which reinforces the right of all couples and individuals to found a family freely and responsibly,<sup>47</sup> and on the right of man and woman to have the same rights to decide on the number and spacing of their children.

The right to reproduction is also expressly confirmed for PWDs such as in the CRPD<sup>48</sup> and further in General Comment No. 5 to the ICESCR which states that PWDs must not be denied the opportunity to experience their sexuality and parenthood.<sup>49</sup> While the ICESCR Committee notes that these rights are commonly denied to both sexes, it explicitly mentions that women with disabilities also have the right to protection and support in relation to motherhood and pregnancy.<sup>49</sup> In addition, the CEDAW Committee has recommended that states take special measures to ensure that women with disabilities have equal access to healthcare, including reproductive health services.<sup>50</sup>

Comparably, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol) extends women's rights to sexual and reproductive health to include the right to control their fertility; the right to decide the number and spacing of children; the right to choose any method of contraception; and the right to have family planning education.<sup>51</sup> By this, the right to reproduction is not merely in the act of having children, but further extends the duty of the state to a facilitative environment including education and healthcare services.

Despite these very progressive standards, the world has not always felt that PWDs should have the right to reproduce. Historically, many nations have had laws that prohibit PWDs to bear children, among them Germany which in 1933 enacted the Law for the Prevention of Genetically Diseased Offspring. This law permitted forced sterilisation of anyone who had epilepsy, schizophrenia, mental impairment, genetic

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46. Art. 16

47. Art. 23, para. 2

48. Art. 23, para. 1 (a) and (b).

49. General Comment 5 (PWDS), UN Office of the High Commissioner for Human Rights: retrieved from <<http://www.unhchr.ch/tbs/doc.nsf/0/4b0c449a9ab4ff72c12563ed0054f17d>>, (accessed on 10 October 2011).

50. General Recommendation No. 24, 14-15, 17.

51. General Comment No. 2 on Article 14.1 (a), (b), (c) and (f) and Article 14. 2 (a) and (c), Maputo Protocol.

visual impairment, hereditary deafness or manic depression.<sup>52</sup> In the United States, Harry Laughlin's 1914 Model Eugenical Sterilization Law permitted forced sterilisation of persons who had mental impairment or who were deaf or blind.<sup>53</sup>

The right to procreate for women with disabilities is limited on a number of justifications, one being the threat of harm to others. Benatar argues, for example, that autonomy rights cannot permit risking severe harm to children. Those who risk transmitting HIV, for instance, cannot assert a right to reproduce.<sup>54</sup> In this regard, society's interest in restricting the right of parenthood for women with disabilities is premised on the need to limit more creation of disability. This view, however, is limiting in that it omits the supposition that fathers too may pass on the disability to their children.

Fortunately, this reasoning has been challenged at the international level. According to the UN Special Rapporteur on Violence Against Women, "society's fear that women with disabilities will pass their disability on to their children has resulted in discrimination against women with disabilities from having children."<sup>55</sup>

Another stereotype usually cited in justifying the restriction of parenthood for women with disabilities is that these women are in need of care themselves and thus cannot look after others. As Rannveig Traustadottir states, the traditional image of the mother as the sole caretaker and nurturer of her child is still the image society uses as its reference point.<sup>56</sup> Generally in patriarchal societies such as Uganda, the bulk of care is provided by women in the immediate family, either wife or daughter in the case of elderly care, and mother in case of childcare.

A combination of cultural and socio-economic reasons keeps the gender bias in place, foremost being the fact that the value of women's time in the labour market is quite low compared to that of men.<sup>57</sup> As a result, care work which often happens at home is relegated to women on the assumption that they do not earn much outside the home as compared to their male counterparts. This position is further reinforced by

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52. J. Rosenberg, *Sterilisation in Nazi German* (2016), retrieved from: <<https://www.thoughtco.com/sterilization-in-nazi-germany/>>, (accessed on 27 February 2018).

53. Lombardo P. *Eugenic, sterilization laws*, retrieved from: <<http://eugenicsarchive.org/html/eugenics/essay8text.html>>, (accessed 27 February 2018).

54. D. BENATAR AND D. ARCHAND, *PROCREATION AND PARENTHOOD: THE ETHICS OF BEARING AND REARING CHILDREN*, OXFORD UNIVERSITY PRESS (2010), at 34.

55. Report of the UN Special Rapporteur on Violence against Women, A/HRC/29/27/Add.2 accessed at [www.ohchr.org/EN/HRBodies/HRC/.../Session29/.../A\\_HRC\\_29\\_27\\_Add\\_2\\_en.doc](http://www.ohchr.org/EN/HRBodies/HRC/.../Session29/.../A_HRC_29_27_Add_2_en.doc), on 11 October 2017.

56. Traustadottir, *supra* note 42.

57. A. Aya, *The Changing Shape of Care Diamond: The Case of Child and Elderly Care in Japan*, Gender and Development Program Paper No. 9, Geneva: UNRISD, 2010.

care policies that leave women with no alternative but to interrupt their careers in their 20s and 30s in order to take care of their children. This understanding of the care economy is that it is often women who provide care for others. Unfortunately, this supposition intensifies the pressure on the care economy, and on women in particular in playing their dual roles as care givers and as income earners.<sup>58</sup> Thus, it is difficult for many to imagine how a mother with a disability can fill the caring and nurturing mothering role, if they too deserve care.

On the basis that they too need care, courts have denied parents with disabilities the right to care for their children. In the United States, for example, dependency statutes allow the court to reach the determination that a parent is unfit (a determination necessary to terminate parental rights) on the basis of the parent's disability.<sup>59</sup> In every state, disability may be considered in determining the best interest of a child for purposes of a custody determination in family or dependency court. In theory, a nexus should always be shown between the disability and harm to the child, so that a child is taken from a custodial parent only when the parent's disability is creating a detriment that cannot be alleviated. However, this is not the reality.<sup>60</sup>

The attitude of the courts towards parenting and disability is evident in the case of *Carney v. Carney*.<sup>61</sup> Here, the court found a father with a physical disability unable to "do anything for [his] boys .....except maybe talk to them and teach them, [and] be a tutor, which is good but not good enough."<sup>62</sup> On appeal, the California Supreme Court reprimanded the Superior Court for "stereotyping persons with disabilities as incapable of being good parents."<sup>63</sup>

In other instances, parents who are deaf are viewed as incapable of effectively stimulating language skills while parents who are blind are thought to be unable to provide their children necessary attention or discipline.<sup>64</sup> And, as in *Carney*, courts routinely find parents with spinal cord injuries and other physical impairments unequipped to adequately supervise their children. The holding in this case reinforces

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58. S. Cook and X.Y. Dong, *Harsh Choices: Chinese Women's Paid Work and Unpaid Care Responsibilities under Economic Reform*, 42(4) DEVELOPMENT AND CHANGE (2011), 947- 966.

59. Robyn Powell, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*, National Council on Disability (2012), retrieved from: <<https://www.ncd.gov/publications/2012/>>, (accessed 26 February 2018).

60. *Id.*

61. 42 Cal.5d 437.

62. Susan Kerr, *The Application of the Americans with Disabilities Act to the Termination of the Parental Rights of Individuals with Mental Disabilities*, 16(2) JOURNAL OF CONTEMPORARY HEALTH LAW & POLICY (2000), at 405.

63. *Id.*

64. *Id.*

society's bias towards ability, while dismissing non-obvious strengths of PWDs which are just as important in preserving familial bonds.

Additionally, when women with disabilities do become mothers they encounter many difficulties because the non-disabled world assumes that the disability makes them unfit to be mothers. Many lose custody of their children in divorce while others may have their children removed from their care by social welfare agencies, solely on the grounds that they have a disability.<sup>65</sup> For example, after divorce, the custody of children is usually given to a violent husband rather than to a wife with disabilities because she is considered "not physically capable to take care of children."<sup>66</sup> Moreover, motherhood, when experienced by women with disabilities, is mostly restricted to women who have physical disabilities. Mothers with mental retardation are even more invisible than other mothers with disabilities and very little is known about their lives and struggles.<sup>67</sup>

For these and other reasons, society does not expect women with disabilities to practice the right of reproduction, and in fact, does not prepare these women accordingly either through sexual knowledge or information on pregnancy and child bearing.<sup>68</sup>

*1. Sterilisation*—Because women with disabilities are generally perceived as not being able to fulfill their gender-assigned roles of reproduction, sterilisation becomes a natural solution for their families. For purposes of this article, "forced sterilisation" targeted at women with disabilities refers to the situation in which a person is sterilised after expressly refusing the procedure, without her knowledge, or is not given an opportunity to provide consent. Forced or coerced sterilisation of women and girls with disabilities is often undertaken as a way to control menstrual cycles which takes away reproductive capacity without free and informed consent.

Women with disabilities are particularly vulnerable to forced sterilisations performed under the auspices of legitimate medical care or as the result of decisions made by their parents, guardians, or doctors without the individual woman's consent.

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65. Traustadottir, *supra* note 42.

66. INTERNATIONAL NETWORK OF WOMEN WITH DISABILITIES (INWWD), DOCUMENT ON VIOLENCE AGAINST WOMEN WITH DISABILITIES (2010), at 8.

67. Traustadottir, *supra* note 42.

68. See, C. Thomas, *The baby and the bath water: Disabled women and motherhood in social context*, 19(5) SOCIAL HEALTH (1997), 622–643, which narrates the case of one woman with disability, Danai who believed that her mother did not share information on childbearing with her because she has albinism. According to Thomas, society creates stigma and once a person does not refute such creation, she may begin to develop negative thoughts, feelings, low self-esteem and low self-worth.

The Special Rapporteur on Violence against Women has referred to forced sterilisation of women with disabilities as a form of violence and classified it as a “global problem.” According to her, no group has ever been as severely restricted, or negatively treated, in respect of their reproductive rights as women with disabilities.<sup>69</sup>

Additional to the statement by the UN Special Rapporteur, other international pronouncements against forced sterilisation include the report by the UN Special Rapporteur on the Right to Health which recognises that forced sterilisations, rape and other forms of sexual violence, which women with mental disabilities are vulnerable to, are inherently inconsistent with their sexual and reproductive health rights and freedoms.<sup>70</sup>

Also, the statute governing the International Criminal Court defined and codified, for the first time in International Criminal Law, enforced sterilisation as a crime against humanity and a war crime. According to the Rome Statute, forced sterilisation together with other listed reproductive and sexual crimes are comparable to the most atrocious international crimes and, in many cases, amount to torture and genocide. Furthermore, and for the first time, there is recognition that violations of women’s self-determination on issues related to reproduction—both forced pregnancies and forced sterilisation—constitute very serious crimes according to international humanitarian law.<sup>71</sup>

However, courts have not been so bold as to take away the discretion from the state or parents in applying sterilisation to women with disabilities. This is evident from a case before the European Court of Human Rights, *Gauer and Others v. France*,<sup>72</sup> which concerned sterilisation for purposes of contraception of five young

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69. SRVAW, Rep. of the Special Rapporteur (2012), para. 28.

70. Paul Hunt, Report by the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, Advancement of Women, U.N. Doc. E/CN.4/2005/51 (Feb. 11, 2005), para 38.

71. The Committee on Economic, Social and Cultural Rights has stated that forced sterilization of girls and women with disabilities is a breach of Article 10, protecting the family, of the *International Covenant on Economic, Social and Cultural Rights*. The Human Rights Committee addresses the prohibition of forced sterilization in the *International Covenant on Civil and Political Rights* through Article 7, prohibiting torture, cruel, inhuman or degrading treatment; Article 17, ensuring the right to privacy; and Article 24, mandating special protection for children. Furthermore, the Committee on the Rights of the Child has identified forced sterilization of girls with disabilities as a form of violence and noted that State parties to the *Convention on the Rights of the Child* are expected to prohibit by law the forced sterilization of children with disabilities. The Committee has also explained that the principle of the “best interests of the child” cannot be used to justify practices which conflict with the child’s human dignity and right to physical integrity.

72. *Appl. No. 65121/08, Aug 2011. Decision on the admissibility delivered on 23 October 2012.*

women with mental disabilities. The five applicants submitted in particular that there had been an interference with their physical integrity as a result of the sterilisation which had been carried out without seeking their consent and alleged a violation of their rights to respect for their private lives and their rights to found families. They further submitted that they had been subjected to discrimination as a result of their disabilities. The European Court failed to pronounce itself on the substantive merits of the case, and instead relied on the fact that the application had been lodged out of time and therefore declared it inadmissible.

What is clear from the foregoing discussion is that whereas the law on right to marriage and reproduction guarantees equal treatment for persons with or without disabilities, the enjoyment of the same especially by women with disabilities is limited. In the place of autonomy and the right to make their own decisions for women with disabilities, there are substituted decision-making regimes such as guardianship or even parents. As a result, the right of women with disabilities to marry and bear children has largely been disregarded or ignored. Unfortunately, even the courts have not been bold enough to return these rights to women with disabilities, leaving them as sexual objects rather than sexual subjects and bona fide rights holders.

#### **IV. RIGHTS AND RESILIENCE: EXPERIENCES OF MARRIAGE AND REPRODUCTION FOR WOMEN WITH DISABILITIES IN UGANDA**

##### *A. Methodology*

This section discusses findings from interviews with a cross-section of women with disabilities in Mpigi, central Uganda. Whereas there are many types of disability including physical impairments affecting movement, sensory impairments such as visual or hearing impairments, neurological impairments such as epilepsy and cognitive impairments such as autism or Down Syndrome, this study focused on women with physical and visual impairments on the basis that they were in position to share information without the use of a translator.

Individual interviews were conducted with 12 women, 11 of whom had physical disabilities and only one with a visual impairment. The interviews were semi-structured and focus on the following themes: family and community attitudes and treatment of women with a disability when in intimate relationships or upon having babies; knowledge of laws on disability; and existent social support. The discussions with the respondents were targeted so as to allow them to give a 'personal experience' narrative. Through this, their concerns and experiences on sexual rights, the effects of disability and social support groups were interrogated.

Content analysis of the data consisted of coding for themes from each interview, organising and summarising experiences by theme, and then locating pertinent quotes. During the data collection and analysis the researcher synthesised and reflected upon the interview responses.

### *B. Experiences of Sexual and Reproductive Needs and Rights*

*1. Marriage and Reproduction*—Generally, women with disabilities in Uganda are familiar with the fact that they should enjoy their sexual and reproductive rights as much as any other woman. Though shy, many of the respondents narrated that they were in stable relationships, mutually initiated and some had even experienced the joy of motherhood. Whereas a pregnancy might initially be frowned upon, the society quickly came to respect the right of women with disability to choose when to have children and with whom. One pointer to the fact that the Ugandan society is generally accommodative of disability is the fact that all the partners of the women interviewed are without disability. This by itself speaks towards a recognition that women with disabilities are sexual beings capable of exercising their right to choice and deserving of any sexual partner so desired.

Nantume's story is a good illustration of the right to sexual autonomy and reproduction. Nantume, 38 years, is a trader selling charcoal, tomatoes and potatoes. She has six children. She had her first three children from her husband with whom they had had a customary marriage. She later entered into a second relationship which bore an additional three children. In her words, she said she sought a second relationship because she wanted more children and also because "she was seeking revenging from her first partner who had left her." This story is one that illustrates the power by women with disabilities to choose, both intimate partner and children.

None of the stories shared raised the aspect of incest. Because women with disabilities are often left at home with limited social interaction, there is a presumption that their first sexual experiences will be limited to close blood relatives. The respondents consistently emphasised that their choice of partner and sexual relations were consensual. Of course, this may not rule out possible cases of incest but it was noteworthy that this issue never surfaced.

Similarly, sterilisation does not surface as a common occurrence in controlling sexual and reproductive rights of women with disabilities in Uganda and none of the respondents met had undergone it. This can be read in two ways: one is that Ugandan society is more open to the exercise of sexual and reproductive rights by women with disabilities; and two, that health services in Uganda are generally stretched and limited to basic primary healthcare, and that sterilisation operations are more complex and

therefore unaffordable and inaccessible especially to lower level community populations such as the one where this study occurred. Whichever is true, it is reassuring that the women in this sample had not been subjected to this violation of their sexual and reproductive health rights.

However, many of the respondents shared experiences of discrimination and stigma suffered at health centres during antenatal visits and delivery. It is clear from their narrations that socio-cultural ambivalence towards women with disabilities becoming parents persists and this often happens at health centres when they seek sexual and reproductive health care services. Often, they are questioned why they bothered to conceive in their state. The message that is commonly conveyed either blatantly or covertly is that women with disabilities have no place in the realm of sexuality, which includes childbearing, because they are disabled.

Notably also, women with disabilities in Uganda are discriminated against from the onset of pregnancy right through to motherhood, including being ignored and mistreated during antenatal visits, to actual verbal abuse during delivery. According to Christine Peta, the zone of childbearing represents a continuous terrain of oppression which attacks the most fundamental of the human rights of women with disabilities. Aspects such as communication barriers between women with disabilities and health workers increase feelings of discomfort and humiliation,<sup>73</sup> and these ring true in the case of Uganda.

Furthermore, a significant number of the respondents in this study expressed anger about the negative attitude as well as the inability of the healthcare staff to provide them with appropriate sexual and reproductive health information and services. The fact that these health workers were mostly fellow women did not help much in these situations.

In sharing about her experiences of delivery, Nantume confirmed that the delivery beds in the hospital are too high and the health workers use insulting language. A recent report on women and disabilities in Uganda confirms that the healthcare system lacks “access facilities” and appropriate etiquette to handle the health needs of these women.<sup>74</sup> Hospital staff often reject the idea that female patients with disabilities are interested in engaging in intimate relationships, and any display of sexual interest or conduct is considered ‘unusual.’<sup>75</sup> In these inimical circumstances, women with disabilities will often be discouraged from seeking professional health services and

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73. Christine Peta, *Disability is not asexuality: the childbearing experiences and aspirations of women with disability in Zimbabwe*, 25(50) JOURNAL OF REPRODUCTIVE HEALTH MATTERS (2017).

74. *Women with disabilities decry midwives dehumanizing treatment*, NEW VISION, April 2017.

