PROTECTION OF THE RIGHTS OF PERSONS LIVING WITH COGNITIVE DISABILITIES IN THE CONTEXT OF HIV & AIDS UNDER THE AFRICAN HUMAN RIGHTS SYSTEM

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DEDICATION

I express my absolute gratitude to the almighty for his grace and unconditional love and mostly for the strength he gave me to reach completion. I also dedicate this to Mutule, my family, friends and all who rendered support through the year.

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May the Lord bless you all abundantly

ABSTRACT

The purpose of this paper is to analyse the link between human rights and, HIV and AIDS. It also assesses whether persons who experience inequality, prejudice, marginalisation and limitations in their social, economic and cultural rights are at a greater risk of HIV exposure. The study aims to assess whether persons living with cognitive disabilities have been a marginalised in the international and regional responses to HIV and AIDS, because cognitive disabilities impact on the basic social skills of an individual such as reading, writing, interacting with people and affect the ability of an individual to learn new things and infer information from social cues and body language. The author will therefore review specific international human rights instruments, African human rights instruments and some national policies and legislation in order to examine this, and based on the findings will provide recommendations accordingly.

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List of Abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
AU	African Union
CEDAW	Convention for the Elimination of all forms of Discrimination against Women
CRC	Convention on the Rights of the Child
CRPD	United Nations Convention on the Rights of Persons Living with Disabilities
ECOSOC	Economic and Social Council
HIV	Human Immune Deficiency Virus
ICASA	International Conference on AIDS and STIs in Africa
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICIDH	International Classification of Impairment, Disabilities and Handicaps
NGO	Non-Governmental Organisation
OAS	Organisation of American States
OAU	Organisation of African Unity
StRE	Standard Rules on the Equalisation of Opportunities for Persons with Disabilities
STI	Sexually transmitted infection
UN	United Nations
WHO	World Health Organisation
WPA	World Programme of Action concerning the disabled

CHAPTER ONE

Different but equal: Protection of the rights of persons living with cognitive disabilities in the context of HIV and AIDS under the African human rights system

1. Introduction

There is an urgent need to establish a legal response to address the vulnerability of persons living with disabilities to exposure of HIV infection. The wrongful assumption of their sexuality has created high levels of marginalisation and there is need to safeguard the various rights of persons living with disabilities such the right to health, information, human dignity and equality in the context of HIV and AIDS.

This paper focuses on the challenges faced by persons with cognitive disabilities. Cognitive disability is no less than visual, hearing or physical disabilities. The reason why the focus is on cognitive disabilities is because this specific category of disability impacts on the basic social skills of an individual such as reading, writing, interacting with people as well as learning new things and inferring information from social cues and body language.[1]

In addition, individuals with cognitive disabilities are often of average intelligence, it is merely learning disability yet often they are treated as 'insane'.[2] Accommodation needs to be made in the spread of information regarding HIV prevention for the specific needs of persons with cognitive disabilities in the same vain as a person with a physical disability needs a wheelchair.

The position adopted is that the inadequate inclusion of the specific needs of persons living with cognitive disabilities in matters concerning HIV prevention and AIDS treatment under the African human rights system directly affects their rights which include the right to health which entails access to preventive information,[3] education, information, equality and human dignity.

[1] 'Cognitive or learning disabilities' http://www.muhlenberg.edu/careercenter/emplguide/cognitive.html (accessed 20 August 2012).
[2] J Hanass-Hancock 'Interweaving conceptualizations of gender and disability in the context of vulnerability to HIV/AIDS' (2009) 27 *Sexuality and Disability* 35.
[3] African Commission on Human and People's Rights (ACHPR) Resolution on access to health and needed medicines in Africa (ACHPR/Res.141 (XXXXIIII) 08).

1.1 Background to the Study

South African Judge and HIV Activist, Edwin Cameron has noted that 'the role of the law in a public health crisis, such as the HIV and AIDS pandemic, should be to contain the epidemic and to mitigate its impact.[4] In other words, 'the law should aim to save the uninfected from infection and to protect the infected from unjust consequences of public panic'.[5]

Internationally, the link between human rights and HIV is well recognised and 'persons who experience inequality, prejudice, marginalisation and limitations on their social, economic and cultural rights are at a greater risk of HIV exposure'.[6] Persons living with disabilities have been a marginalised population since time immemorial and it has been noted that 'they have been greatly sidelined in the international and national responses to HIV and AIDS'.[7] Persons living with disabilities are particularly vulnerable to discrimination and other violations of their human rights.[8] This in turn may increase their vulnerability to HIV infection and may undermine their ability to access available HIV related services.[9]

A cognitive disability is one that affects the ability of the brain to receive process, analyze, or store information.[10] People with cognitive disabilities have trouble learning new things, making generalizations from one situation to another, and expressing themselves through spoken or written language.[11] This necessarily entails that more often than not, persons with cognitive disabilities are incapable of immediately processing information regarding HIV in many contexts, starting from school set ups, the home and society at large.

Consequently, persons living with cognitive disabilities are at an increased risk of exposure to HIV, firstly because they are prone to sexual abuse in the form of rape and sexual violence and have limited access to justice,[12] secondly, their lack of knowledge can often lead them to high HIV risk behaviours such as unprotected sex or multiple sex partners due to insufficient access to HIV prevention and support information.