75. Interview with a respondent, 24 July 2017, Mpigi.

Nagujja, 21 years, is a good illustration of this. Nagujja, a mother of five, had her first child at 14 years. To date, she does not use any form of birth control and yet she does not want to have more children. Just like other women in Uganda, she faces an unmet need for family planning, and in her case, mostly because she is unwilling to seek professional health and family planning care services from health centres.<sup>76</sup> It is no surprise therefore that with such negative response from the formal healthcare system, women such as Nantume instead resort to traditional birth attendants for delivery services. According to Nantume, “traditional birth attendants are more respectful and gentler.”<sup>77</sup>

Interestingly, another respondent, Mutiibwa, aged 27 and mother of one and pregnant, preferred the services of private health centres to those of government hospitals. According to her, the response of health practitioners is more friendly in these private settings, largely because patients are paying customers. However, she shared that even there, women with disabilities are always pitied, which to her is an unwanted expression of care.

Another aspect of focus in relation to reproductive rights of women with disabilities is that of the interplay of power. Power dynamics are centrefold within intimate relations of women with disabilities and have a direct link with the rights to reproduction and marriage. Nambatya, aged 37 and very physically challenged (drags herself on the ground), has three children with her partner but they are not legally married. She lives with her grandmother and her partner visits only when he so wishes. He does not provide much economic or social support because he is rarely there. “I have no control over him, he comes and goes when it suits him,” she says.

Similarly, Nantongo, a third wife in a polygamous marriage, states that she is happy for whatever time she gets to share with her husband. Mutiibwa, on the other hand, avers that finding a sexual partner was mainly by chance rather than by choice. These narrations indicate the powerlessness of women with disabilities to control their men. There is a feeling that women with disabilities are more on the receiving end than equal partners in intimate relationships.

Likewise, power dynamics is the aspect of early sexual encounters for most women with disabilities. Kisakye, who is visually impaired, first had an intimate relationship at 16 years, just as Nambogga. Nantongo, another respondent, got pregnant at 17 years. The vulnerability that comes with disability, together with other factors such as isolation, limited knowledge on sexual and reproductive rights and young age,

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76. According to the National Housing and Population Census of 2014, the total fertility rate is 5.8 children per woman which is rather on the higher side. *See*, UBOS, *supra* note 4.

77. Interview with respondent, 24 July 2017.

make women with disabilities easy targets and often result into multiple levels of discrimination and powerlessness. All in all, the experiences and enjoyment of the right to marriage and reproduction for many women with disabilities in Uganda remain illusory.

2. *Seeking Legal Solutions to Sexual Rights Violations*—With knowledge and social interaction come confidence and self-esteem. It is noted that all the respondents in this study are active members of a community-based organisation of women with disabilities. In a sense, therefore, most have been recipients of knowledge on the rights of persons with disabilities. The confidence with which these women affirmed their sexual and reproductive rights can largely be attributed to sensitisation and capacity building from community initiatives by the organisation to which they belong.

That said, it is clear that women with disabilities in Uganda generally have a very limited appreciation of the relevant laws on disability rights. Beyond the two respondents who had university degrees, none of the other respondents could identify any laws or policies on disability in Uganda beyond the constitution. They also had limited understanding of the remedies possible in case of violations, explaining the limited recourse to the law.

For instance, both Nantongo and Nagujja, aged 32 and 21 years respectively, got pregnant below the age of 18. In such a case, the men responsible should have been charged with defilement, a serious criminal offence with a maximum sentence of life imprisonment. However, in both cases, the family did not pursue legal measures on the basis that they had limited knowledge of the law.

Limitations in legal responses, however, are not exceptional to Uganda. The facts of the case *I.C. v. Romania*<sup>78</sup> have telling effects on the legal environment in Uganda. The case concerned the applicant's alleged rape when she was 14 years old and the ensuing investigation. The applicant complained that there having been no physical evidence of assault, the criminal justice system in Romania had been more inclined to believe the men involved in the abuse rather than her. Furthermore, the authorities, refusing to take into consideration her young age and physical/psychological vulnerability, had shown no concern for the need to protect her as a minor. She pursued the matter in the European Court of Human Rights.

This case, when viewed with different lenses, reflects the situation of Uganda's legal system. The European Court found that the investigation of the case had been deficient, notably on account of the Romanian state's failure to effectively apply the criminal law system for punishing all forms of rape and sexual abuse, a factor that could

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78. No. 36934/08) 24 May 2016.

just as easily be applied in the Ugandan scenario. Further, the court noted in particular that neither the prosecutors nor the judges deciding on the case had taken a context-sensitive approach, failing to take into account the applicant's young age, her slight intellectual disability and the fact that the alleged rape, involving three men, had taken place at night in cold weather – all factors which had heightened her vulnerability.

Indeed, particular attention should have been focused on analysing the validity of the applicant's consent to the sexual acts in the light of her slight intellectual disability. This set of facts especially regarding the response of the prosecutors or the judges could very much be replicated in Uganda. In consideration of all these limitations, the court held that there was a violation of Article 3 (prohibition of inhuman and degrading treatment).

Another useful legal resource is the case of *X and Y v. the Netherlands*<sup>79</sup> where a girl with a mental handicap was raped in the home for children with mental disabilities where she lived by a relative of the person in charge, the day after her sixteenth birthday (which was the age of consent for sexual intercourse in the Netherlands). She was traumatised by the experience but deemed unfit to sign an official complaint given her low mental age. Her father (the first applicant) signed in her place, but proceedings were not brought against the perpetrator because the girl had to make the complaint herself. In this instance, the legal system denied a woman with disabilities a legal remedy on grounds of lack of competence. Observing that the Dutch Criminal Code had not provided her with practical and effective protection, the European Court therefore concluded, taking account of the nature of the wrongdoing in question, that the second applicant had been the victim of a violation of article 8 of the Convention on Privacy.

What is important to note is that families of women with disabilities find it hard to seek legal remedies for abuses against their daughters, which in turn generally translates into the condoning of violation of the sexual and reproductive rights of women with disabilities in Uganda.

Besides the legal hurdles, there are other factors that hinder referral of violations of sexual rights to the justice system. A further probe into the two cases above indicate that there was surprise from family members when they learnt that their daughters were pregnant. Rather than seeking out the males responsible with the objective to punish, the families sought to negotiate long-term relationships. As Nagujja relays: “...my mother was eager to know which man was ready to love me.” From such a reaction, it is not far-fetched to conclude that families of young women with disabilities are glad that their daughters can, just like other young girls, attract

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79. No. 8978/80) 26 March 1985.

young men, perhaps even for marriage. In this light, pursuing justice and punishment against these young men is out of the question.

3. *Social Support for Women with Disabilities*—General Comment No. 5 to the ICESCR states that persons with disabilities must not be denied the opportunity to experience their sexuality, to have sexual relationships and experience parenthood.<sup>80</sup> While the ICESCR Committee notes that these rights are commonly denied to both sexes, it explicitly mentions that women with disabilities also have the right to protection and support in relation to motherhood and pregnancy.<sup>80</sup> Therefore, a key aspect of the observance of sexual and reproductive rights by women with disabilities is the extent to which they receive social support.

There is community stigma about taking responsibility for having a child with a woman with a disability. As narrated by Nambogga, “*when I told my boyfriend that I was pregnant, he threatened to kill me if I ever told anyone that he was responsible. Then he stopped visiting me.*” With the responsible males missing in the picture, the task of providing core care and social support has fallen to mothers and sometimes grandmothers. In only one instance was a husband mentioned as providing support to his partner especially upon childbirth.

The foregoing discussion cannot be detached from the general struggles that men face with regard to fatherhood and nurturing of children. The classic stereotypical portrayal of a father appears as an authoritarian, impervious and detached male.<sup>81</sup> With this picture in mind, it is not surprising to find that fathers are perceived as ‘hard to reach’ and therefore absent parents.<sup>82</sup>

In reviewing literature for their work with fathers of children with disabilities, Carpenter and Herbert (1997) became increasingly aware how little was known about the reactions of fathers to their situation, particularly in the very early days following the birth of their child.<sup>83</sup> According to Carpenter and Herbert, fathers found it difficult,

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80. General Comment 5 (PWDS), Office of the High Commissioner for Human Rights: retrieved from: <<http://www.unhcr.ch/tbs/doc.nsf/0/4b0c449a9ab4ff72c12563ed0054f17d>>, (accessed on 10 October 2011).

81. McConkey, 1994, ‘the invisible parent’ (Ballard, 1994), ‘the peripheral parent’ (Herbert and Carpenter, 1994), in Barry Carpenter, *Fairer to Fathers. The role of schools in nurturing positive fatherhood – A United Kingdom perspective*, Kairaranga, Vol. 8, Issue 2, 2007.

82. *Id.*

83. E. Herbert and B. Carpenter, *The Secondary Partners: Professional Perceptions and Fathers’ Reflections*, 8(1) CHILDREN AND SOCIETY (1994), 31 – 41, in D. Davys, D. Mitchell and R.E. Martin, *Fathers of people with an intellectual disability: A review of the literature*, retrieved from <<http://usir.salford.ac.uk/38814/>>, (accessed 6 March 2018).

in contrast to mothers, to assert their involvement with babies with disabilities. As a result, grief went unrecognised and unexpressed, which drew the fathers further away from the caring and nurturing role of their children. Also, society did not expect them to get involved with this caring and supportive role. With this in mind, it is no surprise therefore that Nambogga's situation above played out the way it did, leaving her as a sole parent. As such, whereas women with disabilities would love to exercise their sexual and reproductive rights with full social support and especially from their male partners, this has limitations.

Another angle to provision of social support is through children of women with disabilities. Older children sometimes take up the role of nurturer of their mothers with disability, in cases such as provision of escort services to access healthcare services and tending younger siblings. In fact, children are perceived as a form of social protection and insurance. As Mutiibwa states, "*I foresee that I am going to be single mother. I have been advised by an elder relative that a woman with a disability should have many children in order to have insurance for better maintenance in the future.*"<sup>84</sup> Naturally, having many children especially for a woman with disabilities such as Mutiibwa might pose health risks. Unfortunately, it is probably seen as one of the solutions to the socio-economic dilemma that women in her condition often suffer. This is because children often provide for care in the day-to-day lives of women with disabilities, and are a further assurance of welfare and survival when the children are older and can provide for them financially and otherwise.

In conclusion, the absence of state sponsored social support in sexual and reproductive rights for women with disabilities has left this role solely to the family, especially female relatives.

*4. Intersectionality and Multiple Discrimination*—Intersectionality means that several forms of discrimination, which are based on a number of identity layers, may intersect and produce new forms of discrimination. An intersectionality approach begins with the premise that forms of oppression overlap, defining unique social groups. It thus posits that the consequences of race/ethnicity and gender cannot be understood sufficiently by studying these phenomena separately; rather, understanding their overall effects necessitates examining how race/ethnicity/gender structurally interrelate, overlap or intersect to establish access to resources (both material and relational) that promote, and exposures to the risks that undermine, health across the life

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84. Interview with respondent, 24 July 2017.

course.<sup>85</sup>

Disability is always intimately connected to other identity markers such as gender, culture and class. Women with disabilities suffer multiple discrimination based on a number of factors. One is poverty and economic disempowerment. Impoverished women who have disabilities make up some of the most isolated and overlooked people in the world.<sup>86</sup> Gender, socio-economic status, and disability create multiple layers of discrimination. Megan Humphrey focuses on the way these intersectional forces impact the ways in which impoverished women with disabilities experience violence, making them two to four times as prone to violence as their able-bodied counterparts. According to Humphrey, in low resource settings, women with disabilities encounter many forms of violence including caretaker abuse, forced sterilisation, and sexual violence.<sup>87</sup>

Additionally, poverty and disability have a mutually destructive relationship; disability causes poverty and poverty causes disability. Having a disability makes one much more likely to fall into poverty or to worsen existing poverty. Having a disability often requires extra medical attention or assistive devices, both of which add a heavy burden on the household income. Additionally, the experience of poverty makes it difficult to meet basic needs which, if unmet, can lead to disability. Working together, gender and disability create an extreme form of marginalisation.

Most of the respondents interviewed were economically destitute with limited means for their own socio-economic welfare. Most have to rely on parents for their livelihood. Economic disadvantage goes hand-in-hand with limited opportunities of education. Out of the 12 women interviewed, only two had a university degree; the rest had basic primary level education. Poor socio-economic living conditions generally have a specific impact on the living conditions of women with disabilities.

In relation to sexual and reproductive rights, poorer women have less bargaining power or choice over sexual partners. Additionally, they have limited access to healthcare services such as family planning. This position is well documented. Research indicates that economically vulnerable women are less likely to terminate a potentially dangerous relationship and less likely to use contraception.<sup>88</sup>

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85. D. Warner and Tyson H. Brown, *Understanding How Race/Ethnicity and Gender Define Age-Trajectories of Disability: An Intersectionality Approach*, 72(8) SOCSCI MED. (2011), 1236–1248.

86. Megan Humphrey, *The Intersectionality of Poverty, Disability, and Gender as a framework to understand violence against women with disabilities: A Case Study of South Africa*, Clark University Clark Digital Commons International Development, Community and Environment (IDCE) 5-2016.

87. *Id.*

88. H. Anderson, K. Marcovici and K. Taylor, *The UNGASS, Gender and Women's Vulnerability to HIV/AIDS in Latin America and the Caribbean* (2000).

Another aspect of intersectionality is the rural-urban divide. Women with disabilities in rural areas are further away from healthcare services and basic necessities of life such as piped water. This intersection with disability gives women with disabilities different faces of vulnerability.

In conclusion, the experiences of women with disabilities in the expressions of their sexual rights regarding marriage and reproduction are largely perpetual struggles for acceptance as sexual beings and for recognition of their rights just as any other person.

## V. CONCLUSION

This article sought to interrogate the capacity of women with disabilities in Uganda to enjoy sexual and/or romantic relationships and their experiences of parenthood through a rights-based and legalistic approach. It is commonly and yet incorrectly assumed that women with disabilities are asexual and therefore unable to enjoy the sexual rights of marriage and reproduction. This is despite the strong legal and human rights framework guaranteeing these rights for all persons.

In reality, however, sexual rights for women with disabilities have largely been ignored by the wider society at several levels, including family members, the community and even professional personnel such as healthcare practitioners. The medical model of disability continues to dominate. According to the medical model, women with disabilities, and in particular those with intellectual and psychosocial disabilities, are viewed as unfit to engage in sexual activity and unable or unfit to exercise parental rights and responsibilities. As a result of this long-standing and continuing discrimination, women with disabilities have frequently been considered asexual.

All is not lost, however. There are many interventions happening at different levels in communities that are facilitating an enabling environment for women with disabilities to enjoy their sexual rights just as any other. The interventions of organisations such as the National Union of Women with Disabilities Uganda (NUWODU) and its regional branches gives hope to many. NUWODU collaboratively builds the knowledge and skills of women with disabilities, thereby strengthening their socio-economic welfare, confidence and self-esteem. Through trainings such as 'Choice not Chance,' NUWODU has enabled women with disabilities to appreciate

their power in managing intimate relationships.<sup>89</sup>

Women with disabilities are able to enjoy their rights of association. For instance, one community group—Mpigi Disabled Women’s Organisation—facilitates periodic sessions where women with disabilities are able to come together and share their experiences. By so doing, instances of self-pity, self-hate and isolation are diminished. It is reassuring to know that Kisakye, a visually impaired, young woman with a university degree can share coping mechanisms with older, less economically advantaged women with disabilities. The change starts from within, and women with disabilities should be made to realise their inherent right to exercise and enjoy their rights, sexual rights inclusive.

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89. NUWODU, *Analysis of Sexual and Reproductive Health Policies and Laws of Uganda: Ascertain compliance with WHO/UNFPA Guideline on Women and Girls with Disabilities*, Research Report. April 2017.

## DISABILITY POLICIES, ACCESS TO EMPLOYMENT, AND THE PRIVATE SECTOR IN UGANDA

Dianah Ahumuza Ateenyi\*

### ABSTRACT

*This article argues that although both international and domestic law provide for progressive approaches for the realisation of the right to physical access to employment for persons with disabilities (PWDs), there are still glaring challenges that make this right illusory. These include implementation snags due to lack of sensitisation, absence of regulations, and government reneging on some of its initial commitments like tax incentives, among others. As a result, the law has not translated into better economic empowerment of PWDs especially regarding access to employment in the private sector. This article argues that the fact that there is no legal mandate on employers to enact appropriate policies to ensure access to employment, including physical accessibility, has not made the situation any better. As a result, workplaces continue to be both physically inaccessible and inhibit attitude barriers that deny equal participation and inclusion at the workplace. This article seeks to establish the efficacy of policy standards at the workplace in the realisation of the right to physical access to the workplace and employment of PWDs in the private sector. It reviews selected financial institutions as key private sector players. It also explores whether these standards, where they exist, conform to international, regional and domestic legal standards; and where they are non-existent, this has affected the rights for PWDs to employment.*

### I. INTRODUCTION

Historically, in advanced industrial societies, the employment of PWDs was regarded as a charitable gesture following the two main ideologies: the medical model and the tragedy model which still maintain some credibility in most lay communities.<sup>1</sup> The medical model assumes that disability results from an individual's pathology and can therefore be medically rectified. Emphasis is placed on an individual's "abnormality"

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1. D. Goss *et al*, *Disability and employment: A comparative critique of UK legislation*, 11(4) THE INTERNATIONAL JOURNAL OF HUMAN RESOURCE MANAGEMENT (2000), available at <<http://dx.doi.org/10.1080/09585190050075132>>, (accessed on 6 June 2017).

and an expert's ability to rectify the condition. The tragedy model assumes a disabled person as one deserving pity and care by the able-bodied.<sup>2</sup> These ideologies have shaped both our societal and legislative perspectives in the disability field in Uganda, as much as they have influenced the policies and practices of private sector actors.

Employers continue to make assumptions on the abilities of persons with disabilities based on the medical model or societal labels which often lead to blanket exclusions that deny access to employment for PWDs.<sup>3</sup> Physical access to the workplace and employment generally for PWDs remains a big challenge in Uganda both in the public and private sectors, although there is a general lack of reliable disability statistics on the same. This has also affected advocacy efforts on the issue.<sup>4</sup> The World Health Organisation reports that about 15% of the world's population has a disability.<sup>5</sup> Some would even argue that this is a low estimate given the various ways in which disability is defined across countries.<sup>6</sup>

In 2012, Action for Youth with Disabilities Uganda (AYDU), a local non-governmental organisation, conducted a survey among 164 youth with disabilities on current employment patterns in the public and private sector in Uganda. The survey showed that 24% of the youth with disabilities interviewed were employed in the formal sector, 32% were actively involved in the informal sector and 20% in agriculture. About 9% of the interviewees did voluntary work with different organisations and 15% were totally unemployed. Most of those in the informal sector were involved in trade or other petty businesses.<sup>7</sup> These figures demonstrate the general trend of employment of PWDs. The majority is employed in the informal economy, even though the AYDU found that only 15% of the youth with disabilities interviewed were totally unemployed. This is notwithstanding the fact that most of these people do have the necessary qualifications and skills for formal employment.

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2. *Id.*

3. *See*, interview with a respondent working with Letshego Company Limited.

4. DISABILITY PEOPLE'S ORGANISATIONS (DENMARK) & NATIONAL UNION OF PERSONS WITH DISABILITIES (NUDIPU), EMPLOYMENT OF PERSONS WITH DISABILITIES IN THE FORMAL LABOUR MARKET: UGANDA MAPPING (2016), at 6.

5. Katharina Vornholt *et al*, *Disability and Employment – overview and highlights*, 27(1) EUROPEAN JOURNAL OF WORK AND ORGANIZATIONAL PSYCHOLOGY (2018), retrieved at <<http://www.tandfonline.com/loi/pewo20>>, (accessed on 20<sup>th</sup> August 2018).

6. *Id.*

7. ACTION FOR YOUTH WITH DISABILITIES UGANDA (AYWD), CURRENT EMPLOYMENT PATTERNS OF YOUTH WITH DISABILITIES IN THE PUBLIC AND PRIVATE SECTOR IN UGANDA: BASELINE SURVEY REPORT (2012), at 23.

### A. Methodology

The researcher reviewed relevant international, regional and domestic human rights instruments, laws and domestic policies and the Persons with Disabilities (Amendment) Bill 2016. The researcher also reviewed existing research and scholarly works on the subject. The researcher noted that overtime, a lot of emphasis had been placed on the right to education for PWDs without concrete efforts to ensure the employability of the products of these education efforts, thus the choice of the right under investigation.

The researcher studied the financial sector as a typical example of a private sector undertaking whose major objective would ideally be profit maximisation. The objective was to understand how such objectives interplay with disability rights protection. According to the Bank of Uganda website, the current licenced and supervised financial institutions are 154, including commercial banks, credit institutions, forex bureaux, money remitters and microfinance deposit-taking institutions, with branches spread throughout the country, which demonstrates capacity to employ many of the skilled workforce.

Notwithstanding clear statistics on employment trends of PWDs, according to the 2014 Uganda Bureau of Statistics Statistical Abstract on selected labour market indicators, the total employed population was estimated at 7.9 million people while the employment to population ratio (EPR) was 47.8. The overall unemployment rate (UR) was 9.4% in 2012/13 while the urban unemployment rate was about 8.0%. The time related underemployment rate was about 8.9%, skill related inadequate employment was 5.6%, and the income related inadequate employment was 12.9%.<sup>8</sup>

Among the employed population, 33.8% were employed in the agricultural sector, 21.1% in the manufacturing and industry sectors, and 45.1% in the services sector.<sup>9</sup> Scanty as the statistics are, it is not easy to ascertain the exact percentage of the population employed in the private sector as against those employed in the public sector. But, from the classification above, it can be concluded that the bigger part of the population is engaged in the private sector where the financial sector falls under the service industry.

The researcher carried out interviews with two financial institutions: a commercial bank (DFCU Bank Limited) and a micro deposit-taking institution (Letshego Microfinance Company Limited) within Kampala. Both institutions were randomly selected and the researcher interviewed their heads of human resources.

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8. UGANDA BUREAU OF STATISTICS (UBOS), STATISTICAL ABSTRACT ON SELECTED LABOUR MARKET INDICATORS (2014), at 22; see also, UBOS, STATISTICAL ABSTRACT (2016), at 30.

9. *Id.*

The researcher also held key informant interviews with a representative of the Bank of Uganda in charge of regulation and compliance; the registrar of the Uganda Human Rights Commission as the entity that has the mandate of ensuring observance of human rights and hears complaints on human rights violations; a member of the Equal Opportunities Commission who is in charge of disability rights at the statutory body that handles issues of discrimination and marginalisation; a representative of the National Council for Disability; and a representative from the National Union of Disabled Persons in Uganda (NUDIPU). These respondents were found to be critical in determining the issues under the study.

### *B. Theoretical framework*

Disability scholars<sup>10</sup> have advanced the position that the capitalist system, particularly the commodification of labour, is a crucial factor that contributes to the lack of economic advancement of disabled people.<sup>11</sup> While alluding to Marx's theory of absolute impoverishment, Ernest Mandel clarifies Marx's observation that *capitalism throws out of the production process a section of the proletariat: unemployed, old people, disabled persons, the sick, etc.*<sup>12</sup> Marx called these groups a part of the *poorest stratum bearing the stigmata of wage labor.*<sup>13</sup> From this theory, it is clear that capitalism as a political-economic system led to disablement that directly affected PWDs by putting emphasis on labour considered more productive at the expense of the less productive. Emphasis was placed on physical inability and ignored intellectual skills that could add value at the workplace if the person is reasonably accommodated.

Industrial capitalism specifically created not only a class of proletarians but also a new class of 'disabled' persons who could not physically conform to the 'standard' worker and were therefore excluded from paid work. This led to further discrimination and justification for segregating them from mainstream life and into a variety of institutions, including workhouses, asylums, prisons, colonies and special schools.<sup>14</sup> This did not only violate their rights to work and live in community with others but also

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10. These include Victor Finkelstein, Michael Oliver, Colin Barnes, Paul Abberley, Nirmala Erevelles, Lennard Davis, Brendan Gleeson et al.

11. M. Russell, *What Disability Civil Rights Cannot Do: Employment and political economy*, 17 *DISABILITY AND SOCIETY JOURNAL* (2002), available at <<http://www.tandfonline.com>>, (accessed on 7th August 2017).

12. *Id.*

13. *Id.*

14. Marta Russell & Ravi Malhotra, *Capitalism & Disability*, 38 *SOCIALIST REGISTER* (2002), at 213.

their right to dignity, liberty and non-discrimination, among others.

Liberal economists believed that the current economic system is just and view the injustices and unemployment, low pay, inequality, and poverty that occur within that system as unintended consequences of an otherwise just economy. They are reformists who believed that the existing gross inequalities could be bridged through legislation and other measures aimed at correcting ‘market failure.’<sup>15</sup>

The political economy scholars look to the laws as a source of the current evils, whereas the radical economists believe that the economic system itself is the problem and that the hardships experienced are intentional and are required for the proper functioning of the system. People—including many who are disabled, the poor and even destitute—are excluded from work in such a system not because the system is breaking down, but because it is working exactly as intended.<sup>16</sup> The capitalist economy inherently therefore restricts the liberal application of ‘equal opportunity’ to employment for all because unemployment is an actual intended benefit of the system.<sup>17</sup>

Policy makers are keenly aware that the rights affect the functioning of the economy and at the same time, their operation is affected by the market. An entitlement, for instance, is more likely to be established as a right when it has a relatively low cost.<sup>18</sup> These theories have shaped the current legislative trends and have specifically been manifested in the current debates under the Disability (Amendment) Bill where most of the earlier legislated entitlements have been retracted because of the financial burden of implementing the current Act.

From these theories, disability is seen as a creature of capitalism, which bleeds more discrimination at the workplace since employers will concentrate on looking at the cost of employing a person with disability rather than their potential contribution to the organisation. As such, labour from PWDs may continue to be shunned for the sake of profit maximisation.

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15. Rusell, *supra* note 12.

16. *Id.*

17. *Id.*

18. *Id.*

## II. LEGAL AND POLICY FRAMEWORK GUARANTEEING THE RIGHT TO WORK FOR PWDs

### *A. Access to employment for persons with disabilities under International and Regional Human Rights instruments*

There is sufficient recognition of the rights of PWDs to access employment as seen from the several international and regional human rights instruments that recognise the rights of PWDs to work under favourable conditions without discrimination. They also recognise the need for physical accessibility, affirmative action and reasonable accommodation to enable meaningful realisation of the right to work for PWDs. Notable among these instruments is the Universal Declaration of Human Rights (UDHR) 1948, the International Covenant on Civil and Political Rights (ICCPR) 1966, and the International Covenant on Economic, Social and Cultural Rights (ICESCR) 1966. The ICESCR specifically urges States parties to enact appropriate legislation to give effect to the rights under the covenant.<sup>19</sup> The Covenant, under Article 7, provides for the right to work and states that promotions should be based on seniority and competence.

The Convention of the Rights of Persons with Disabilities (CRPD)<sup>20</sup> provides for progressive principles that would ensure the realisation of the rights specifically for PWDs. These include reasonable accommodation, dignity at the workplace, the right to work and live in community with others, among others. The CRPD additionally requires states parties to establish effective access to general technical and vocational guidance, the need to promote vocational and professional rehabilitation, job retention and return to workplace programmes for PWDs, among others. These are all aimed at achieving better access by PWDs to employment opportunities. The convention specifically requires states to enact policies to ensure the enjoyment by PWDs at the workplace of the rights enshrined in the convention.<sup>21</sup> It is worth noting that since ratification of the CRPD, Uganda has not developed a specific policy on the employment of PWDs. The National Employment Policy of 2011 is too general and does not make adequate provisions for access to employment of special groups including PWDs.

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19. Article 2(1).

20. Ratified on the 25<sup>th</sup> September 2008.

21. Article 27.

At the regional level, the African Charter on Human and Peoples' Rights 1986, while providing for equality and respect of the marginalised groups,<sup>22</sup> emphasises the fact that there should be no justification of domination of a people by another.<sup>23</sup> The African Commission on Human and Peoples' Rights has also adopted a Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa that exclusively legislate on disability rights on the continent. The Protocol captures the CRPD principles and is a welcome development on the continent. Uganda should ratify the Protocol for the better protection of the rights of PWDs.<sup>24</sup>

The UN Guiding Principles on Business and Human Rights (UNGPs) emphasises the responsibility of business enterprises to respect human rights, including internationally recognised human rights. These should be understood, at a minimum, as those expressed in the international Bill of Human Rights and the principles concerning fundamental rights set out in the International Labour Organisation's Declaration on Fundamental Principles and Rights at Work.<sup>25</sup> This Guideline is specific on labour rights especially of the vulnerable workers. Although the Guiding Principles are good for their respect and access to remedy framework, the same are not binding and indeed states/citizens have rarely used them to enforce rights. The researcher also emphasises that while faced with employers who might be big multinational corporations that governments are often reluctant to regulate, mere guiding principles may not be able to achieve much in terms of their human rights obligations.

Principle 6 of the UN Global Compact requires businesses to uphold elimination of discrimination in respect of employment and occupation. It recognises that discrimination can happen at recruitment and treatment at the workplace. It condemns both direct and indirect discrimination; the latter commonly manifesting itself when rules or practices which appear to be neutral in fact perpetuate exclusion. There is need for deliberate policies that incorporate human rights standards as a starting point for the realisation of this cardinal principle.

From the above provisions, it can be concluded that the existing international and regional legal frameworks which Uganda has ratified are comprehensive in spite of challenges like the non-binding nature of some of the instruments. Although progressive legislation is encouraged, unfortunately, research from elsewhere, for example in America, has proved that legislation alone simply was not effective in

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22. Article 18.

23. Article 19.

24. See *New Vision*, Saturday 16<sup>th</sup> June 2018.

25. Rule 12.

increasing access to employment for workers.<sup>26</sup> This was partly attributed to lack of a consistent definition of “disability,” which leads to challenges in interpreting the estimates of relative representation of workers with disabilities across time points and organisations.<sup>27</sup> The confusion over definitions also complicates how organisations respond to disability related issues.<sup>28</sup> This situation is not any different in Uganda as evidenced from the way some of the statutory incentives have been mismanaged, as will be discussed in subsequent sections of this article.

*B. Access to employment of persons with disabilities in the domestic legislation*

The legislative situation in Uganda with regards to the rights to employment for PWDs can be summarised as the unfulfilled promise. One would conclude that Uganda is the safest place for PWDs in terms of economic empowerment, but what is on the ground is to the contrary.

The 1995 constitution provides, among others, for equality and outlaws discrimination based on many grounds. A progressive interpretation of the constitution would include disability among those grounds.<sup>29</sup> The constitution also recognises the rights of PWDs.<sup>30</sup> The Persons with disabilities Act 2006 provides for, among others, the need for government to encourage employers to promote the right of employment of PWDs. On a positive note, this law requires the Minister of Labour to come up with a statutory instrument that determines the quota of PWDs to be employed by both the public and private sectors and publish the same periodically.<sup>31</sup> More than 10 years after the enactment of this Act, no such statutory instrument has been enacted.

The Act obliges every employer to additionally indicate in their job advertisement, where appropriate, that PWDs would be considered, carry out necessary modifications at their work premises to accommodate employees with disabilities, and if possible claim tax exemptions on such modifications and annually report to the Minister returns of employment of PWDs who would in turn report to parliament.<sup>32</sup> There has not been much implementation or follow-up on the quota system.

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26. Alecia M. Santuzzi and Pamela R. Waltz, *Disability in the Workplace: A Unique and Variable Identity*, 42(5) JOURNAL OF MANAGEMENT (2016), at 1121.

27. *Id.*

28. *Id.*

29. Article 21.

30. Article 36.

31. Section 13(3).

32. Section 13(4).

The issue of physical accessibility was partly considered in the case of *Nyeko Okello & Anor v. Centenary Rural Development Bank*<sup>33</sup> where two customers sued the bank for failure of the defendant to make their banking halls physically accessible. A consent judgement was eventually concluded as the defendant agreed to comply with the legal requirements. This case gives an insight on the barriers that potential employees who are PWDs face in accessing employment in a highly commercialised, profit motivated environment where legal adherence is not emphasised by the government as the primary duty bearer.

The Act also provides for progressive measures to ensure that PWDs are employed both within government and the private sector including tax exemptions of up to 15% to employers who employ 10 or more PWDs.<sup>34</sup> The tax incentive was, however, eventually scrapped by the Income Tax (Amendment) Act<sup>35</sup> citing abuse and loss by government of the much-needed revenue.<sup>36</sup> It is estimated that the government was losing significant income (US\$ 15 million per annum) through incentives extended to employers.<sup>37</sup> Without this incentive, there is currently no motivation to encourage employers to employ PWDs in the private sector.

The issue of tax incentives first came into dispute in Uganda in the case of *Crane Bank Ltd v. Commissioner General of Uganda Revenue Authority*.<sup>38</sup> Crane Bank sought a declaration that it was entitled to a 15% tax deduction on all tax payable within the meaning of section 17 of the Persons with disabilities Act for the calendar year ending 31<sup>st</sup> December 2008. The Bank had employed a total of 12 PWDs in the year in issue.

On whether the PWD Act was applicable to the plaintiff claim for a tax deduction, court found that by the time the claim was made by the plaintiff, the Income Tax (Amendment) Act No. 2 of 2008 which repealed section 17 of the PWD Act was already in force and that the tax incentive claim could not be sustained. This development would have far-reaching effects to the employment of PWDs. This is especially for employers who could have based their employment on the same incentive or who could have used the assurance to carry out modifications to ensure physical accessibility and reasonable accommodation. This could not only discourage further recruitments but also possible loss of employment for the currently employed PWDs.

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33. HCCS No. 23 of 2008 (Unreported).

34. Section 17.

35. 2010.

36. THE REPUBLIC OF UGANDA, UGANDA'S INITIAL STATE REPORT ON THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2012), at 14.

37. *Id.*

38. HCCS No. 0106 of 2009 (Unreported).

Although the above discussed contentious initiatives are essential to ensure realisation of the rights of PWDs, research has shown that formal legal protections, particularly those that may be interpreted as establishing hiring quotas for individuals with disabilities, might inadvertently in the long run reinforce the stereotype that individuals with disabilities are weak and cannot compete in the workplace without assistance.<sup>39</sup> Research suggests that new employees who are members of groups targeted by affirmative action programmes may face stigmatisation and discrimination at the workplace because they are considered less competent than other employees.<sup>40</sup> Additionally, beliefs stemming from legislative protections might reinforce reactions of pity, which explains the tragedy model. This might explain why workers with disabilities might receive positive evaluations but are still susceptible to discrimination in workplace personnel decisions.<sup>41</sup>

Affirmative action legislation may be partly hindering the hiring of workers with disabilities because employers fear that they will face undue difficulties in terminating employment if they cannot be successfully accommodated. Research on this matter, mainly from the United States, is ambiguous and on balance probably discouraging but may not attribute the gradual reduction in the number of PWDs employed since the mid 1990's to enactment of progressive legislation.<sup>42</sup> This gives a ray of hope that even when legislation introduces costly initiatives, that alone might not negatively affect the employment of PWDs. These fears notwithstanding, these initiatives are important at the start at least as countries still struggle to bring relevant stakeholders to appreciate the need for equal protection of all without distinction.

The Employment Act 2006—which is the specific law on employment—outlaws discrimination at the workplace and specifically mentions disability among the grounds.<sup>43</sup> The same Act mandates the Labour Advisory Board to develop specific policies to ensure PWDs have access to employment and are reasonably accommodated. However, 11 years after the enactment of the Act, the Labour Advisory Board has never been put in place.<sup>44</sup> Although the Employment Act emphasises the principle of non-discrimination in access to employment and at the workplace, the Act is not comprehensive to ensure adequate legal protection of PWDs

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39. Santuzzi & Waltz, *supra* note 26.

40. *Id.*

41. *Id.*

42. Organisation for Economic Co-operation and Development (OECD), *Sickness, Disability and Work: Keeping on Track in the Economic Downturn*, Background paper presented at the High-Level Forum, Stockholm, Sweden, 14-15 May 2009, at 25.