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[4]E Cameroon 'using the law in the HIV pandemic: sword or shield' Lecture at Birkbeck College, London 28 June 2007 http://www.nat.org.uk/document/307 (Accessed 22 August 2012).
[5](n 4 above).
[6]'UNAIDS International Guidelines on HIV/AIDS and Human Rights; Joint United Nations Programme on HIV/AIDS' in L Gerntholtz *et al*. 'Disability Rights and HIV/AIDS in Eastern and Southern Africa Final Report August' (2010) 3.
[7]As above.
[8](n 6 above) 8.
[9](n 6 above) 8.
[10]'Defining Disability, types and categories' http://www.disabled-world.com/disability/types/ (accessed 6 August 2012).
[11]As above.
[12]Hannas-Hancock (n 2 above) 35.

Finally, they are often unable to easily receive HIV education and preventive information because they are perceived to be at lower risk of exposure or because they are unable to be in school due to their limited cognitive capacity. In addition, it is generally difficult for women with cognitive disabilities to access reproductive and sexual health services.[13] Cognitive disabilities are common among patients with HIV and persons with HIV and cognitive disabilities are often denied access to HIV treatment.[14] The exclusion of persons with cognitive disabilities from HIV care and preventive information is a concerning human rights issue.

This paper discusses some of these human rights issues and examines some of the reasons for the increased vulnerability of persons living with cognitive disabilities to HIV exposure. The paper also provides recommendations on how a legal response can be created to promote equality. It is not disputed that other groups in society experience restrictions or limitations in the care and treatment of HIV as well as information on prevention. However, this paper insists that persons living with cognitive disabilities tend to experience extreme hardships in this area of concern.

By way of summary, this research recommends that human rights jurisprudence concerning responses to HIV and AIDS requires consideration of disability specific issues. The conclusions and overall position of this research is that persons living with cognitive disabilities are at an increased risk of exposure to HIV infection and are less likely to access prevention, testing and treatment in the absence of legal frameworks to guarantee their protection and address their specific needs in this area of concern.

This paper reviews key international, regional and national instruments relating to disability and identifies a limitation in the extent to which the African human rights system has contributed to the effective protection of the rights of persons living with disabilities in the context of HIV and AIDS given the multifaceted nature of the concept of disability.

1.2 Problem statement

Persons living with disabilities have since time immemorial been victims of human rights violations and social exclusion. Today, 'a substantial percentage of the world's population are living with a disability

[13] As above.
[14] Health and Human Rights http://www.hhrjournal.org/index.php/hhr/article/view/434/671 (accessed 20 August 2012).

for various reasons and many of them live in harsh conditions'.[15] Many policies which promote the social exclusion of persons living with disabilities are initiated by governments[16] and yet the state has the responsibility to protect, respect and fulfil their rights.

Persons living with cognitive disabilities have trouble learning new things, making generalizations from one situation to another, and expressing themselves through spoken or written language. It is not mental retardation but rather a learning disability.[17] More often than not, persons with cognitive disabilities are incapable of immediately processing information regarding HIV in many contexts such as school set ups, the home and society as a whole. Therefore, persons with cognitive disabilities are at an increased risk of exposure to HIV and are prone to sexual abuse yet they have limited access to justice.[18]

In Africa, persons living with cognitive disabilities suffer extreme human rights violations and are highly vulnerable to exposure of HIV which exposes them to an even greater risk of stigma and discrimination.[19] Although disability is a global phenomenon, Africa is still enhancing the literature around the subject. The lack of a proper address of the vulnerability of persons living with cognitive disabilities in the context of HIV and AIDS in Africa manifests itself in the manner in which disability rights are protected under the African human rights system.[20]

1.3 Research question

Does the African human rights system adequately address the specific needs of persons with cognitive disabilities in the context of HIV and AIDS?

The specific research questions are:

a. Why is it important to consider the specific needs of persons with cognitive disabilities in the context of HIV and AIDS in the regional human rights system?

b. What is the international standard pertaining to the protection of the rights of persons living with cognitive disabilities in the context of HIV/AIDS?

[15]Human Rights and disability at http://www.unhcr.ch/disability/intro.htm (accessed 20 August 2012).
[16]S Yee & M Breslin Disability rights law and policy (2002) http://www.dredf.org/international/bookintro (10 August 2012).
[17](n 1 above).
[18](n 2 above) 38.
[19]HIV/AIDS and Disability Global Survey http://cira.med.yale.edu/globalsurvey (accessed on 17 August 2012).
[20]This paper will identify the gaps in the African human rights system for the protection of disability rights, more so with respect to HIV &AIDS reference being made to the African Charter on Human and People's Rights.

c. To what extent does the African human rights system address the problems faced by persons living with cognitive disabilities in respect of their marginalisation in HIV and AIDS related matters?

d. What measures can be adopted to ensure the protection of the rights of persons living with cognitive disabilities under the African human rights system in the context of HIV and AIDS?