43. Section 6.

44. Section 34.

in the labour market since it was never made in contemplation of the challenges that PWDs face at the workplace.<sup>45</sup> That could possibly explain why the Act does not mandate employers to develop disability policies at the workplace.

From the domestic legislation, there is clear demonstration of lack of political will on the part of government to prioritise these issues. There are also inconsistencies in the law: The government giving with one hand and taking away with the other.

### *C. Relevant Policies*

The 2002 National Disability Policy is too general and does not provide specific solutions to the challenges of access to employment by PWDs. This is one of the reasons the National Council for Disability advocates for a stand-alone policy that specifically addresses these issues.<sup>46</sup>

The National Employment Policy for Uganda of 2011 gives statistics of PWDs, and recognises the discrimination and stigmatisation that PWDs face in the labour market, both at recruitment and at work. It also recognises both the physical and technological infrastructural challenges that PWDs face in the labour market. It does not provide any policy direction to address these challenges. It is a broad policy that does not adequately address the specific needs and strategies of special groups such as PWDs.

## **III. THE ROLE OF DISABILITY POLICIES AT THE WORKPLACE IN ENABLING ACCESS TO EMPLOYMENT**

### *A. The justification for disability policies at the workplace*

Developed countries have found it beneficial to come up with disability management processes at the workplace rather than relying solely on statutory obligations, legislative mandates, or imposed regulations, which in themselves have not yielded the desired outcomes.<sup>47</sup> Experience shows that positive changes in the area of disability rights takes place far more rapidly when effective domestic legislation is coupled with policies

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45. Interview with Ms. Deborah Iyute, Programme Officer, NUDIPU, on 4<sup>th</sup> August 2017.

46. Interview with Mari Samuel, Programme Officer, Capacity Building & Resource Mobilisation, National Council for Disability, held at Kampala on 25<sup>th</sup> July 2017.

47. Donald E. Shrey and Norman C. Hursh, *Workplace Disability Management: International Trends and Perspectives*, 9(1) JOURNAL OF OCCUPATIONAL REHABILITATION (1999), at 55.

to promote these rights.<sup>48</sup> Disability legislation must therefore be accompanied by efforts to develop effective and integrated policies, programmes and services in order to have a real impact on the lives of PWDs especially in the employment sector.

The 2009 OECD High-Level Policy Forum on Sickness, Disability and Work noted that while dealing with a population with many disadvantaging factors such as sickness, economic recession and high unemployment rates, emphasis should be put on policy messages about the need for a culture of inclusion. The Forum argued that,

Even in the present economic context, countries must implement both short-term strategies that seek to retain, recruit or reintegrate workers with health conditions or disabilities as well as continue to implement wider structural reforms that promote capacity rather than incapacity. The culture of inclusion that they promote has the potential to satisfy the goals of disability rights and neoliberal policy.<sup>49</sup>

The emphasis on the need for disability policies at the workplace at least in the short run aims to rectify the injustices PWDs face in the labour market generally, as the country continues to engage the relevant stakeholders for broader policy and legal reforms.

### *B. Disability Identity and the workplace*

Santuzzi and Waltz advance the theory that appreciation of the concept of disability identity is crucial for any organisational intervention selection. They point out that disability identity may be affected by intra individual factors such as labelling, interpersonal factors, organisational factors and the challenge of disability definitions. They caution that although practices to recruit and integrate members of other protected and underrepresented groups in organisations might be applied to workers with disabilities, the full integration of workers with disabilities requires organisational practices to be dynamic and attentive to variability in the extent to which workers adopt disability identity into their work.<sup>50</sup> The proposed disability policies would in the long run lead to such practises.

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48. Parker S. Harris, R. Owen & R. Gould, Parity of participation in liberal welfare states: Human rights, neoliberalism, disability and employment (2012), accessed at <<http://www.tandfonline.com/loi/cdso20>>, (accessed on 7th August 2017).

49. OECD, *supra* note 42, at 15.

50. Santuzzi & Waltz, *supra* note 26, at 42.

C. *Review of findings from selected Financial Institutions and key stake holders*

The mission – “Lets improve Life” – of this particular MDI<sup>51</sup> is progressive, and so are some of its core values, which include accessibility and inclusiveness. Although the company has a disability policy that emphasises equal opportunity for all, it employs only one PWD out of a total workforce of 245 countrywide. The policy and practice do not make a deliberate attempt to employ PWDs because “*the nature of our operations in some of the cases does not favour them but if there is a vacancy that suits a physically disabled person we take them on merit upon expression of interest.*”<sup>52</sup>

The above statement summaries the major hypothesis of this article: many employers look at physical disablement rather than any other factors while dealing with PWDs. Other forms of disability such as intellectual disability are not recognised. Secondly, the principle of reasonable accommodation is new to this kind of employer. Lastly but equally important, the workplace does not seem to have an affirmative action policy or practice for handling PWDs as a vulnerable or marginalised group.

On the issue of physical accessibility of the workplace, the company does not fully comply with the standards set in the Disability Act, with evidence of branches that are inaccessible due to lack of lifts and ramps and washrooms that are appropriate for PWDs, among others.

The researcher found that there were very limited attempts to implement the provisions of the law on access to employment and physical accessibility that the one employee employed in the total workplace of the company could not have been as a result of deliberate attempts to comply. DFCU Bank Limited, a commercial bank that has been in business for the last 17 years, employs a total workforce of 1,100 employees, 16 of whom are PWDs. They do not have a disability policy but are in final stages of developing one.<sup>53</sup> DFCU Bank also understood the need to employ PWDs as a corporate social responsibility, reflecting the tragedy model as seen in the quotation below:

In order for DFCU to realise its value of corporate social responsibility, the bank is committed to giving equal opportunities to everyone including PWDs. DFCU is fully focused on being a socially responsible employer.

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51. Interview with respondents from Letshego, *supra* note 3.

52. *Id.*

53. Interview with a DFCU respondent.

According to NUDIPU, most employers in the private sector claim to be “equal opportunity” employers and hence see no the need for stand-alone policies on disability at the workplace.<sup>54</sup> This approach is flawed as it does not consider affirmative action principles and the “hidden” discrimination that manifests itself during recruitment processes.<sup>55</sup> Most premises lacked ramps, appropriate washrooms for PWDs, appropriate audio devices where written ones made access to premises safer, and had access control barriers towards the lift area where such lifts existed.<sup>56</sup>

The Equal Opportunities Commission also re-echoed the concerns of the DPOs that the fact that most organisations will not even know their legal obligations under the law, there is urgent need to legally oblige employers to adopt disability policies and ensure compliance with the same.<sup>57</sup>

#### D. Regulation and Compliance

The Bank of Uganda has the sole mandate of licensing, supervising, inspecting and regulating both commercial banks and MDIs. This gives it powers to issue and revoke licenses, require compliance, issue conditional licenses, and require corrective measures where there is non-compliance with the law. The Central Bank indicated that in executing its supervisory functions, it requires all financial institutions to comply with all the governing laws, including human rights standards. However, when probed further, its representative was not aware of the existence of the Persons with Disabilities Act, the relevant international conventions like the CRPD, let alone the basic principles from the same laws.<sup>58</sup> There was reference to the several regulations and guidelines that financial institutions are supposed to comply with but these were mainly technical guidelines on supervision, insider lending, capital adequacy, corporate governance, and consumer protection, among others.<sup>59</sup>

On how the Central Bank ensures that financial institutions reasonably accommodate their employees with disabilities, a respondent from the banking sector regulator observed as follows:

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54. Interview with a NUDIPU respondent, *supra* note 45.

55. *Id.*

56. See for example, the Dfcu house at Kyadondo, Kampala.

57. Interview with Ms. Zamina Malole, Commissioner and member of the Equal Opportunities Commission in charge of Disability, held at Kampala on 1<sup>st</sup> August 2017.

58. Interview with the Principal Bank Examiner, Bank of Uganda, held on 23<sup>rd</sup> June 2017 at Kampala.

59. See <<http://www.bou.org>>.

Regulated financial institutions mostly provide accommodation for expatriate and senior staff. In these cases, the accommodation is provided by a third party whom the institution pays.

It therefore became clear that in some instances, the regulator did not have the capacity to appreciate issues of disability when carrying out its mandate.

Financial institutions are required to employ compliance personnel who are normally senior officers with legal knowledge and are expected to be conversant with all the relevant laws and contemporary legal issues, and to ensure compliance. It, however, remained unclear on how this could be achieved when the regulator is ignorant of the same. The respondent also intimated that sometimes financial institutions are required to appoint a designated staff to ensure compliance with specific legislative requirements,<sup>60</sup> but disability issues are rarely given priority.

The respondent also noted that the Central Bank did not require financial institutions to employ a certain quota of PWDs and was unaware of the legal provision that provided for the same.<sup>61</sup> The researcher observed that although the Central Bank has a complaint handling mechanism, most complaints received and handled revolved around breach of contractual obligations between financial institutions and customers, and not on issues of disability and discrimination generally.<sup>62</sup>

The National Council for Disability (NCD), on the other hand, did not feel that its mandate extended to ensuring that PWDs have access to employment. They have, however, been engaged in advocacy for the enactment of regulations under the Persons with Disabilities Act and for the current Persons with Disabilities (Amendment) Bill.<sup>63</sup> The NCD has also been advocating for the revision of the minimum wage since most PWDs are employed at low rank positions.<sup>64</sup> Respondents from both NCD and NUDIPU observed that they receive many cases related to discrimination in access to employment but refer them to EOC because of both resource and capacity challenges.

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60. See, the Anti-Money Laundering Act, 2003 which requires financial institutions to appoint anti-money laundering officers.

61. See *supra* note 58.

62. *Id.*

63. Interview with Mari Samuel, Programme Officer, Capacity Building & Resource Mobilisation, National Council for Disability Held at Kampala on 25th July 2017.

64. *Id.*

#### *D. Dispute Resolution*

Ms. Iyute of NUDIPU recognises that it is hard for PWDs to get evidence of disability-based discrimination at the time of recruitment, which is a major hindrance since most employers will hide behind other legitimate reasons to deny PWDs employment. This challenge was experienced in the case of *Atuhereze Moses v. A.G.*<sup>65</sup> where the applicant's claim of discrimination in recruitment was dismissed for lack of evidence. DPOs and NCD have however been forwarding most of the clients to the EOC who have resolved some of the cases through mediation.<sup>66</sup>

### IV. CONCLUSION

The theories and research discussed indicate many challenges that PWDs face in physically accessing the workplace and employment generally within the private sector, ranging from deep-rooted political economy theories, attitude and cultural mindsets, weak legal and institutional frameworks, and limited precedents that would encourage victims to seek redress in defence of their disability rights, among others. It is also clear that most of the legislative and practical interventions reflect the models that have been used to understand disability, most of which are archaic. It is, however, clear that emphasis on disability policies at the workplace that are home-grown and compliant with international, regional and domestic human rights and legal standards would be more acceptable, implementable and would ensure realisation by PWDs of their human rights entitlements. Consequently, the article advocates for the fast-tracking of the enactment of the National Action Plan on Human Rights that will ensure the obligations of business actors vis-a-vis human rights protection. The NCD and EOC, working together with the regulators, should exercise their mandate and ensure that the private sector fully complies with its obligations under the different laws and standards.

The article also makes a case for the enactment of national policies on employment of PWDs. Care should also be taken in the current amendment process of the Disability Act not to lose some gains that had been made in the struggle. The issue of tax incentives should, for example, be carefully thought-out. Government should come up with policies that blacklist organisations that do not demonstrate a diverse workforce which reflects the principles of affirmative action.<sup>67</sup> For private employers such as financial institutions, this can be achieved at licensing level where all applicants

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65. UHRC 29/2008.

66. See *supra* note 45.

67. Santuzzi & Waltz, *supra* note 26.

are supposed to demonstrate their staffing structure, uniqueness of products and strategic and business sense.<sup>68</sup>

The academia, non-governmental organisations, and legal aid service providers need to do more in ensuring sensitisation and awareness of the rights and obligations of employers and employees under the disability discourse. Legal aid entities should be able to litigate some of the cases that violate these rights so as to set precedents. Public interest cases would also go a long way in ensuring access to employment for PWDs.

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68. *See*, the Financial Institutions Act 2004 (as amended by Act and the Micro Deposit Taking Institutions Act respectively).

## **IN-VITRO FERTILIZATION IN DEVELOPING COUNTRIES: EMERGING ISSUES**

Dennis Odigie\* & Florence Iyasere\*\*

### **ABSTRACT**

*In vitro fertilisation (IVF) is a process for bringing succor to couples who are victims of involuntary childlessness. Being a relatively new frontier in reproductive technology, its practice and propriety have generated widespread controversy along religious, cultural and moral lines. The practice of IVF in developing countries is confronted with a mirage of challenges. Some of the challenges include the high cost of treatment, inadequately trained physicians in reproductive health technology, lack of proper government policy on reproductive health, lack of comprehensive guidelines, regressive regulatory standards, lack of political will and legislative framework to streamline the practice, amongst others. These loopholes have been exploited by quack doctors, who have violated the rights of vulnerable couples with little regard to legal or ethical principles. In view of these challenges, this article highlights the need for an effective regulatory and legislative framework for IVF services in developing countries in order to prevent the exploitation of victims of involuntary childlessness. It advocates the need for developing countries to adopt templates on reproductive health policies and practice similar to those in developed jurisdictions.*

### **I. INTRODUCTION**

The practice of in-vitro fertilisation (IVF) is an example of exponential progress in medicine which has revolutionised reproduction and given succor to couples suffering involuntary childlessness. The development of IVF technology has strengthened the frontiers of assisted reproductive techniques, which at inception generated widespread controversies that made them almost unpopular at first instance in most developing countries. Despite this challenge, IVF has evolved to become the cornerstone of fertility treatment in developing countries for couples experiencing delay in

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conception.<sup>1</sup>

Currently, over four million children have been born through this technique.<sup>2</sup> In Nigeria, for example, the clamour for the treatment has increased amongst couples who have become victims of involuntary childlessness.<sup>3</sup> One in every four couples in the country has difficulty conceiving through natural means.<sup>4</sup>

The regulations governing IVF treatments vary from one country to another. In the United Kingdom, for example, clinics which administer fertility treatment (that involve human gametes) such as IVF are supposed to be licensed.<sup>5</sup> Unfortunately, no such requirement exists in Nigeria and most of the developing countries. This loophole has provided a safe platform for quacks and unprincipled medical personnel to infiltrate the practice, compromise standards and thrive in this crucial area of medical practice with impunity.

In the United Kingdom, the Human Fertilisation and Embryology Authority (HFEA)<sup>6</sup> is the statutory body charged with the responsibility of overseeing compliance with the relevant laws on IVF technology. The body also performs annual audit of the results of treatment from all licensed clinics, and such results are published annually. Furthermore, all licensed clinics are mandated to ensure that there is no mix-up of human semen. Strict guidelines exist for the creation, manipulation and use of gametes. Criminal sanctions are provided for infringements of the set guidelines. Unfortunately, there is no such regulatory body to ensure standards or discourage quackery in Nigeria and in most of the developing countries.

## II. CONCEPTUAL OVERVIEW OF IN-VITRO FERTILISATION

IVF is a treatment in which eggs are removed from a woman, fertilised with sperm outside the body and inserted into the uterus of the same or another woman. This procedure includes the extraction of eggs, collection of sperm, fertilisation in culture

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1. Otherwise referred to as involuntary childlessness.

2. R. Ajayi, IVF: Ajayi makes case for regulation in Nigeria, retrieved from <http://www.smsforhealth.com/news/details.php> (accessed 10 July 2017).

3. Involuntary childlessness is the inability to fulfill the desire to have a biologically related child. Such physical inability can be caused by ones reproductive dysfunction (e.g. low sperm count or blocked fallopian tubes), the reproductive dysfunction of one's partner.

4. O. Onche, IVF Still an All-Comers Affairs in Nigeria, retrieved from <http://www.geneticsandsociety.org/article.php> (accessed 10 July 2017).

5. Human Fertilization and Embryology Act 1990, section 3(1).

6. The Human Fertilization and Embryology Authority is a statutory licensing body set up under section 5 of the Human Fertilization Embryology Act 1990.

and introduction into the uterus at the eight cell stage. In a successful procedure, pregnancy begins when the embryo is implanted into the uterine wall. However, the most common challenge associated with IVF is failed implantation.

The practice of artificial insemination or manual introduction of sperm into the cervix has long been known as a possible means of human conception.<sup>7</sup> The first creation of live human embryos outside the human body through IVF was in 1978.<sup>8</sup> Joy Louise Brown was the first child to be conceived through IVF in July 1978. Since Brown's birth, nearly four million babies have been born through this assisted reproduction technique.<sup>9</sup> Her birth evoked vociferous condemnation, which prompted the government to set up "The Warnock Committee on Human Fertilisation and Embryology."<sup>10</sup> In the United Kingdom, IVF treatment is governed by the Human Fertilisation and Embryology Act of 1990 which was amended by the British parliament in 2008. The act lays down stringent conditions for obtaining a license from the HFEA.

#### *A. The English Human Fertilisation and Embryology Act 1990*

The principle underlying the Human Fertilisation Embryology Act of 1990 was modeled after the Warnock Committee Report Recommendation on Human Fertilisation and Embryology. Although the act was amended in 2008<sup>11</sup> following new scientific developments, legal and ethical issues have continued to trail the rationale behind the regulatory framework on IVF treatment in the United Kingdom to date. The 1990 act provides for the establishment of a statutory regulatory authority known as the HFEA.<sup>12</sup> The body is charged with the responsibility of ensuring compliance with applicable laws, and enforcement of penal sanctions against offenders. The HFEA ensures that fertility treatments are administered in accordance with laid down procedures, structures, complex web of discretion, restraints, control and

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7. [1996] 2 F.L.R. 15 AT 21.

8. Professor Robert Edwards pioneered in vitro fertilization technique. He worked alongside a renowned Dr Patrick Steptoe to produce the world's first test tube baby.

9. 'Birthday honors: test tube baby pioneer knight', BBC News, 10<sup>th</sup> June 2011, retrieved from <<http://www.geneticsandsociety.org/article.php>>, (accessed 10 July 2017).