1.4 Significance of study

In 2008, the International AIDS Conference XVII and the International Conference on AIDS and STIs in Africa (ICASA) focused on disability as an issue in HIV and AIDS.[21] The research in this field is growing in recent years and literature about HIV, AIDS, disability and the vulnerability of persons living with disabilities to HIV infection has been published. The issue of great concern is with respect to access for persons living with disabilities to HIV prevention and AIDS treatment information and facilities.[22] In addition to this, the Joint United Nations Programme on HIV and AIDS recognised in its policy brief on disability that persons living with disabilities are a key group at increased risk of exposure to HIV infection.[23]

This paper aims to contribute to this area of knowledge by identifying the challenges which are faced by persons with cognitive disabilities in the context of HIV and AIDS related matters and to provide recommendations on what can be done to address some of the challenges. Although it is not an isolated problem, it is certainly one needing address as with other vulnerable groups. Given the challenges faced by persons living with cognitive disabilities which will be discussed, it is hoped that this paper will contribute to the knowledge on the legal response that needs to be given towards the protection of the right to information, health, equality and human dignity for persons living with disabilities with particular reference to the problems arising from the responses and programs aimed at addressing the HIV pandemic at regional level.

[21](n 6 above) 12.
[22]As above.
[23]'International Norms and Standards Relating to Disability' http://www.un.org/esa/socdev/enable (accesses 29 August 2012).

There is not much literature on the subject concerning the rights of persons living with cognitive disabilities in the context of HIV and AIDS under the African human rights system and it is hoped that this paper will contribute to the literature on the topic under review.

1.5 Objectives of study

Human rights jurisprudence affirms that persons living with disabilities are among one of the groups that are more vulnerable to discrimination and marginalisation and their vulnerability in the context of HIV and AIDS has been insufficiently addressed in human rights instruments.[24] A cognitive disability is one that affects the ability of the brain ability to receive process, analyze, or store information.[25] People with cognitive disabilities have trouble learning new things, making generalizations from one situation to another, and expressing themselves through spoken or written language.[26] Therefore, persons with cognitive disabilities face challenges perceiving and comprehending information relating to HIV and AIDS.

Most persons living with cognitive disabilities are often at risk for exposure to HIV infection due to sexual violence, intimidation, the need to feel a sense of belonging or lack of preventive information. In addition, they are less likely to access prevention, treatment and testing and experience challenges while trying to access education and health services in general.[27] Reports have indicated that most persons living with disabilities in African have a higher HIV prevalence.[28]

This paper aims to review the legal response regarding the protection of the rights of persons living with cognitive disabilities in Africa and the various factors which play a role in their vulnerability to contracting HIV. It sets to bring out some of the factors that contribute to the high prevalence rate of HIV among persons living with cognitive disabilities and aims to recommend ways in which the rights of this vulnerable group in the context of HIV and AIDS can be protected. In this regard, this paper shall describe the nature and content of specific African human rights instruments protecting the rights of persons living with disabilities and specifically recommend measures aimed at mainstreaming the rights of persons living with cognitive disabilities in HIV and AIDS related matters.

[24] As above.
[25] (n 10 above).
[26] As above.
[27] HIV/AIDS and Disability Global Survey http://cira.med.yale.edu/globalsurvey (accessed on 17 August 2012).
[28] 'UNAIDS: Disability and HIV policy brief' http://www.who.int/disabilities (accessed on 17 August 2012).

1.6 Literature review

For purposes of this research, the author has consulted African human rights instruments and case law in order to identify any gaps and to make the necessary suggestions for reform. The main aim is to identify existing gaps in matters concerning the protection of the rights of persons living with cognitive disabilities in the context of HIV and AIDS. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has also been consulted in so far as it is the principal convention which addresses the rights of persons living with disabilities. Other literature that has been reviewed includes books, reports and journals such as;

Kristen Hughes et al. (2007) *Human Rights Protected, nine southern African country reports on HIV, AIDS and the law* which analyses the situation of HIV and AIDS and human rights in Southern Africa particularly addressing the limitations on access to HIV and AIDS medicines and identifies the discordance between policy, legislation and practice. It contains reports on HIV, AIDS and the law in Zambia, South Africa, Botswana, Lesotho, Malawi, Mozambique, Namibia, Swaziland and Zimbabwe. What this literature will assist the researcher with is the identification of the specific domestic responses to the HIV pandemic and to establish whether adequate consideration has been made for the peculiar challenges faced by persons living with cognitive disabilities in the legislation, policy and practice.

Liesl Gerntholtz, Kitty Grant and Dr. Jill Hanass-Hancock *Disability Rights and HIV/AIDS in Eastern and Southern Africa Final Report August* (2010) this report examines the extent to which Eastern and Southern African countries have ratified key regional conventions and domesticated obligations under them in order to ensure the protection of the rights of persons living with disabilities in the context of HIV and AIDS. The researcher aims to assess whether there are gaps that exist in the regional protection of the rights of persons living with cognitive disabilities who are exposed to HIV infection as a result of their vulnerability or those who suffer severe marginalisation as a result of their status. Most of the literature on the subject does not address some of the possible remedies which can be sought by such individuals or what can and should be done to help protect them from such abuses.

M Langford (2008) *Social Rights Jurisprudence: Emerging trends in international and comparative law* provides insight on the normative content of the right to health and other socio-economic rights and describes the right to health care and access to treatment or other health services as part of the broader right. The researcher aims to justify why mainstreaming of the rights of persons living with cognitive disabilities in the programmes for HIV prevention and AIDS treatment forms part of the protected

rights of individuals under human rights instruments who also include persons living with cognitive disabilities.