10. Committee on Human Fertilization and Embryology (1984 cmmd 9314, chairman dame Mary Warnock).

11. Human Fertilisation Embryology Act 2008.

12. The Human Fertilisation and Embryology Authority (hereafter referred to as HFEA).

accountability.<sup>13</sup> The body is also responsible with the issuance of licenses to practitioners under a strict code of practice.<sup>14</sup> A breach of the code of practice by any practitioner may result in the revocation of the license.<sup>15</sup> The act also vests the HFEA with the powers to grant or withhold licenses, formulate policies and issue mandatory discretion.<sup>16</sup> Failure to comply with any of the mandatory discretions constitutes an offence.<sup>17</sup>

Under section 3(1)<sup>18</sup> of the Human Fertilisation Embryology Act, IVF treatment can only be carried out under a license from the HFEA. The section thus provides “no person shall bring about the creation of an embryo; or keep or use an embryo except in pursuance of a license.” Schedule 2 paragraph (1) provides that a license under this paragraph may authorise any of the following in the course of providing treatment services:

- (i) Bring about the creation of embryo in vitro;
- (ii) Keep embryos;
- (iii) Use gamete;
- (iv) Practices designed to secure that embryos are in a suitable condition to be placed in a woman or to determine whether embryos are suitable for this purpose;
- (v) Placing any embryo in a woman

According to schedule 2 paragraph 5, a license shall be granted for a period not exceeding five years.

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13. J. Montgomery, *Rights, Restraints and pragmatism: The Human Fertilisation and Embryology Act 1990*, 54(4) MODERN LAW REVIEW (1991), cited in M. STAUCH, *ET AL*, SOURCES ON MEDICAL LAW (2ND ED.,) (2002), at 373.

14. License for the creation of an embryo outside the body is provided for under section 3(1)(a) and 1(2) of the 1990 Act. License for the storage or use of embryos is provided for by section 3 (1) (b) 1990 Act. Section 4 (1) (a) provides for license for the storage of gametes. The HFE Authority granted license for cell nuclear transplant in August 2004.

15. HFE Act 1990, section 18(1)(c).

16. *Id.*, sections 22 & 24.

17. *Id.*, section 41(2).

18. The Human Fertilisation and Embryology Act 1990 of England (as amended in 2008).

### B. Consent to Use or Storage of Gametes or Embryo

An important aspect of the 1990 Act is the weight accorded to the acquisition of consent from gamete providers. Schedule 3 of the act provides that consent must be given in writing. In this schedule, 'effective consent' means a consent which has not been withdrawn.<sup>19</sup> Under schedule 3 paragraph 2(1) consent to the use of any embryo must specify one or more of the following purposes:-

- (a) Use in providing treatment, services to the person giving consent or that person and another specified person together;
- (b) Use in providing treatment services to person not including the person giving consent; or
- (c) Use for the purpose of any project of research and may specify condition subject to which the embryo may be used.

Schedule 3 paragraph 2 (2) provides that consent to the storage of any gamete or embryo must:

- (a) Specify the maximum period of storage (if less than the statutory storage period); and
- (b) State what is to be done with the gametes or embryos if the person who gave the consent dies or is unable because of incapacity to vary the terms of the consent or to revoke it, and may specify conditions subject to which the gametes or embryo may remain in storage.

Thus, by schedule 3 para. 2 (2) (b), consent to storage given by gamete providers can be varied, revoked or withdrawn.<sup>20</sup> However, such consent cannot be withdrawn or varied once the gamete or embryo has been used for treatment.<sup>21</sup> The meaning of the word "used" was considered in *Evans v. Amicus Healthcare*.<sup>22</sup> In this case, Natalie Evans wished to have an embryo implanted that had been created from her eggs and the sperm of the man from which she had subsequently separated. Since these embryos

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19. Schedule 3 Para 1(3)1990 Act.

20. By schedule 3 Para. 4 (1) of the 1990 Act, the terms of any consent under this schedule may from time to time be varied, and the consent may be withdrawn by notice given by the person who gave the consent to the person keeping the gametes or embryo to which the consent is relevant.

21. Schedule 3 Para. 4(2) 1990 Act.

22. [2004] EWCA Civ 727.

were created just before she had hysterectomy,<sup>23</sup> her only chance to have a genetically related child was to have the embryo implanted. The man had written to the clinic to notify it of the separation and requested that the embryos be destroyed. Evans challenged this position.

The Court of Appeal held that the embryos could only be said to have been used once they were implanted. In his judgment, Arden, L.J. stated: "In the context of the withdrawal of consent under schedule 3 paragraph 4, the word 'use' refers to the final stage." It was therefore held that the embryos had not been used since no implantation had been done, and the man who provided the sperm could still withdraw his consent to the storage and use of the embryo.<sup>24</sup> Evans subsequently lost her application in the European Court of Human Rights and, ultimately, the Grand Chamber of the European Court of Human Rights.<sup>25</sup>

### *C. In-Vitro Fertilization and Subsequent Use of Embryo*

Schedule 3 paragraph 6 (1) of the 1990 Act provides that "A person's gamete must not be used to bring about the creation of any embryo in vitro unless there is an effective consent by that person to any embryo the creation of which may be brought about with the use of those gametes being used for one or more of the purposes mentioned in paragraph 2(1) above." Under sub paragraph (2), "An embryo the creation of which was brought about in vitro must not be received by any person unless there is an effective consent by each person whose gametes were used to bring about the creation of the embryo to the use for one or more of the purposes mentioned in paragraph 2(1) above of the embryo."

Further, under sub paragraph (3), "An embryo the creation of which was brought in vitro must not be used for any purpose unless there is an effective consent by each person whose gametes were used to bring about the creation of the embryo for the use of that purpose and the embryo is used in accordance with that consent."

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23. This means the removal by operation of ovaries of a woman.

24. The 2008 Act has made modification to the law on withdrawal of consent. Schedule 3 Para. 4A introduced into the 1990 Act a one year "cooling period". This provision allows the embryos or gametes to be lawfully stored to allow the party withdrawing consent to change his or her mind, if not, after expiry of the one year period, the embryo is allowed to perish. *See*, D. SHAUN, PATTINSON, *MEDICAL LAW AND ETHICS*, 2ND ED. LONDON THOMAS REUTERS (2009), at 281.

25. *Evans v. UK* (6339/05) (2008)46 E.H.R.R.34 (April 10 2007, Grand Chamber) affirming: (2006)43 E.H.R.R.21.

*D. Consent to Storage of Gametes and Embryos*

Schedule 3, paragraph 8 of the 1990 Act provides for storage of gametes and embryos in the following terms:

- (1) A person's gamete must not be kept in storage unless there is an effective consent by that person to their storage and they are stored in accordance with that consent.
- (2) An embryo the creation of which was brought about in vitro must not be kept in storage unless there is an effective consent, by each person whose gametes were used to bring about the creation of the embryo, to the storage of the embryo and the embryo is stored in accordance with those consents.
- (3) An embryo taken from a woman must not be kept in storage unless there is an effective consent by her to its storage and it is stored in accordance with the consent.

The provision of the 2008 Act is in *pari-materia* with that of the 1990 Act, although with some modifications. As stated earlier, the consent of the gamete provider must be obtained in order to continue storage of their gametes/embryo. Such storage could be by cryopreservation (freezing).<sup>26</sup> However, the Human Fertilization and Embryology Act 2008 now fixes the statutory storage period for gametes/embryos for 10 years instead of the five year period under the 1990 Act.

The new Human Fertilization and Embryology (Statutory Storage Period for Embryos and Gametes) Regulation 2009<sup>27</sup> made it possible to extend storage of gametes<sup>28</sup> and embryos<sup>29</sup> for a maximum of 55 years<sup>30</sup> subject to certain conditions. Thus, research centres are under obligation to carry out checks every 10 years to ensure that patients or gamete providers meet laid down conditions. Furthermore, the

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26. The 1990 Act allows for the freezing of gametes and embryos under license. See sections 2 (2) and 14 (1).

27. Formally, the Human Fertilisation and Embryology (Statutory Storage period for Embryos and Gamete) Regulation, 1996.

28. Regulation 2(1)(2) under section 14(4) of the Act specify the maximum storage period in respect of an embryo.

29. Section 14 (3) in respect of gametes regulation.

30. Regulation 3 ensures that embryos lawfully stored from 1 October 2009, by virtue of the Human Fertilization and Embryology (supplementary provision) order 2009 fall within Regulations 3 of the 2009 regulations, and therefore become eligible for extended storage period provided under criteria in that regulations are met.

maximum age for which implantation can be carried out on a woman is 55 years.<sup>31</sup>

From the foregoing, it is apparent that consent for the use or storage of gametes or embryos can be revoked. In the case of *Centre for Reproductive Medicine v. Mrs. U*,<sup>32</sup> the defendant's husband, after initially agreeing to the posthumous use of his sperm to treat his wife, later revoked his consent. The Court of Appeal rejected the defendant's argument that the clinic unduly influenced her husband's change of mind and held that she was not entitled to use the sperm.

The withdrawal of consent by either of the providers to the continued storage of any embryo formed with their gametes (for example following a divorce by the couple) would mean discontinuance of further storage. In such cases, the genetic material must be allowed to perish or destroyed.<sup>33</sup> The court interpreted this principle in the British case of *Human Fertilisation and Embryology Authority ex parte Blood*.<sup>34</sup> Mrs. Blood sought judicial review of the HFEA's refusal to license infertility treatment of her with the sperm of her dead husband. The sperm had been taken from Mr. Blood as he lay in coma shortly before his death from meningitis. Consequently, his written consent for storage or use of his sperm was not obtained as stipulated in the Human Fertilization and Embryonic Act, 1990. According to Lord Wolfe M.R.:

As to storage, section 4(1) makes it clear that it must always be pursuant to a license. That means that storage can only take place lawfully in accordance with the requirements of the license which for the present purpose are contained in schedule 3. This means that there must be consent in writing (paragraph 1 and paragraph 8 which complies with paragraph 2(2) and paragraph 3) before the storage can lawfully take place.<sup>35</sup>

In the circumstance, it was held that although Mrs. Blood could not be lawfully treated with her husband's sperm in Britain, she was entitled to export it and receive treatment in Belgium pursuant to her rights under article 49 of the European Commission Treaty.<sup>36</sup>

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31. Regulation 2(1).

32. [2002] E.W.C.A. Civ, 565, [2002] 1 FLR 927.

33. Davis v. Davis (1992) 842 S.W 2 d, 588, 597.

34. (1997) 2, W.L.R 807.

35. See review of the common law provision relating to the removal of gametes and of consent provisions in the HFE Act 1990.

36. Staunch et al, *supra* note 7, at 382.

Other statutory legislations regulating IVF in the United Kingdom are: 1) the Human Fertilisation and Embryology (Procedure for Revocation, Variation or Refusal of Licenses) Regulations 2009. This regulation provides for circumstances under which the HFEA can revoke, vary or refuse licenses to clinics; 2) the Human Fertilisation Embryology (Appeals) Regulation 2009, which provides for conditions under which clinics can appeal the HFEA's decisions, and 3) the Human Fertilisation and Embryology (Disclosure of Information for Research Purposes) Regulations 2010 which proposes how identifiable information may be disclosed for research purposes.

### **III. IN-VITRO FERTILISATION IN NIGERIA**

Although IVF is currently practiced in Nigeria, there is no legal and regulatory framework governing the practice. In addition, there are no guidelines to determine or limit the maximum number of embryos that can be transferred into a woman's uterus. The implication of the foregoing is that the number of embryos that can be deposited in a woman's womb is at the doctor's discretion, notwithstanding the attendant adverse physical and psychological health implications.

There are also no guidelines on the issue of consent, storage period of gametes, embryo freezing or surrogacy. This has encouraged the proliferation of sub-standard fertility clinics manned by non-experts in fertility and reproductive health. This has raised credibility issues about claims of success, thus resulting in loss of confidence in the practitioners and the treatment they administer.

To date, Nigeria is yet to formulate any policy on IVF technology which would streamline how the practice is carried out and the modalities to be followed by both the practitioners or service providers and the beneficiaries of the practice. The health ministry in Nigeria has also not defined any enlightenment programme on the treatment nor has it put in place a monitoring team to monitor the activities of medical practitioners who administer the treatment. The establishment of such a regulatory body is long overdue. The absence of relevant laws on IVF treatment has grave and negative social implications. Many tend to see the exercise as being socially non-permissible and admission of incompleteness by couples who seek the treatment. The situation is further compounded by the high level of illiteracy, high incidence of poverty among the populace, inadequate qualified medical personnel, high cost of IVF treatment, and low level of awareness of the importance and benefit of the treatment, among others. It is instructive to note that the scenario exemplified by the Nigerian situation is typical of almost all the developing countries around the world.

In most of the developed countries, defined legal and institutional frameworks exist to ensure the regulation, standardisation and affordability of IVF treatment. It is

apposite to mention the role of globalisation in medical care having regards to the fact that we are in an age of medical pluralism, thus no discussion on IVF can ignore the development of medical tourism<sup>37</sup> which has culminated in the movement of deserving couples from developing countries to other countries where IVF treatment is available, legally recognised, affordable and reliable.

In the British case of *Human Fertilisation and Embryology Authority ex parte Blood*,<sup>38</sup> Mrs. Blood had to travel to Belgium for posthumous insemination with her husband's sperm in order to evade regulatory restriction in Britain. In the absence of an enabling law, it would be impossible for government to monitor the activities of medical personnel who administer the treatment, sometimes in ill-equipped and unlicensed fertility clinics. Therefore, it is imperative for government to adopt a harmonised, comprehensive regulatory framework that conforms to international best practices on the administration of the treatment as it obtains in the United Kingdom and many other developed countries.

#### IV. LESSONS FROM OTHER JURISDICTIONS

Laws regulating IVF treatment vary from one country to another. While some countries like the United States and Japan have developed legislations and guidelines for the regulation of IVF treatment, others like Nigeria, Greece and Canada have neither of the two. Countries like Saudi Arabia and Egypt forbid all forms of assisted conception treatment using donor egg, sperm and embryo and surrogacy. Yet others like Japan and Norway permit the practice.

The United Kingdom, France, Germany and Australia have legislations and regulatory mechanisms that prescribe the maximum number of embryo that can be transferred into the womb. In the United Kingdom, the Human Fertilisation and Embryology Act 1990 provides that the maximum number of embryo that can be transferred into a woman who is 35 years or younger in her first IVF treatment is two, and three for 40 years and above or those with previously failed IVF treatment. According to the IFFS surveillance 2010, which looked at the roles and regulations relating to assisted conception of more than 100 countries, 14 countries had an upper limit of three embryos, 12 had a limit of four and 6 countries had a limit of five. Kuwait had a limit of six embryos, while Panama had no limit on the number of

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37. India is a hub for vitro fertilization treatment and surrogacy.

38. (1997) 2 W.L.R 807.

embryos transferred.<sup>39</sup> In 2003, China banned the use of IVF by unmarried women or couples with certain infectious diseases. The law also prohibits availability of IVF to lesbian couples.

Costa Rica has a complete ban on IVF technology. The technique is perceived as a violation of life and a lack of respect for the embryo, thus upholding the view that the embryo should never be handled or manipulated outside the body. In Germany, legislation was enacted to prohibit IVF clinics from removing and fertilising more eggs than could be implanted in one cycle. Thus, there is no 'spare' embryo in Germany.

IVF treatment is a sensitive ethical and moral issue against the background of increased and fast paced medical and scientific developments. Although this technology is now generally accepted as a means of addressing involuntary childlessness, it is still not without controversy. Those opposed to the practice contend that only the supreme being has power to give a child, arguing that scientists should not be allowed to play God. They argue that insemination through artificial means separates the conjugal act from the procreative act, thus threatening the institution of the family. This school of thought is also concerned about the ownership and legal status of the embryo in the event of divorce or death of either of the couple.

The Roman Catholic Church opposes all kinds of IVF and contraception. It posits that IVF is unnatural and constitutes a threat to the unity of the family and the dignity of the human person. The church holds the view that it is not objectively evil to be infertile, and therefore advocates adoption as an option to assisted reproduction.

## V. CONCLUSION

In this article, we have highlighted the socio-legal perspectives to IVF technology, with emphasis on its role in ameliorating the emotional trauma of desperate couples who hitherto suffered involuntary childlessness. This article has identified the major challenges facing the administration of IVF technology in developing economies including Nigeria, the most crucial being the absence of a legal framework on IVF, high cost of treatment, inadequate medical personnel and lack of modern facilities. This has constrained many desperate couples who have resorted to unprincipled and avaricious medical practitioners, who in most cases exploit them with impunity. It is suggested that Nigeria and other developing economies should adopt the United Kingdom model of IVF treatment. By this way, women's reproductive autonomy and

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39. Dr Marcus, *Laws and Regulations Governing Assisted Conception*, retrieved from <<http://www.ivf-infertility.com/ivf/standard/regulations.php>> (accessed 11 July 2015).

the right of self-determination would be guaranteed.

The foregoing exposition of the socio-legal, cultural and legal challenges in the practice of IVF in developing economies render imperative the following recommendations as a panacea for the implementation of a sustainable regime of the treatment in developing countries:

- i) African governments must address institutional and infrastructural deficiency through a purpose-driven policy on IVF technology and address the issue of quack doctors and brain drain. By so doing, developing countries would align their policy with the progressive stance of the developed states that have enacted stringent regulations governing IVF treatment.
- ii) There is need for the enactment of effective legislation for the administration and regulation of IVF treatment, backed by enforcement and sanctions for breach.
- iii) There is need for the establishment of monitoring and evaluation units in the relevant ministries. This will ensure compliance with standards by medical personnel involved in the administration of IVF treatment. The units would also be responsible for ensuring that only professionally qualified medical personnel are allowed to administer IVF treatment to deserving patients. This will reduce quackery in the profession, promote standards and restore confidence.
- iv) There is need for adequate funding and subsidy of IVF treatment. Such funding must be properly harnessed and managed for the advancement of cost effective, efficient and affordable IVF treatment for impoverished couples desiring such care.
- v) Further, government must encourage a coalition of input from medical professionals and encourage cross-national and transnational collaboration especially in the area of medical research as this will foster and promote proficiency in IVF technology.
- vi) Emphasis must be placed on education and sensitisation enlightenment programmes of the public on the advantages of IVF as an alternative to natural reproduction. These would change the negative mindsets and disposition to the treatment.
- vii) There should be provision of adequate medical equipment in government hospitals, and training of medical personnel to render qualitative services to patients.