Ilze Grobbelaar-du Plessis and Tobias van Reenen (eds) (2011) *Aspects of Disability Law in Africa* provides details of the specific national frameworks for the promotion and protection of disability rights in the African human rights system. It is from this literature that some of the best practice in the protection of the rights of persons with disability will be identified.

P Collins (2009) *HIV prevalence among men and women admitted to a South Africa public psychiatric hospital* 7 AIDS Care Journal provides details to the fact that persons with cognitive disabilities are highly vulnerable to the risk of HIV infection. The researcher aims to provide examples of some of the measures that are taken to prevent the marginalisation of persons living with cognitive disabilities such the Law in Uganda which provides a higher criminal sentence towards persons who knowingly infect persons with mental disabilities with HIV.

Compendium of key documents relating to human rights and HIV in Eastern and Southern Africa (2005) provides a compilation of key regional, sub-regional and domestic instruments which address issues of human rights and HIV in Eastern and Southern Africa. The researcher aims to analyse the various regional instruments for the protection of the rights of persons living with cognitive disabilities in the context of HIV and AIDS in order to ascertain the gaps that exist in the regional protection and to propose methods which may address this inadequacy.

1.7 Methodology

In order to answer the research questions, the researcher will carry out internet and desk study consisting of books, articles, presentations and legal instruments to assess the theoretical foundation for this paper and to obtain a sound and contextual basis on the subject under review. A combination of comparative and analytical approaches will be used in this study.

1.8 Chapters overview

This research paper specifically addresses the challenges faced by persons living with cognitive disabilities in the context of HIV and AIDS due to the fact that this type of disability affects the ability

of the brain ability to receive process, analyze, or store information,[29] and because people with cognitive disabilities have trouble learning new things, making generalizations from one situation to another, and expressing themselves through spoken or written language.[30] This makes them vulnerable to exclusion, abuse and exposes them to high risk behaviours due to their lack of knowledge.

Chapter 1: Introduces the study, discusses the research questions and methodology, outlines the significance of the study and discusses the contribution which the research aims to make in light of the already existing literature on the topic under review.

Chapter 2: Discusses some of the key concepts relevant to the topic under review, provides a background to the study and addresses some of the reasons for the marginalisation and vulnerability of persons living with cognitive disabilities to HIV and AIDS in the African context. It addresses some of the reasons why persons with cognitive disabilities are vulnerable to HIV and AIDS and how they have been marginalised in the care, treatment and awareness of HIV and AIDS. This chapter also identifies some key human rights that are affected by the marginalisation

Chapter 3: Analyses the duty of states with respect to the rights of persons living with cognitive disabilities in the context of HIV and AIDS and examines the international framework in place to protect the rights of persons living with disabilities. What this chapter aims to do is to identify the United Nations standard for the protection of the rights of persons living with cognitive disabilities, particularly in the context of HIV and AIDS.

Chapter 4: Analyses the jurisprudence of the African human rights system in order to ascertain whether there has been adequate consideration for the rights of persons living with disabilities and specifically cognitive disabilities. It further highlights the challenges that exist as a result of the lack of mainstreaming of the specific needs of persons living with cognitive disabilities in the regional response to HIV and AIDS.

Chapter 5: Provides conclusions and recommendations for addressing the subject under review by highlighting recommendations of some of the measures that can be adopted at regional and domestic level in order to protect the rights of persons living with cognitive disabilities in the context of HIV and AIDS.

[29](n 10 above).
[30]As above.

CHAPTER TWO

2.1 Defining disability

The concept of disability is a highly elusive subject. There is no consensus on a comprehensive definition of the term and this difficulty in adopting a comprehensive definition is due to the fact that perceptions and approaches towards disability vary. The CRPD provides that persons with disabilities 'include those that have long-term physical, mental, intellectual or sensory impairments which in interaction with the environment hinder their equal participation in society'.[31]

The World Health Organisation (WHO) defines disability by distinguishing between impairment, disability and handicap.[32] It defines impairment as 'any loss or abnormality of psychological or anatomical structure or function and disability is defined as any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'.[33] A handicap is defined as a 'disadvantage for a given individual, resulting from impairment or a disability that prevents the fulfilment of a role that is considered normal (depending on age, sex and social and cultural factors) for that individual'.[34]

The definition adopted by the WHO has been criticized for locating the problem within the individual and portraying much of a similarity between impairment and a disability. This is so because 'while impairment refers to physical or cognitive limitations that an individual may have, disability has more to do with socially imposed restrictions. It is about how the environment makes it impossible for a person living with a disability to actually lead a normal life by creating barriers'.[35]

2.2 The various approaches to disability

Due to the complexities surrounding the definition of disability, various approaches to disability have been adopted to frame the context within which disability can be defined. There are essentially three main approaches to disability; however these are not conclusive as there are other approaches which have been framed such as the 'economic model to disability to explain the development of social security welfare and disability grants for disabled people'.[36] The various approaches to disability include the medical or welfare approach, the human rights approach and the social approach.

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[31] Article 1 of the United Nations Convention on the Rights of Persons with Disabilities, 2006.
[32] 'International Classification of Impairments, Disabilities and Handicaps (ICIDH), Geneva: World Health Organisation 1980' http://www.disabled-world.com/disability/types/ (accessed 6 September 2012).
[33] As above.
[34] C Ngwena 'Deconstructing the definition of 'disability' under the Employment Equity Act: Social deconstruction' (2006) 22 *South African Journal on Human Rights* 613.
[35] Ngwena (n 34 above) 614.
[36] J Bickenbach *Physical Disability and Social Policy* (1993) 8.

2.2.1 The medical or welfare approach

The medical or welfare approach is highly focused on the individual; it is also referred to as the individual impairment model.[37] This approach considers persons living with disabilities as different from non-disabled persons and in need of intervention. It 'views the physiological or psychological condition itself as the problem. The medical approach locates the disability within the person and views persons living with disabilities as objects for medical intervention'.[38]

The criterion for eligibility to welfare and charity is inability to function in mainstream society and to provide for oneself.[39] Therefore, persons living with disabilities are viewed as being in need of assistance such as rehabilitation to enable them deal with the disability or to find a cure for the condition. The individual is the focus under this approach whereby a disability is considered to be a defect or sickness which must be cured.

2.2.2 The Social approach

The first premise of the social approach is that human difference is not innate, but something socially constructed and applied through labels such as "the disabled".[40] In other words, disability is not a problem, but social attitudes towards persons living with disabilities for example stigma, and environmental barriers. It is the social environments which impose limitations upon persons living with disabilities. Disabilities are viewed as an outcome of the interaction with the social environment. This approach puts emphasis on societal and environmental barriers. It is the failure of the physical and social environment to adjust to the needs of persons living with disabilities which creates the problem of disability.[41]

Thus, norms, habits and symbols of the *able* in society create structural barriers for persons living with disabilities.[42] This approach endorses the concepts of affirmative action and reasonable accommodation. The social approach treats persons living with disabilities as actors in their own right in the framing of

[37]M Oliver *Understanding disability, from theory to practice* (1995) 11.
[38]F Armstrong & L Barton *Disability, human rights and education: Cross cultural perspectives* (1999) 10.
[39]Ngwena (n 34 above) 614.
[40]G Quinn & T Degener *Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability* (2002)11.
[41]H Hahn 'Public support for rehabilitation programs: The analysis of US Disability Policy' (1986) 1 *Disability, Handicap & Society* 121.
[42]Ngwena (n 34 above) 614.

public policy, empowering the individual and emphasising on the integration of persons living with disabilities into society and the economy because disability is a highly social construction which depends on what society as a whole accepts it to be.[43]

2.2.3 The human rights approach

The human rights approach focuses on the removal of barriers to equal participation and elimination of discrimination. It emphasises the inherent dignity of a human being and locates the main problem outside the person emphasising that 'the state has a responsibility to tackle socially created obstacles in order to ensure full respect for the dignity and equal rights of all persons.'[44]

This approach was adequately elaborated by the African Commission in the case of *Purohit and Moore v The Gambia*,[45] which is a landmark case in Africa in respect of the rights of persons living with disabilities. The human rights approach recognises and acknowledges that persons living with disabilities are equal citizens and should therefore enjoy equal rights and responsibilities and that for persons living with disabilities to accomplish their possibilities, they should be given necessary opportunities.[46]

This case was submitted on behalf of mental health patients detained under the Lunatics Detention Act (LDA) of The Gambia. They alleged that under the LDA there was no definition of 'lunatic' and that there was a requirement to acquire consent to treatment or to review treatment. In addition, legal aid was not available to the patients under the Act, and the patients were not allowed to vote.[47]

The Commission in this case emphasised that persons living with disabilities, just as any other person, have the right to participate in and enjoy life to the fullest and that branding a person with a mental illness as either a 'lunatic' or 'idiot' deprives them of their dignity.[48] The Commission further elaborated that mentally disabled persons share and would like to realize the same hopes, dreams, and

[43]Ngwena (n 34 above) 614.
[44]*Purohit and Moore v The Gambia* (2003) AHRLR 96 (ACHPR 2003).
[45]As above.
[46] (n 44 above).
[47](n 44 above).
[48](n 44 above) paragraph 59.

goals as other human beings.[49] It is clear from this that emphasis was made to the fact that the rights of persons living with disabilities are the same as other peoples' rights.

In addition to this, the Commission noted that the objectives of the LDA fell short of guaranteeing mental health patients the right to the best attainable state of mental and physical health under article 16 and article 18 of the African Charter, which provides that there is need to provide special care to persons living with disabilities.[50] This decision has set a firm foundation due to the willingness of the Commission to find the rights guaranteed under the African Charter as equally applicable to persons living with disabilities.

A human rights based approach to disabilities recognizes persons living with disabilities as rights holders as opposed to the welfare approach which does not recognize persons living with disabilities as autonomous individuals with rights.[51] The Commission in the *Purohit* case recognized them as equal to other human beings and not welfare cases, thereby upholding the rights based approach. In the same manner, persons living with cognitive disabilities ought to have their special needs considered in respect of all rights in order to enable them accomplish their possibilities and live to their fullest ability. The author adopts the social approach and the human rights approach for purposes of the topic under review by acknowledging that no matter the category of disability, all persons living with disabilities are entitled to equality in the enjoyment of all human rights.