## THE FINAL CUT: ACCOMMODATION OF ASYLUM VICTIMS OF FEMALE GENITAL MUTILATION IN THE WEST

Patricia N. Jjemba\*

### ABSTRACT

*This article seeks to assess pragmatic concerns related to female asylum seekers from countries that practice female genital mutilation (FGM). These women have requested for asylum on the basis of experiencing human rights violations due to being subjected to the practice of FGM. The article provides a foundation and insights into the practice of FGM, as well as a conceptual understanding of the practice and the reasons for its persistence. It reviews varying perspectives on the tradition from both international and Western vantage points. It examines international, European, and American asylum and human rights laws in order to provide a juridical understanding of the legal doctrines and principles that follow female asylum seekers. The article provides case studies to illustrate issues precisely related to genital mutilation-based asylum claims. It also offers policy recommendations on how countries, especially those of the West, would better accommodate these asylum seekers upon arrival.*

### I. INTRODUCTION

“Allau Akbar, Allau Akbar, Allau Akabar—”<sup>1</sup> Fauziya’s hands touched the cool, hard concrete floor as she fervently repeated her daily prayers.<sup>2</sup> “Kasinga! Kasinga!”<sup>3</sup> The prison guard bellowed her name over the loudspeaker, insistently, as if to hurry her along.<sup>4</sup> But after spending 14 long months in this American prison, Fauziya refused to be rushed.<sup>5</sup> Only 19 years old, she was far away from her native home of Togo, and the four walls of this prison cell were now her reality.<sup>6</sup> At the age of 17, her father’s death

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1. FAUZIYA KASSINDJA & LAYLI MILLER BASHIR, DO THEY HEAR YOU WHEN YOU CRY (1998)

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2. *Id.*

3. *Id.*, at 2.

4. *Id.*

5. *Id.*

6. *Id.*

led her uncle, Mouhamadou, to become her “legal guardian.”<sup>7</sup>

Her uncle Mouhamadou and his wife soon bargained with a man over 30 years older than Fauziya for her hand in marriage.<sup>8</sup> Arranged to be this man’s fourth bride, Fauziya was to have her “woman parts cut off before...[becoming] his wife.”<sup>9</sup> Fauziya had heard stories of women spreading a girl’s legs, holding her down with all restraint, and the eldest woman using a knife to cut the girl’s woman parts off.<sup>10</sup> *Kakia*, also known as female circumcision or female genital mutilation, was a common tradition within her tribe.<sup>11</sup> However, Fauziya’s father was opposed to the practice and had protected four of her eldest sisters from undergoing this painful practice.<sup>12</sup> The death of Fauziya’s father just a few weeks before left her without her father’s protection and she was expected to undergo the cut and marry.<sup>13</sup> With her mother and sisters’ help, Fauziya fled her home country—Togo—and escaped undergoing the practice of *kakia*.<sup>14</sup> She became a refugee and sought asylum in USA, where she was also referred to as inmate Kasinga.<sup>15</sup> She was always visited by her lawyer.<sup>16</sup>

While Fauziya’s story is heartbreaking, it is all too familiar. This article seeks to assess poignant pragmatic concerns related to female asylum seekers from countries practicing female genital mutilation (FGM), which is also known as “genital circumcision,” or “cutting.” These women have requested for asylum on the basis of experiencing human rights violations due to being subjected to the practice of FGM.

First, the background will provide a foundation and insights into the practice of FGM. It will provide a conceptual understanding of the practice and the reasons for its continued application. It will also review varying perspectives on the tradition from both international and Western vantage points. Secondly, it will examine international, European, and American asylum and human rights laws in order to provide a juridical understanding of the legal doctrines and principles that follow female asylum seekers. Thirdly, the article will provide case studies to illustrate issues precisely related to genital mutilation-based asylum claims. Finally, it will provide policy recommendations on how countries, especially those of the West, would better

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7. *Id.*

8. *Id.*, at 2.

9. *Id.*

10. *Id.*, at 3.

11. *Id.*, at 2.

12. *Id.*

13. *Id.*

14. *Id.* at 3.

15. *Id.*

16. *Id.*

accommodate these asylum seekers upon arrival.

## II. A CONCEPTUAL UNDERSTANDING OF THE PRACTICE OF FGM

The World Health Organization (WHO) characterises the practice of FGM as alteration or “injury to female genital organs” for purposes unrelated to medical necessity.<sup>17</sup> The procedure itself involves the removal of the female genital organs, either completely or partially.<sup>18</sup> The practice is categorised into four types, based in part on complete or partial removal of particular genital organs: I – *Clitoridectomy*; II – *Excision*; III – *Infibulation*; and IV- all other destructive methods against genital organs for reasons unrelated to medical necessity.<sup>19</sup>

Type I, *Clitoridectomy*, involves the removal of all or part of a female’s clitoris.<sup>20</sup> Type II, *Excision*, entails partial or total removal of both the clitoris and labia minora.<sup>21</sup> This can be done “with or without excision of the labia majora.”<sup>22</sup> Known as *Infibulation*, type III refers to instances whereby “cutting and repositioning the inner or outer labia, with or without removal of the clitoris” tightens a woman’s vaginal opening.<sup>23</sup> Finally, type IV refers to all other detrimental methods used against genital organs for non-medical purposes.<sup>24</sup>

### A. Justifications for Female Genital Mutilation

To date, over 3,000,000 girls and women per year suffer some form of FGM.<sup>25</sup> Ultimately, girls and women that undergo the practice obtain absolutely no health benefit and instead, in many instances, suffer unwarranted physical, psychological, and emotional harm. This therefore poses questions as to why the practice has persisted for hundreds of years despite its attendant consequences. Some of the reasons that explain why young girls and women undergo the practice are maintaining their sexual purity,

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17. WHO, *Female Genital Mutilation Fact Sheet N°241*, WHO: Geneva, retrieved from <http://www.who.int/mediacentre/factsheets/fs241/en/>.

18. *Id.*

19. Layli Miller Bashir, *Female Genital Mutilation in the United States: An Exemption of Criminal and Asylum Law*, 4 AM. U. J. GENDER & L., 415, 420 (1996).

20. *Id.*

21. *Id.*

22. *Id.*

23. *Id.*

24. *Id.*

25. WHO, *supra* note 17.

upholding hygiene-related cleanliness, and adhering to religious practices.<sup>26</sup> Many cultures consider the practice a “rite of passage” into womanhood.<sup>27</sup> It is most prevalent in Africa, the Middle East, and some areas in Asia.<sup>28</sup>

### 1. Varied Views on the Practice

i) *The International Community* —International bodies such as the United Nations have acknowledged and encouraged the overall respect of cultural practices. However, as a whole, the international community has overtly condemned the continuation of female genital cutting as a practice and has deemed it a human rights violation of a woman’s body and liberty rights.<sup>29</sup>

The United Nations Convention Against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment (Convention Against Torture) serves as an illustration of an international commitment to safeguarding women and children exposed to FGM. Article 1 of the convention defines *torture* as “an act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for...any reason based on discrimination of any kind.”<sup>30</sup> Given this rationale, the painful, physically invasive and surgical abscission of one’s genital organs would likely constitute as a form of torture. Furthermore, exposure of females to this practice, as opposed to their male counterparts, exhibits discrimination based on sex, thus, satisfying the second requirement outlined in Article 1.<sup>31</sup>

Likewise, the United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) serves as another example of an international pledge to protect women and girls subject to genital mutilation. Under this convention, “discrimination against women” is defined in part I of Article 1 as “any

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26. *Why is it Practiced*, END FGM EU, (last visited April 13, 2015), retrieved from <http://www.endfgm.eu/en/female-genital-mutilation/what-is-fgm/why-is-it-practised/>.

27. Sarah Boseley, *What is Female Genital Mutilation and Where Does it Happen?*, THE GUARDIAN, retrieved from <http://www.theguardian.com/society/2014/feb/06/what-is-female-genital-mutilation-where-happen>.

28. Natalie J. Friedenthal, *It’s Not All Mutilation: Distinguishing Between Female Genital Mutilation and Female Circumcision*, 19 N.Y. INT’L L. REV., 111, 113 (2006) (discussing the general history of female genital mutilation, including the religious groups it is most prevalent).

29. *The Truth About Female Genital Mutilation: UNICEF Unveils the Most Comprehensive Data Yet*, INT’L BUS. TIMES, retrieved from <http://www.ibtimes.com/truth-about-female-genital-mutilation-unicef-unveils-most-comprehensive-data-yet-1356515>.

30. Convention Against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment, U.N. G.A. Res. 39/46 Annex (1984) [hereinafter Convention Against Torture].

31. *Id.* ¶1.

distinction, exclusion, or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment, or exercise by women [.]”<sup>32</sup> Again, genital circumcision undeniably thrives on its distinction of exclusively subjecting females to the practice. Such discriminate distinction should cause concern among member states considering its explicit prohibition under CEDAW.

The preceding distinction has been qualified in some societies as a means of preserving a woman’s chastity or restraining her potential desire for sexual satisfaction. Yet, this ultimately exhibits the social and cultural patterns that CEDAW seeks to circumvent. In fact, Article 5 of the CEDAW urges states parties to take “appropriate measures” to reshape cultural and social patterns associated with men and women.<sup>33</sup> Article 5 goes on to assert CEDAW’s comprehensive intent to eliminate biases and practices “based on the inferiority or superiority of either of the sexes.”<sup>34</sup> Consequently, CEDAW’s provision epitomises the international community’s move to break free from gender biases associated with age-old traditions such as genital circumcision.

In an attempt to curb FGM, numerous global entities have embarked on a campaign to educate people on the dangers associated with the practice and to end its worldwide practice. For example, 6 February has been internationally gazetted as “International Day of Zero Tolerance to FGM/C.” On this day, people, entities, and communities all over the world create awareness about the practice and seek means to bring it to an end.<sup>35</sup> The first annual Girl Summit was also held in the summer of 2014 and this also serves as a platform for informing the international community about the dangers of FGM and urging it to make efforts to eliminate the practice. Various movements and campaigns have also contributed to creating awareness about the practice and have urged the international community to end it.

*ii) Western Views*—Generally, the Western world has a limited understanding of the existence of genital cutting. Those familiar with the practice are still ignorant of the deep-rooted reasons for its continuation. The Western world, however, is increasingly becoming a strong proponent to end the age-old tradition. Because of its harsh health risks, violent nature of the practice, and physical and psychological

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32. Convention on the Elimination of All Forms of Discrimination Against Women, Dec. 18, 1979, 1249 U.N.T.S. 13, U.N. Doc. A/34/180 [hereinafter CEDAW]. CEDAW entered into force on September 3, 1981.

33. *Id.*

34. *Id.*

35. USAID, International Day of Zero Tolerance to FGM/C, retrieved from <http://www.usaid.gov/what-we-do/global-health/cross-cutting-areas/gender-equality/international-day-zero-tolerance-fgmc>.

repercussions of genital mutilation, the West has increasingly stepped up efforts to end the practice.<sup>36</sup> One could argue that the West's increasing interest in the practice relates to its growing existence in the shadows of Western societies. As immigration and globalisation rapidly expand, traditions such as FGM cross geographical borders. While many view FGM as a problem for African and Middle East countries, the reality is that the practice has had rippling effects in the West too. Recognising this, the Western nations have begun implementing laws to punish the perpetrators involved in the practice. For instance, in England, the practice is considered a form of child abuse.<sup>37</sup> Moreover, the United States is actively working to end FGM across the globe through women's empowerment and the implementation of laws combatting the practice.

The West has also exhibited its opposition to the practice through grassroots efforts. Western-based human rights organisations such as Amnesty International have encouraged communities to abandon the practice of genital mutilation and instead replace the tradition with alternative ceremonial rituals.<sup>38</sup> The West has an overall negative view of FGM and is working to remove its existence.

### III. HUMAN RIGHTS AND ASYLUM AT A GLANCE

#### A. *The Western Front: How American Asylum Laws Address Female Genital Mutilation*

Asylum based on claims of genital mutilation is an infant concept in American law. Decided in 1997, *In re Kasinga* established the first binding precedent for immigration courts to use FGM as a form of persecution required for refugee status.<sup>39</sup> As a general matter, section 1158 of the United States Annotated Code provides that,

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36. Gayle Tzemach Lemmon, *The West Steps Forward in the Fight Against Female Genital Mutilation*, COUNCIL ON FOREIGN RELATIONS, retrieved from <http://blogs.cfr.org/development-channel/2014/10/01/the-west-steps-forward-in-the-fight-against-female-genital-mutilation/>).

37. *Id.*

38. *Id.*

39. See *In re Kasinga*, 21 I. & N. Dec. 357 (B.I.A. 1997). Seventeen year-old Kasinga was a member of a group in Togo that resisted female genital mutilation. When time came for Kasinga to undergo the local practice, she fled her native home of Togo and sought asylum in the United States. The Board finally granted her asylum after she proved: 1) she met the criteria for "refugee" described in section 208 of the Immigration Nationality Act (INA); 2) showed she was part of a specific persecuted group; and 3) she was a credible witness.

[a]ny alien who is physically present in the United States or who arrives in the United States (whether or not at a designated port of arrival and including an alien who is brought to the United States after having been interdicted in international or United States waters) irrespective of such alien's status, may apply for asylum.<sup>40</sup>

However, section 1158 generally provides the backdrop for asylum. C.F.R. section 1208.13 offers explicit guidelines as to what an asylum seeker must establish to earn eligibility.<sup>41</sup> Under the statute, the applicant bears the burden of proof<sup>42</sup> to establish past persecution,<sup>43</sup> well-founded fear based on past persecution or otherwise well-founded fear of future persecution<sup>44</sup> and reasonableness of internal relocation.<sup>45</sup> Courts have deconstructed the statute to three prongs, which are evidence of 1) persecution or fear of persecution in the alternative; 2) membership to a particular race, religion, nationality, social group, or political opinion; and 3) well-founded fear of persecution based on one's membership in one of the aforementioned classes.<sup>46</sup>

Consequently, a woman or girl seeking asylum in the United States on grounds related to genital mutilation must establish that 1) she is a female; 2) she belongs to a specific group; 3) the group she belongs to practices FGM.<sup>47</sup> The United States further offers refuge via asylum programmes to "persons *outside* the U.S. and their immediate relatives and... for persons *in* the U.S. and their immediate relatives."<sup>48</sup> This is often referred to as derivative asylum.

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40. 8 U.S.C.A. §1158 (2009).

41. 8 C.F.R. § 1208.13 (2013).

42. §1208.13 (a).

43. §1208.13 (b) (1). See also, *INS v. Cardozo-Fonseca*, 480 U.S. 421, 449 (1987) (The Court determined an alien does not need to prove that it is more likely than not that he or she will in fact be persecuted in his or her country of origin).

44. §1208.13 (b) (1), (2).

45. §1208.13 (b) (3).

46. YULE KIM, CONG. RESEARCH SERV. RS22810, ASYLUM LAW AND FEMALE GENITAL MUTILATION: RECENT DEVELOPMENTS (2008).

47. *Id.*

48. Daniel C. Martin and James E. Yankay, U.S. Dep't of Homeland Security Office of Imm., REFUGEES AND ASYLEES: STATISTICS ANNUAL FLOW REPORT FOR 2013, (2014) available at [http://www.dhs.gov/sites/default/files/publications/ois\\_rfa\\_fr\\_2013.pdf](http://www.dhs.gov/sites/default/files/publications/ois_rfa_fr_2013.pdf).

*B. The Western Front: How European Asylum Laws Address Female Genital Mutilation*

Law and policy promoters in the European Union (EU) have also sought to generally provide access to refugees, but the institution's unique make-up of sovereign states has resulted in a confusing "intergovernmental" approach to asylum.<sup>49</sup> In pursuit of homogenisation of the asylum process amongst EU member states, the institution constructed the Common European Asylum System (CEAS).<sup>50</sup> However, members have struggled "to ensure that member states adhere to common standards with respect to asylum seekers."<sup>51</sup> Ultimately, EU states have struggled with the "intertwined responsibilities under CEAS...EU law"<sup>52</sup> and arguably, individual state law.

Enacted in December 2005, the Asylum Procedures Directive<sup>53</sup> sought to close the gap on these discrepancies. The directive provides general guidance on how EU members should provide adequate access to procedure to applicants for asylum.<sup>54</sup> Furthermore, the directive obligates applicants to, for example, qualify under refugee status as defined in Council Directive 2004/83/EC,<sup>55</sup> partake in a personal interview,<sup>56</sup> and obtain proper legal assistance.<sup>57</sup> However, states have more autonomy in implementing their own specific asylum requirements.

For example, France generally requires an applicant to first obtain refugee status as defined under the Geneva Convention, paragraph 4 of the Preamble of the French Constitution, or articles 6 and 7 of the United Nations High Commissioner for Refugees (UNHCR).<sup>58</sup> An applicant must then either make a claim for subsidiary

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49. Randall Hansen, *Asylum Policy in the European Union*, 14 GEO. IMMIGR. L.J. 779, 781 (2000).

50. Sillas W. Allard, *Casualties of Dishonesty: The Exclusion of Asylum Seekers Under the Auspices of the Common European Asylum System*, 24 EMORY INT'L L. REV. 295, 296 (2010).

51. Lillian M. Langford, *The Other Euro Crisis: Rights Violations Under the Common European Asylum System and the Unraveling of EU Solidarity*, 26, HARV. HUM. RTS. J., 217, 218 (2013) (describing European Union states' struggle with maintaining obligations to CEAS and the EU).

52. *Id.*

53. See Council Directive 2005/85, 2005 O.J. (L 326) 13 (EC) (establishing minimum requirements for granting or withdrawing an applicant refugee status).