2.3 Defining cognitive disabilities

Disability is conceptualised as being a multidimensional experience for the person involved.[52] There may be effects on organs or body parts and there may be effects on a person's participation in areas of life. Therefore, 'three dimensions of disability are recognised. Firstly, body structure and function, secondly, activity restrictions and finally participation restrictions'.[53] This classification recognises the role of physical and social environmental factors in affecting disability outcomes.

Cognitive disabilities are present in people who suffer from varying learning disabilities and cannot therefore perceive things in the ordinary manner that an average member of society can.[54] Cognition refers to understanding, the ability to comprehend what one sees and hears, and to infer information

[49](n 44 above) paragraph 61.
[50](n 44 above) paragraph 83.
[51]A Kanter 'The promise and challenge of the United Nations Convention on the Rights of Persons with Disabilities' (2007) 34 *Syracuse Journal of International Law and Commerce* 294.
[52]I Marini *Psychosocial Aspects of Disability* (2011) 3.
[53]As above.
[54](n 10 above).

from social cues and body language.[55] Thus, people with cognitive disabilities have trouble learning new things, making generalizations from one situation to another, and expressing themselves through spoken or written language. It is essentially a learning disability.[56]

Cognitive disabilities impact on the basic skills, social skills, or both of an individual. In most cases the individual has difficulty reading social cues and interacting with people. In addition, they suffer from poor memory and need extra effort in order to learn something.[57] Therefore, individuals with cognitive disabilities are not insane but simply need special treatment in order to get them to comprehend and perceive knowledge regarding any matter.

The reason why this particular group of persons with disabilities has been considered is because more often than not, they are the least able to immediately comprehend information and to an even greater extent, are unable to explain their lack of understanding to anyone, whether through sign language, body language or other means that are possible for most other types of disabilities.

2.4 A human rights based approach to the vulnerability of persons living with cognitive disabilities in the context of HIV and AIDS

HIV is the leading infectious killer of adults and children in the world today, and it is noted that there are numerous individuals living with HIV globally.[58] Although it is true that any member of the general population can become infected with HIV, the burden of the disease is heavier among certain populations. Chief among these are patients who also suffer from varying disabilities.[59] There is need to encourage a human rights response to the challenges faced by persons living with cognitive disabilities in the context of HIV and AIDS. Persons living with cognitive disabilities have been marginalised in relation to HIV and AIDS information and facilities, and this violates their right to human dignity, equality, information and their right to health, among others.

[55](n 10 above).
[56]Marini (n 52 above) 4.
[57]Marini (n 52 above) 12.
[58]'Joint United Nations Program on HIV/AIDS: UNAIDS Report on the Global AIDS Epidemic 2010' http://www.unaids.org/globalreport/Epi_slides.htm (accessed 20 September 2012).
[59]T Senn and M Carey 'HIV testing among individuals with a severe mental illness: Review, suggestions for research, and clinical implications' (2009) 3 *Psychological Medicine* 355.

One important human right that is directly affected by the inadequate inclusion of the special needs of persons living with cognitive disabilities in the context of HIV and AIDS related information and facilities is the right to health. This is so because the right to health is all encompassing as it addresses the question of availability, accessibility and affordability. Accessibility to health services and education on preventive measures as well as treatment are essential means to the realisation of the right to health because it serves a crucial role in ensuring the right is realized.

Article 25 of the CRPD recognizes that persons living with disabilities have the right to enjoyment of the highest attainable standard of health without discrimination on the basis of disability. State parties are mandated to take all appropriate measures to ensure access for persons with disabilities to health services and to provide them with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs. In addition to this, the convention requires state parties to provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities.

Further, the Committee Economic Social and Cultural Rights in General Comment number 14 describes as 'part of the normative content of the right to the highest attainable standard of health to mean that health facilities, goods and services have to be accessible to everyone without discrimination, physical accessibility, affordability and quality.[60] Further, the African Commission General Resolution on access to health and needed medicines urges states to 'guarantee the full scope of access to needed medicine including the availability in sufficient quantities and the development of new medicines needed for the highest attainable level of health'.[61] It also calls upon states to fulfil access to medicine by adopting all necessary measures to promote, provide and facilitate access to medicine.[62]

Given this, persons living with cognitive disabilities are no exception to the guarantee of the right to health as contemplated and described above, it is a legal requirement that the means by which information on prevention and treatment is disseminated ensure equal access to all as well as all other matters concerned in the fight against HIV to be disability specific in order to fulfil the prohibition on discrimination in respect of the fulfilment of the right to health and equality by state parties.

[60]Committee on Economic Social and Cultural Rights, General Comment No 14: Adopted at the 22nd session of the Committee on Economic, Social and Cultural Rights, 11 August 2000. E/C. 12/2000/4.
[61]African Commission on Human and People's Rights (ACHPR) Resolution on access to health and needed medicines in Africa (ACHPR/Res.141 (XXXXIIII) 08).
[62]As above.

Persons living with cognitive disabilities are vulnerable to contracting HIV because their exposure is heightened by the fact that they are a minority group often subject to discrimination and high levels of marginalisation thus opening them up to abuse, exclusion in education on modes of prevention and treatment based on the assumption that they may not be sexually active. They also fall prey to sexual exploitation and lack access to information, testing and treatment.

Given that the African Commission in the *Purohit* case noted that persons living with disabilities are right holders in the same way that all other persons are, persons with cognitive disabilities are entitled to their full realisation of their right to health as guaranteed under article 25 of the CRPD and to the highest attainable standard of mental and physical health as guaranteed under article 16 of the African Charter. All of this requires that programmes concerning awareness on HIV prevention as well as all other health services in that respect consider the specific needs of person with cognitive disabilities in order to fulfil their rights.

The right to health in the context of HIV and AIDS is important because it covers the question of access to information and services regarding treatment and prevention which is an area in which arguably, reasonable accommodation[63] has not been made for the specific needs of persons living with cognitive disabilities. In the same way that the right to health is an important social economic right for able bodied persons, it is a highly equal right for persons living with cognitive disabilities.

Further, inherent in every human being is the inviolable self-worth known as human dignity.[64] Dignity requires that each individual should be deemed to be of immeasurable value, which is a departure from the worldview that determined individual worth based on economic input, but rather focuses on inherent self-worth.[65] Human dignity is a core human entitlement to which every human being no matter their race, sex, gender, status or condition is entitled.

However, persons living with cognitive disabilities continue to face violations, exclusion and marginalisation in many aspects of their social life. Global thinking has now changed and persons living with disabilities are considered subjects and not objects, entitled to independent living and

[63]Reasonable accommodation in article 2 of the UN Convention on the Rights of Persons with Disabilities is defined as 'necessary and appropriate modification and adjustment 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.'
[64](n 44 above) paragraph 57.
[65]Quinn & Degener (n 40 above) 24.

equality of treatment.[66] Every individual is important in society and must participate in decisions affecting their lives. Further, human equality is a central value to the system of basic freedoms found in human rights law. Thus, all human beings, no matter their form or nature of disability, are inherently equal and self worthy.

Furthermore, the Declaration on rights of mentally retarded persons[67] provides in article 1 that mentally retarded persons enjoy the same rights as all other human beings and further outlines the human rights which persons living with disabilities are entitled to. The specific rights referred to in the Declaration are the right to education, training and rehabilitation, which are some of the other specific rights directly affected by the marginalisation of persons living with cognitive disabilities in respect of the inability to ensure that information regarding HIV prevention is made to meet their specific needs, such as ensure that the information conveyed in a more simplistic manner in order to ensure equal benefit from the information.

Human rights jurisprudence acknowledges that the status of vulnerable groups such as women, children, older persons and persons living with disabilities makes them more vulnerable to discrimination and marginalisation.[68] The United Nations recognises the link between disability and HIV by providing that 'the consequences of deficiencies and disablement are serious because persons living with disabilities are often subject to social, cultural and economic disadvantages which impede their access to health care, education, vocational training and employment and if they have challenges perceiving information, the chances of overcoming their disablement are diminished, making it more difficult for them to take part in community life.[69]

There is growing need to advocate for improved inclusion of the specific needs of persons living with different types of disabilities within the legal frameworks on HIV, in terms of the obligation placed upon states by the CRPD to integrate disability into all national laws, policies and programs.[70] This is so because the human rights dimension in the context of HIV related matters for persons living with disabilities has 'not been routinely identified as a key population at a higher risk of HIV exposure within country level responses to HIV due to the assumptions about their sexuality thus creating a

[66]As above.
[67]General Assembly Resolution 2856 (XXVI) of 20 December 1971.
[68]Defining disability (n 23 above).
[69]UNAIDS (n 6 above) 4.
[70]Article 25 of the CRPD.

perception that they are less likely to contract HIV or at a lower risk'.[71] This has greatly contributed to their continued vulnerability to HIV exposure and marginalisation.

The wrongful assumption of the sexuality of persons living with cognitive disabilities makes them more vulnerable as a group in every society. The 'limited understanding and inaccessibility of existing health services for persons living with disabilities has led to their exclusion from many responses to the HIV epidemic'.[72] For persons living with cognitive disabilities, the challenge is even greater due to the fact that they are generally unable to perceive or assimilate any relevant information concerning HIV and AIDS. This exposes them to high risk behaviours and consequently the risk of contracting HIV.

With respect to vulnerabilities, most studies reveal that 'persons living with disabilities experience barriers to prevention, interventions and treatment. For instance, most special schools are excluded from prevention campaigns or lack sex education'.[73] It has also been noted that clinics tend to be inaccessible for persons deemed 'mentally incapacitated', transport unaffordable or not suitable for most persons with extreme physical disabilities and in addition, prevention information is often impossible to comprehend for persons with learning and developmental disabilities.[74]

Further, for persons living with cognitive disabilities and visual impairments, hospital billboards are practically inaccessible because they are designed for persons who are capable of seeing what is being advertised, perceiving it and assimilating the information relayed on them. Further, 'most studies reveal that volunteer counselling and testing staff, practitioners, nurses and police officers are not trained or able to communicate with persons who have learning disabilities or other peculiar conditions and confidentiality is thus often compromised.[75]

Furthermore, studies reveal that young persons with learning disabilities have critical gaps and erroneous information regarding knowledge of HIV and AIDS.[76] This is often as a result of the fact that teachers of children with intellectual or learning disabilities tend not to feel able or willing to teach