54. *Id.*

55. *Id.*

56. *Id.*

57. *Id.*

58. United Nations High Commission for Refugees, *National Asylum Procedures in France*, DUBLIN II, FRANCE, 2 (2006).

protection or stateless person status.<sup>59</sup> Under the subsidiary protection claim, most applicable to FGM assertions, protection may be granted to one “who establishes she is exposed to...death penalty; torture or inhuman or degrading sentences or treatments; serious, direct and individual threat to a civilian’s life or person.”<sup>60</sup>

#### IV. THE PRACTICE OF FEMALE GENITAL CUTTING IN SELECTED COUNTRIES

Cases of FGM encompass distinct complexities. This section assesses the data from women hailing from Guinea, Egypt, Ethiopia, and Yemen. The first three (Guinea, Egypt, and Ethiopia) represent countries with some of the highest rates of mutilation, while Yemen perpetuates the practice mainly for patriarchic purposes. More importantly, each of these countries represents a different cultural experience in terms of a woman’s contact with genital mutilation. Thus, each cultural experience results in various obstacles to overcome in a woman’s quest for asylum in a Western country. This section highlights some of the intricate points of concerns women in such positions face. While the countries serve as vivid case studies, the problems highlighted are not necessarily unique to asylum seekers from those countries.

##### A. *The Case of Guinea*

Those opposed to genital mutilation tend to be most concerned with issue of consent of the victim and whether or not a girl or woman has had a choice to undergo the procedure. The issue of consent is well articulated in the story of Fatou.

Twelve year-old Fatou was excitedly discussing her upcoming summer plans with her brothers when her aunt approached her to go for a walk.<sup>61</sup> Fatou found it peculiar that as they walked, other girls, their aunts, and grandmothers joined them one by one and soon took the girls to bathe.<sup>62</sup> The women then draped Fatou and the other girls in towels and led them into a room.<sup>63</sup> Although she was unable to see, Fatou heard horrendous cries and sobs as each girl went into another room.<sup>64</sup> Fatou soon learned the

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59. *Id.*, at 3.

60. *Id.*

61. Timothy La Rose, *In Guinea, One Girl’s Story of Violence Reveals Commonplace Nightmare*, UNICEF, retrieved from [http://www.unicef.org/infobycountry/guinea\\_71072.html](http://www.unicef.org/infobycountry/guinea_71072.html), (last updated July 23, 2014).

62. *Id.*

63. *Id.*

64. *Id.*

reasons for the sobs, as she underwent the traditional cut—without anesthesia.<sup>65</sup>

To date, Guinea has the highest rate of women and girls who have undergone FGM. Despite the practice being illegal in the country, an estimated 99% of women aged between 15 and 49 have undergone the procedure.<sup>66</sup> Those who oppose FGM often base their argument on the fact that it ignores the aspect of obtaining consent from the victims. Consent in this instance refers to permission to and distinct understanding of the cutting process. A girl should fully comprehend the physical stress, pain, and potential complications she may endure from FGM.

Note 10 of UNHCR's Guidance Note on Refugee Claims Relating to Female Genital Mutilation (Guidance Note) identifies informed consent as a point of great concern as it relates to children subject to FGM.<sup>67</sup> It recognises the frequent instance where a young girl has an inability to vocalise her fear. A girl may also be ignorant to the potential risks or hazards associated with genital mutilation. Under some circumstances, a young girl may even anticipate the tradition. She may, nevertheless, experience fear or apprehension related to the looming procedure. Such fear or apprehension can be considered legitimate, given that cutting is treated as a form of persecution.<sup>68</sup> Moreover, fear of the ambiguous nature associated with cutting is a precise indicator that the young girl is in fact unassuming.

Note 10 also places a duty on the "decision-makers to make an objective assessment of the risk facing the child, regardless of the absence of an expression of fear."<sup>69</sup> Such analysis in many ways reflects consent from the caretaker's point of view over a practice many Guinean girls and women do not fully comprehend. As a result, in situations where infibulation is against a minor child, many other states incorporate parental or guardian consent on behalf of the child by implementing prohibitive statutes. American jurisprudence provides a colourful illustration as to the kinds of laws local jurisdictions implement as a means to punish parents, guardians, and anyone else engaged in genital mutilation of another.

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65. *Id.*

66. UNICEF, *Guinea FGM/C Country Profile*, Nov. 2005, available at [http://www.childinfo.org/files/Guinea\\_FGC\\_profile\\_English.pdf](http://www.childinfo.org/files/Guinea_FGC_profile_English.pdf); See also, *Too Much Pain: Female Genital Mutilation & Asylum in the European Union*, THE UN REFUGEE AGENCY, available at [http://www.childinfo.org/files/Guinea\\_FGC\\_profile\\_English.pdf](http://www.childinfo.org/files/Guinea_FGC_profile_English.pdf).

67. Division of Int'l Protection Services, *Guidance Note on Refugee Claims Relating to Female Genital Mutilation*, (May 2009) <http://www.refworld.org/pdfid/4a0c28492.pdf> [hereinafter *Guidance Note*].

68. *Guidance Note*.

69. *Id.*

Given these kinds of proscriptions, the cutting experience in Guinea is of grave concern. UNICEF estimates that as of 1999 more than 60% of cut girls and women underwent the practice before they reached the age of nine.<sup>70</sup> Even more alarming is that 14% underwent the practice before the age of four.<sup>71</sup> These cases are extremely worrying since children of such ages are unable to consent to such traumatic procedures as FGM.

As of 2011, UNHCR estimated that women in Guinea were primarily seeking asylum in the EU countries of Belgium, France, Italy, and Sweden.<sup>72</sup> As the highest documented rate, the estimated number of female applicants for asylum in Belgium between the ages of 14 and 64 reached 626 out of 655 applications filed to the authorities in the country.<sup>73</sup> All the applications filed by these girls and women were likely associated with FGM.<sup>74</sup> The second highest documented rate was France, where female asylum applicants between the ages of 14 and 64, connected in some way with FGM, reached an alarming 593 out of 620 applications.<sup>75</sup> The third highest rate was the Netherlands, where FGM has affected 100 out of 105 female applicants from the aforementioned age ranges.<sup>76</sup> Few or none of the statistics showed Guinean asylees seeking refuge in the United States.

### *B. The Case of Egypt*

In Egypt, the medicalisation of the practice is a new phenomenon that poses great risk to girls and women around the world. Egypt is one of the countries that have criminalised the practice of FGM. The criminalisation of the practice extended to medical professionals who refused to halt the practice in their hospitals and clinics. For example, in January 2015, Dr. Raslan Fadl was convicted of manslaughter and sentenced to two years imprisonment after a young girl died in his care, making him the first medical professional in Egypt to be convicted of engaging in FGM.<sup>77</sup> Thirteen-

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70. *Id.*

71. *Id.*

72. Too Much Pain: Female Genital Mutilation & Asylum in the European Union, *supra* note 66.

73. *Id.*

74. *Id.*

75. *Id.*

76. *Id.*

77. Emma Batha, *Egypt Doctor Convicted Over Girl's Death in Landmark FGM Case*, THOMAS REUTERS, retrieved from <http://www.reuters.com/article/2015/01/26/us-egypt-trial-fgm-idUSKBN0KZ11Q20150126>, (accessed January 26, 2015).

year-old Suhair al-Bataa was forced by her father to undergo the procedure under Dr. Fadl's supervision.<sup>78</sup> Originally acquitted of all charges, Dr. Fadl's conviction was monumental in the judicial system's monitoring of medical professionals' role in curbing FGM.<sup>79</sup>

In Egypt, FGM is particularly compelling because in many instances, trained healthcare professionals have historically performed the procedure. This includes trained doctors, nurses, and midwives. Approximately 77% of women who have reportedly undergone FGM indicate that a medical professional conducted the operation.<sup>80</sup> The theory here is that girls and women experience far fewer health-related problems when a trained healthcare professional performs the operation. However, that has not always been the case. Considering the procedure provides no medical benefit whatsoever, complications are almost inevitable.

Despite Egypt's attempt at the medicalisation of genital mutilation, the physical risks and consequences of the practice remained a primary point of contention. The reality was that even in a medical setting, women and young girls still faced the risk of various genealogical complications that include sexual abnormalities and dysfunctions, lingering pain, scarring, complications passing urine, and dysmenorrhea.<sup>81</sup> Finally, acknowledging these astounding risks and facing pressure from the United Nations, Egypt finally banned all forms of the practice in 2007.<sup>82</sup>

While the Egyptian government initially banned FGM in 1997, it made various exceptions that allowed the practice to continue.<sup>83</sup> However, in 2007, the government found itself combatting outrage over the death of a 12-year-old girl who had undergone the procedure for nine dollars at a private clinic.<sup>84</sup> The young girl suffered immensely during the course of her procedure, which was considered by many as a mishandled operation.<sup>85</sup> She went on to suffer further as the medical team gave her an overdose of anesthesia, ultimately resulting in her death.<sup>86</sup> Members of the Egyptian Health

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78. Guerlin Orla, *Egypt's FGM Trial 'Convicts Doctor of Manslaughter'*, BBC NEWS, retrieved from <http://www.bbc.com/news/world-middle-east-30983027> (accessed January 26, 2015).

79. Batha, *supra* note 77.

80. UNICEF, *Female Genital Mutilation/Cutting: A Statistical Overview and Exploration of the Dynamics of Change* (July 2013) available at [http://www.childinfo.org/files/FGCM\\_Lo\\_res.pdf](http://www.childinfo.org/files/FGCM_Lo_res.pdf).

81. *Id.*

82. Ian Black, *Egypt Bans Female Circumcision After Death of 12-Year-Old Girl*, THE GUARDIAN (June 29, 2007), retrieved from <http://www.theguardian.com/world/2007/jun/30/gender.humanrights>.

83. *Id.*

84. *Id.*

85. *Id.*

86. *Id.*

Ministry finally implemented an overarching ban prohibiting *any* medical professional from conducting the operation in public or private practice.<sup>87</sup> The ministry threatened grave consequences for any healthcare professional who ignored the ban and proceeded to conduct cutting operations.<sup>88</sup>

Yet, although medical professionals are now legally restricted from perpetuating the practice, many still continue to provide FGM services in government and private clinics.<sup>89</sup> The physical ramifications of FGM have just recently been introduced in Egyptian medical schools, which still lead many doctors, nurses, and midwives to believe the practice remains of some medical benefit or necessity.<sup>90</sup> While some healthcare professionals have argued that they are simply adhering to the cultural demand for the procedure, the reality is that the practice is extremely lucrative.<sup>91</sup>

As of 2011, UNHCR estimated that the majority of Egyptian women aged between 14 and 64 who have likely been exposed to FGM are seeking asylum in the United Kingdom.<sup>92</sup> Ultimately, 50 out of 55 girls and women asylum aspirants bore some likely connection with FGM.<sup>93</sup> Sweden, France, and Italy tie for second place in terms of female asylum applicants in the aforementioned age range, whereby each country is documented as having had 27 applicants each,<sup>94</sup> with all three countries each possessing 30 female applicants overall.<sup>95</sup> Few or none of statistics show where in the United States Guinean asylees are seeking refuge.

### C. The Case of Ethiopia

The situation in Ethiopia reflects the challenges young girls face while undergoing FGM and the conflicts with exist between the practice and the international doctrines

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87. Magdi Abdelhadi, *Egypt Forbids Female Circumcision*, BBC NEWS, (June 28, 2007), retrieved from [http://news.bbc.co.uk/2/hi/middle\\_east/6251426.stm](http://news.bbc.co.uk/2/hi/middle_east/6251426.stm).

88. *Id.*

89. Hanan Fayed, *Licensed Doctors Performed 76% of Egypt's FGM: Health Ministry*, CAIRO POST, retrieved from [http://www.thecairopost.com/news/139710/inside\\_egypt/licensed-doctors-perform-76-of-egypts-fgm-health-ministry](http://www.thecairopost.com/news/139710/inside_egypt/licensed-doctors-perform-76-of-egypts-fgm-health-ministry) (accessed March 2, 2015).

90. Patrick Kingsley, *In Egypt, Social Pressure Means FGM is Still the Norm*, THE GUARDIAN, retrieved from <http://www.theguardian.com/world/2015/feb/06/female-genital-mutilation-egypt> (accessed February 6, 2015).

91. Fayed, *supra* note 89.

92. Too Much Pain: Female Genital Mutilation & Asylum in the European Union, *supra* note 66.

93. *Id.*

94. *Id.*

95. *Id.*

set in place to protect the rights of children. This is demonstrated in the story of Abay, who, while seeking asylum for herself and a minor-aged daughter, narrated her own horrific encounter with FGM at the hands of her mother.<sup>96</sup> What proved to be generational and cultural pressure to continue the practice with her four daughters led Abay to flee to the United States from her native Ethiopia.<sup>97</sup>

While the immigration judge in the matter found no “imminent fear [of female genital mutilation], but rather a general ambiguous fear,” the appeals court placed great emphasis on the minor child’s fear of being subjected to the practice upon return to her grandmother in Ethiopia.<sup>98</sup> Most paramount was the court’s reference to the UNHCR Handbook on Procedures and Criteria for Determining Refugee Status (1992).<sup>99</sup> The handbook instructs adjudicators to analyse claims for asylum while bearing in mind that “very young children may be incapable of express fear to the same degree or the same level of detail as adults.”<sup>100</sup> Given this guidance, the court found Abay’s daughter sufficiently proved fear as required to establish oneself as a “refugee” under the act.<sup>101</sup>

Considered an honored tradition, statistics show close to 80% of women in Ethiopia aged between 15 and 49 undergo FGM.<sup>102</sup> Most alarming is Ethiopia’s tremendously high rate of infant girls enduring various forms of FGM.<sup>103</sup> Statistics indicate that more than half of the women who have undergone the procedure have been cut in their infancy, that is, before their first birthday.<sup>104</sup> This raises a critical point given the international community’s adamant assertion of the rights of a child.

The United Nations Convention on the Rights of the Child (CRC) serves as an example of the international community’s commitment to advocacy and protection of children. Enacted in November 1989, the CRC undoubtedly seeks to protect the rights and autonomy of a child. In its preamble, the CRC even references its legislative predecessor, the Geneva Declaration of the Rights of the Child of 1924, by stressing that “the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after

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96. *Abay v. Ashcroft*, 368 F.3d 634 (US Ct. App. 6th Cir. 2004).

97. *Id.*, at 639.

98. *Id.*, at 639-40.

99. *Id.*, at 640.

100. *Id.*

101. *Id.*

102. FGM/C Country Profile, UNICEF, (Nov. 2005) available at [http://www.childinfo.org/files/Ethiopia\\_FGC\\_profile\\_English.pdf](http://www.childinfo.org/files/Ethiopia_FGC_profile_English.pdf).

103. *Id.*

104. *Id.*

birth.”<sup>105</sup> Although the CRC alludes to the vitality of traditional and cultural values of a people, article 19 of the CRC vigorously impedes upon its members a responsibility to safeguard children from physical or mental violence and abuse.<sup>106</sup> Under the CRC, “[s]tates parties shall take all appropriate legislative, administrative, social, and educational measures to protect the child from all forms of physical or mental violence, injury, or abuse[.]”<sup>107</sup> Thus, an infant child’s exposure to such physical stress and infiltration can assuredly be categorised as violence, which is prohibited under the guide of the CRC. Ethiopian parents’ consent to the practice overtly contradicts their responsibility outlined in the CRC’s preamble. The CRC commands families of member states to uphold responsibility to protect children primarily because of their vulnerability.<sup>108</sup>

Furthermore, African countries have also made a commitment to the protection of children in a way that should thwart the continuance of FGM. The African Charter on the Rights and Welfare of the Child (ACRWC) in part also acknowledges the unique components of an African child’s traditional, cultural, and socio-economic circumstances that make safeguards that much more imperative.<sup>109</sup> The ACRWC, however, proceeds to curb any misconception about African nations’ stance on culture and tradition vis-a-viz adopted human rights principles. Under chapter 1 article 1 of the ACRWC, “[a]ny custom, tradition, cultural or religious practice that is inconsistent with the rights, duties, and obligations...in the present Charter shall to the extent of such inconsistency be discouraged.”<sup>110</sup>

Article 21 of the ACRWC specifically touches on the protection of children against harmful social and cultural practices<sup>111</sup> and urges states to implement measures to effectively eradicate practices that are “prejudicial to health or life of a child” and “discriminatory to the child on the grounds of sex.”<sup>112</sup> While the ACRWC almost exactly mirrors the CRC in purpose, language and structure, this provision is omitted from the CRC and is, thus, undeniably unique to the cultural experience. Young Ethiopian girls’ vulnerability to FGM as a cultural practice is poignant to their

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105. Convention on the Rights of the Child, Nov. 20, 1989, 1577 U.N.T.S 3, 28, I.L.M. 1448 [hereinafter CRC].

106. *Id.*

107. *Id.*

108. *Id.*

109. African Charter on the Rights and Welfare of the Child, OAU Doc CAB/LEG/153/Rev 2, reprinted in Human Rights Law in Africa (1997).

110. *Id.*

111. *Id.*

112. *Id.*

increased risk of health problems and discomfort. Furthermore, the fact that parents only subject their daughters to the practice harps upon the ACRWC's prohibition on discriminatory practices against a particular sex. While the ACRWC provides a progressive movement towards the elimination of the practice, the reality is that Ethiopian girls and young women are high risk of enduring genital mutilation.

Although with much reservation, Ethiopian parents often bear the burden of consenting to exposing their daughters to the age-old practice. Parents also often feel pressured by older family members and the greater community. They feel obliged to concur for fear that their daughters will be isolated, shunned, and incapable of marriage unless they comply with the practice.<sup>113</sup> Yet, this is at the expense of the child.

The UNHCR, in its 2011 report, estimates that 123 out of 165 girls and women aged between 14 and 64 sought asylum in Germany for reasons likely related to FGM.<sup>114</sup> Italy held the second highest rate of applicants with 82 out of 110 female asylum seekers potentially in some regard by genital mutilation.<sup>115</sup> Sweden came in third place<sup>116</sup> with 52 out of 70 total female asylum seekers' applications related to FGM.<sup>117</sup> Few or none of the Ethiopian asylees sought refuge in the United States.

#### D. The Case of Yemen

In a practice predominantly involving women, it is important to consider what role, if any, men play in the evolution of FGM. According to Soheir Stolba, female genital mutilation is a deeply rooted practice in Yemen.<sup>118</sup> Stolba's assertion provides illustrative accounts of the practice in the country.<sup>119</sup> According to her, 95% of the time, girls undergo the procedure at home with mothers being the primary decision-makers.<sup>120</sup> To date, Yemen has not outlawed the practice, but has implemented a

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113. Indrias Getachew, *Battling An Ancient Tradition: Female Genital Mutilation in Ethiopia*, UNICEF, retrieved from [http://www.unicef.org/protection/ethiopia\\_34881.html](http://www.unicef.org/protection/ethiopia_34881.html).

114. Too Much Pain: Female Genital Mutilation & Asylum in the European Union, *supra* note 66.

115. *Id.*

116. *Id.*

117. *Id.*

118. Amel Al-Ariqi, *Yemen: 24 Percent of Yemeni Women Experience Genital Mutilation*, YEMEN TIMES, (Feb. 27, 2007).

119. *Id.*

120. *Id.*

ministerial decree prohibiting the procedure in government and health facilities.<sup>121</sup> A recorded 24% of Yemeni women have undergone FGM in some form or fashion.<sup>122</sup> Local women also trained in ear piercing, birthing, and female genital cutting often perform the procedures.<sup>123</sup> The reality is that in most cases, young women and girls undergo the practice at home with the primary consent of their mothers, as opposed to their fathers.<sup>124</sup> This calls into question what role, if any, men have in mobilising and preserving the practice.

Scholars have determined that a man's role in the practice of genital mutilation generally varies across societal bounds. In most of the cases, when asked about the history and purpose of the practice, men often refer to the expertise of their mothers, wives, sisters, aunts, and female cousins. In many regards, "[female genital mutilation] is women's business."<sup>125</sup> As a result, there are those who seek to better understand what contribution men have in the traditional practice.

For example, social anthropologist Khalid Roy identifies five unequivocal male responses that are prevalent in Yemen and other states that practice FGM.<sup>126</sup> He compresses these responses into: 1) Mr. Apathetic, 2) Mr. Aggressive, 3) Mr. Anxious, 4) Mr. Misinformed, and 5) Mr. Apologist.<sup>127</sup> According to Roy, men that express an indifferent opinion or response to FGM are apathetic.<sup>128</sup> Here, since older women tend to carry out the gruesome procedure, "men can afford to be blasé."<sup>129</sup> In Roy's opinion, such physical, graphic visual understanding of what the practice physically entails would help men better conceptualise the ghastly procedure and diminish its correlation with male circumcision.<sup>130</sup>

Alternatively, Roy categorises men who are adamant "when consummating [their] marriage to a woman who has undergone the cut" as aggressive.<sup>131</sup> Yemen, like

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121. U.S. Dep. of State, YEMEN: REPORT ON FEMALE GENITAL MUTILATION (FGM) OR FEMALE GENITAL CUTTING (FGC) (June 1, 2001), available at <http://2001-2009.state.gov/g/wi/rls/rep/crfgm/10112.htm> [hereinafter Report on FGM].

122. Al-Ariqi, *supra* Yemen: 24 Percent of Yemeni Women Experience Genital Mutilation.

123. *Id.*

124. *Id.*

125. Khalid Roy, *What Kind of Men Support FGM? An Illustrated Guide*, THE GUARDIAN (Aug. 1, 2014), retrieved from <http://www.theguardian.com/global-development-professionals-network/2014/aug/01/what-kind-of-men-support-fgm-an-illustrated-guide>.

126. *Id.*

127. *Id.*

128. *Id.*

129. *Id.*

130. *Id.*

131. *Id.*

other countries where FGM is prevalent, is a society constructed around the idea that masculinity centres on dominance, control, and aggression towards women. Thus, the heinous cutting experience along with the domineering, vehement, and aggressive push from a man only exacerbates the issue.<sup>132</sup>

Khalid further classifies fathers and husbands who experience apprehension as a result of their daughters or wives enduring FGM as anxious.<sup>133</sup> Men in this category often inadvertently struggle with confusion as it relates to their masculinity, the pain their daughters or wives experience, and a loss of autonomy in the process.<sup>134</sup> Ultimately, men find themselves searching for ways to rationalise the continuation of the practice, but become stressed when one of their own has to undergo the procedure.<sup>135</sup> Khalid contends that such forced rationalisation can only be curbed by increased open dialogue contesting social and cultural justifications for the practice's continuance.<sup>136</sup>

According to Khalid, some men's ignorance can simply render them misinformed.<sup>137</sup> He describes some men's reliance on religious indoctrination as a means of justifying FGM and campaigns to end the practice as "[W]estern conspiracy to corrupt and liberate women."<sup>138</sup> In a nation where virtually all people practice Islam, Yemeni women serve as an example of those who endure cutting as result of some form of religious rationalisation. For example, the Quran, Bible or other religious doctrines make no mention of female circumcision, yet religious proponents find reasons for religious necessity. Khalid emphasises the need for assurance in religious communities that liberating women through ending genital mutilation does not somehow violate their religious obligations.<sup>139</sup>

Finally, Khalid labels men who minimise the practice as a local tradition are apologists.<sup>140</sup> This would include men outside of the country who fear being designated as neo-colonialism sympathisers, but who are, in Khalid's opinion, really ambivalent to "the suffering of young girls and women."<sup>141</sup> The reality is that men and other diverse entities do play a role in FGM.

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132. Khalid, *supra* note 125.

133. *Id.*

134. *Id.*

135. *Id.*

136. *Id.*

137. *Id.*

138. Khalid, *supra* note 125.

139. *Id.*

140. *Id.*

141. *Id.*

The UNHCR estimated that the United Kingdom had the highest rate of female applicants aged between the ages of 14 and 64 applying for asylum for reasons related to FGM.<sup>142</sup> In 2011, 11 out of 30 girls and women filed for asylum on these grounds.<sup>143</sup> In second position was Sweden, where 10 out of 25 applicants were female.<sup>144</sup> Lastly, Germany came in third position with four out of 10 women overall founding an asylum claim on the basis of persecution related to FGM.<sup>145</sup> Few or none of the Yemeni asylees sought refuge in the United States.

## V. POLICY RECOMMENDATIONS FOR WESTERN STATES

### A. Legal reforms

As a safe haven, the West has a responsibility to protect the interests of asylees both in law and policy. Given typical circumstances, FGM largely tramples upon a woman's informed consent rights. Therefore, as a preliminary matter, Western hosts should offer asylees educational tools that expose them to a general understanding of consent. Women should undeniably become privy to the concept of consent to understand they have been or could have been violated as well as prevent any future violations.

In addition, the West must lead by example when it comes to supporting policy aimed at combating genital mutilation. Legally binding after ratification, research shows the CRC has been the most successful UN human rights treaty given, with the exception of two nations, "every self-governed nation... has both signed and ratified the CRC."<sup>146</sup> Yet the United States' decision to not join CEDAW or the CRC is ironic and detrimental to the expansion of human rights. In general, the United States has only ratified four of the seven human rights conventions<sup>147</sup> and has added certain reservations to the ones it has ratified. Its biggest concerns with ratification of human rights conventions relate to national sovereignty, federalism, reproductive, and family rights.<sup>148</sup>

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142. Too Much Pain: Female Genital Mutilation & Asylum in the European Union, *supra* note 66.

143. *Id.*

144. *Id.*

145. *Id.*

146. Lainie Rutkow & Joshua T. Lozman, *Suffer the Children?: A Call for the United States Ratification of the United Nations Convention on the Rights of the Child*, 19 HARV. HUM. RTS. J. 161, 162 (2006).

147. *Id.*

148. *Id.*

Yet, early on, the CRC states that the family is the ‘fundamental group of society’ and that ‘parents have common responsibilities for the upbringing and development of the child.’ Articles 12 and 13 of the CRC focus on children’s right to freedom of expression. However, Article 13 describes specific restrictions to this freedom, including restriction ‘[f]or the protection of...morals.’ The term ‘morals’ is not defined in the CRC, which allows each party to interpret the term.<sup>149</sup>

Ultimately, the United States’ role is particularly vital in the human rights movement given its powerful and influential role in the international arena. Thus, its signature and ratification of CEDAW and the CRC are critical in supporting FGM asylees in the West.

Finally, while many Western states grant asylum based on claims of exposure or reasonable fear of exposure to genital mutilation, it is difficult to make a successful claim. In the United States, for example, derivative asylum only offers refugee status to spouses and children.<sup>150</sup> Under this system, parents or extended family members are unable to attain asylum unless they have themselves established refugee status on some other basis. This becomes problematic considering that various family members may flee to the West to protect their nieces, granddaughters, or cousins from cutting. Legal parameters should, thus, reflect and accommodate for legitimate asylee circumstances.

#### *B. A Shift in Medical Accommodations*

Western medical professionals need both medical and psychological training to best accommodate victims and potential victims of FGM. Global medical specialists acknowledge that victims face immense health hazards due to the ghastly “conditions under which... [circumcisions] are performed.”<sup>151</sup> Having been illegalised in many nations, most women and girls undergo the practice in localised settings often without anesthesia or sterilised medical utensils.<sup>152</sup>

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149. Rutkow & Lozman, *supra* note 146.

150. Melanie A. Conroy, *Refugees Themselves: The Asylum Case for Parents of Children at Risk of Female Genital Mutilation*, 22 HARV. HUM. RTS. J. 109, 112 (2009).

151. Nahid M.D. Toubia, *Female Circumcision as a Public Health Issue*, 331, NEW ENG. J. MED. 712, 715 (1994).

152. *Id.*, at 127.

These procedures commonly take place under primitive surgical conditions, often in a family home, lacking basic sanitation, anesthesia or proper surgical instruments. The same instruments are often used to cut the genitals of several girls consecutively without any use of antiseptic. The practice may cause physical, as well as psychological damage to a woman. Physical harm includes tetanus, rupture of the vaginal walls, formation of dermoid cysts on scar lines, septicemia, lengthy periods of obstructed labor, chronic uterine and vaginal infections, obstruction of menstrual blood flow and increased risks of injury, and death to both the infant and the mother during childbirth.<sup>153</sup>

Infibulation, for example, aggressively obstructs a woman's vaginal opening by only leaving enough space to allow urine to pass.<sup>154</sup> The size of the opening has sometimes been described as "the kernel of corn."<sup>155</sup> Infibulation, therefore, particularly raises long-term risks because of its cumbersome and dangerous "interference with a [woman's] menstrual and urine flow."<sup>156</sup> More concerning is the risk that infibulation poses to women who have yet not been deinfibulated, who experience enormous pain during childbirth.<sup>157</sup> Deinfibulation involves cutting a girl or woman yet again to allow for intercourse and childbirth.<sup>158</sup> Many women undergo deinfibulation immediately after marriage or prior to childbirth<sup>159</sup> but struggle to find competent doctors to perform the surgery. This has the potential to cause unimaginable tearing of tissue.<sup>160</sup> Furthermore, the prevalence of the practice amongst girls from infancy through adolescence all the way to women in their adulthood<sup>161</sup> gives doctors a wide range of potential patients that may need corrective surgery.

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153. Rutkow & Lozman, *supra* note 146.

154. Toubia, *supra* note 151.

155. Karen Hughes, *The Criminalization of Female Genital Mutilation in the United States*, 4 J.L. & POL'Y 321, 322 (1995).

156. Toubia, *supra* note 151.

157. *Id.*

158. Daliah Setareh, *Women Escaping Genital Mutilation—Seeking Asylum in the United States*, 6 UCLA WOMEN'S L.J., 123-59 (1995).

159. WHO, *Female Genital Mutilation: Caring for Patients and Safeguarding Children*, WORLD HEALTH ORGANIZATION; GENEVA (July 2001).

160. Toubia, *supra* note 151.

161. Wondimu Shanko Yirga, Nega Assefa Kassa, Mengistu Welday, Gebremichael, Arja R. Aro, *Female Genital Mutilation: Prevalence, Perceptions, and Effect on Women's Health in Kersa District of Ethiopia*, 4 INT'L J. WOMEN'S HEALTH, 45, 46 (2012).

Ultimately, this would suggest that there is a vital need for Western medical personnel to get a better understanding of the physical complications a woman faces having endured FGM. She will undoubtedly need specialised medical care well into various stages of her life. Such care will have to encompass practical reconstructive surgery needs, childbirth accommodations that protect mother and child, menstruation regularity assistance, urinary tract assistance, sex therapy, and possibly even menopausal-stage aid.

Very few studies have been conducted to gauge the psychological implications of cutting.<sup>162</sup> Yet, it is well founded throughout the medical community that physical complications only exacerbate psychological trauma.<sup>163</sup> Therefore, lay opinions suggest that girls and women endure “fear, trauma, and after-effects of the operation.”<sup>164</sup> Some women experience intense anxiety, fear, and even depression related to concern of over their genitals, dysmenorrhea, and potential infertility.<sup>165</sup> Many others experience a distinct inability to experience sexual pleasure, which can be both a mental and physical inhibition.<sup>166</sup> This is in addition to a woman’s “denial and acceptance of social norms.”<sup>167</sup> Women’s internal psychological struggles connected to such shock are an area medical professionals need to investigate.

### C. Prioritize the protection of Children’s Rights

The continued practice of FGM amongst young girls brings to light intricate problems that child and other potential victims may face in the long run. Children, therefore, likely need specialised support upon arrival in the West. The shock and trauma associated with genital mutilation or fear of it extend beyond the physical and include psychological repercussions.<sup>168</sup> For example, children who have undergone infibulation tend to have to endure repeated surgical operations at various stages of their lives.<sup>169</sup> This kind of repeated intrusion on a girl’s sexual organs can cause unimaginable physical, emotional, and psychological discomfort that re-victimised sexual violence victims often face.

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162. Toubia, *supra* note 151.

163. *Id.*

164. *Id.*

165. *Id.*

166. *Id.*

167. *Id.*

168. Hope Lewis, *Between Irua and “Female Genital Mutilation”: Feminist Human Rights and the Cultural Divide*, 8 HARVARD HUM. RTS. L.J. 1,6 (1995).

169. *Id.*

Tension, however, occurs when courts seek to determine the intersection or the point their protection of a child's health and welfare infringes upon a parent's decision-making rights. So, while courts sometimes defer to parental authority based on cultural or religious belief, states also owe children a duty of care when such deferential authority would put a child's life in danger.<sup>170</sup> Child abuse laws can and have in some cases been construed to protect children from undergoing genital mutilation.<sup>171</sup> Consequently, a young girl having attained asylum in the West for fear of undergoing cutting in her home country is still owed protection from her parents, family, or others that could later endanger her life.

Similar to general education on consent, so too is there a vital importance in providing young girls and young women with information about sexual violence. FGM in many ways is a violent act against a young woman. By unwillingly penetrating young women in such a gruesome way, in most cases against their will, a perpetrator robs these women of any potential sexual freedom. No longer will the young women be able to, in most cases, freely explore their bodies or experience pleasure to their highest potential. Young girls and women exposed to genital mutilation should obtain general knowledge about what acts constitute as violence against women as a means to arm themselves retrospectively and prospectively in the Western world.

#### *D. Understanding Social Change*

The Western world should avoid one-dimensional thinking when it comes to understanding the practice of FGM. While the West swiftly condemns the tradition, its credibility is called into question when its culture permits such practices as cosmetic surgery, tattooing, and body piercing.<sup>172</sup> Such practices can in some ways be linked to sexuality or misogynistic representations of women, often constructed or enhanced by men. Procedures like breast augmentations are widely controversial<sup>173</sup> in the West, yet still permissible and highly prevalent. Like FGM, breast augmentation has no real health benefit and instead brings about various health risks such as blood clotting, pain, infection, implant ruptures, and difficulty in detecting cancer.<sup>174</sup> Other procedures such as tattooing and piercing have been described as individualistic.

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170. *Id.*

171. *Id.*

172. Catherine L. Annas, *Irreversible Error: The Power and Prejudice of Female Genital Mutilation*, 12 J. CONTEMP. HEALTH AND POL'Y 325, 342 (1996).

173. *Id.*

174. *Id.*

These kinds of practices are highly idealised and accepted as tradition in the West. And while the West may contend that they at least require consent from the individual,<sup>175</sup> it cannot negate that some cultures have comparable aversion towards them. Therefore, the West should be prepared to reconcile traditionally accepted Western practices with traditions like cutting. Furthermore, rationalisation must be construed to acknowledge and respect the cultural homage cutting seeks to preserve just as tattooing or cosmetic enhancement does.

Embedded in the social context is the discussion of cultural prejudice particularly as it relates to feminism. Eugenie Ann Gifford goes into great detail about the often-missed opportunity to incorporate women from different race, ethnic, or cultural backgrounds in the fight against genital mutilation.<sup>176</sup> He exposes feminist scholars “failing to adequately consider issues of concern to women of color...in effect pretending that there is one prototypical ‘woman,’ and she is white, middle, and American.”<sup>177</sup> This can have huge ramifications on the movement against mutilation because Western women fail to diversely conceptualise FGM.

Moreover, inability to think beyond one’s Western cultural bounds produces “‘cultural imperialism’ of presuming that the moral dictates of their own, dominant society are the ‘right’ ones, and cultural practices which depart from these dictates are ‘wrong’ and should be eradicated.”<sup>178</sup> Gifford also importantly notes that any implication that “all women suffer the same oppression simply because we are women is to lose sight of the many varied tools of patriarchy.”<sup>179</sup> Therefore, social feminist movements and attempts to change male perspectives should diversify their understanding and views to best support victims of FGM.

## VI. CONCLUSION

Even at the height of female liberation and Fauziya’s story, the practice of FGM still persists around the globe. The reality is that many of these women and girls are seeking refuge in Western nations. Yet, their hosts are ill-prepared to handle their demands. The West fundamentally needs to accommodate the unique and delicate needs of these particular asylees. The best approach is to first recognise the poignant pragmatic

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175. *Id.*

176. Eugenie Ann Gifford, “*The Courage to Blaspheme*”: *Confronting Barriers to Resisting Female Genital Mutilation*, 4 UCLA WOMEN’S L.J. 329, note 1 (1994).

177. *Id.*

178. *Id.*

179. *Id.*

concerns related to female asylum seekers from countries where the practice of FGM is rife. In doing so, Western countries will do more to support refugees in countries where they seek refuge.