[71]UNAIDS (n 6 above) 8.
[72]As above.
[73]I Mulindwa 'Study on reproductive health and HIV/AIDS among persons with disabilities in Uganda: Disabled Women's Network and Resource Organisation (DWNRO)' (2003) 7.
[74]N Dawood *et al*. 'Knowledge, attitudes and sexual practices of adolescents with mild mental retardation, in relation to HIV/AIDS' (2006) 5 *African Journal of AIDS Research* 1.
[75]Dawood (n 74 above) 3.
[76]As above.

them about HIV and sexuality based on the wrongful assumption that persons like this are less likely to engage in sexual action.[77]

In addition to this, sexual abuse and exploitation is a common challenge mostly for women with cognitive disabilities. This challenge or problem is further worsened by the fact that although sexual abuse is a reality for persons living with cognitive disabilities, only a few cases are actually reported because people fear that they will not be believed or that they will be subjected to further victimization.[78]

Finally, cultural practices such as polygamy, wife sharing and to some extent gender imbalances when negotiating for sex tend to increase the risk for women living with cognitive disabilities because they are often seen as less worthy than others thus are engaged in multiple partnerships which expose them to a greater infection risk.[79] All of these are challenges faced by persons who cannot directly negotiate for their own positions and tend to expose them to multiple sexual partners. In respect of persons living with cognitive disabilities, the challenge is heightened by the fact that they are often unable to effectively communicate information if special attention is not give to the specific details of it. Moreover, their inability to easily perceive information tends to put them in positions where they can be taken advantage of or in fact abused.

2.5 Conclusion

It has been noted that persons who experience inequality prejudice, marginalisation and limitations on their social, economic and cultural rights are at a greater risk of HIV exposure.[80] Persons living with cognitive disabilities face many challenges in their everyday life and the inadequate inclusion of their specific needs in the context of HIV and AIDS related information and services forms only one of the many challenges. Therefore, in the same manner that the law is developed to respond to the special needs of vulnerable groups in society such as women, children and older persons, there is need to establish a legal response to the peculiar needs of other vulnerable groups such as persons living with disabilities which include the category of those living with cognitive disabilities, particularly in respect of HIV and AIDS related information and services in order to effectively fulfil their right to health, information, privacy and thus uphold their human dignity and equality as human beings.

[77]Dawood (n 74 above) 2.
[78]Hannas-Hancock (n 2 above) 38.
[79]As above.
[80]UNAIDS (n 6 above)

CHAPTER THREE

3.1 Introduction

The protection of human rights requires states to take specific measures to ensure respect for these rights and promotion entails securing respect for the value and meaning of human rights.[81] The primary responsibility to protect and promote human rights and fundamental freedoms of individual in any given society lies mainly with the state.[82] This means that protecting the rights of persons living with cognitive disabilities in the context of HIV and AIDS is a primary responsibility of the state. The state is the principal focus because it has the responsibility to ensure protection of fundamental human rights such as the right to health, information, human dignity, equality and privacy for persons living with cognitive disabilities. This chapter reviews the international framework on the protection of the rights of persons living with disabilities and identifies the role or main obligations placed on states at the international level in respect of persons living with disabilities and specifically, persons living with cognitive disabilities.

It has been argued that international human rights instruments have not provided sufficient protection of the rights of persons living with disabilities in Africa.[83] This is likely to be as a result of the fact that not much acknowledgement has been made to the fact that improving the living conditions of persons living with disabilities is a developmental challenge that may have been overlooked.[84] Moreover, over the years, inclusion and participation of persons living with disabilities in many aspects of social life and development of the society where they live has not been of very good rating.[85]

On a more positive note, a number of regional and international instruments have been developed and have contributed significantly towards ensuring that the challenges faced by persons living with disabilities are viewed from a human rights perspective rather than a medical or welfare perspective.[86] This promotes the focus on encouraging and ensuring inclusion and full participation of persons living with disabilities in all aspect of society such as HIV related matters. This is inspired by the view that

[81]L Le Blanc *The OAS and the promotion and protection of human rights* (1977) 91.
[82]Declaration on the rights and responsibility of individuals, groups and organs of society to promote and protect universally recognised human rights and fundamental freedoms, art. 2. General Assembly Resolution 53/144 of 8 March 1999.
[83]K Mandesi 'UN Convention on the Rights of Persons with Disabilities: How will it provide opportunities for persons with disabilities in the south' Paper presented at the workshop on European disability and development, Brussels Belgium 21 November 2006.
[84]Summary Report of the United Nations Inter Agency meeting held in August (2006) at UN Head Quarters New York.
[85]Mandesi (n 83 above) 2.
[86]United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993.

basic human rights and freedoms should be enjoyed and exercised by all people irrespective of their disability, gender or age.[87]

3.2 Challenges faced by persons living with cognitive disabilities in the context of HIV and AIDS

The significant link between HIV/AIDS and disability is an emerging issue and it tends to be more pronounced when persons living with HIV develop impairments as the disease progresses.[88] A person may be considered to have a disability when social, economic, and political or other barriers hinder their full and effective participation in society on an equal basis with others.

Although the problems arising from the link between HIV and disability are acknowledged as being a matter of concern, the matter has not received due attention despite the fact that persons living with disabilities are found among all key populations at higher risk of exposure to HIV.[89] It has been noted that cognitive disabilities are a type of impairment present in people who suffer from varying learning disabilities and cannot therefore perceive things in the ordinary manner that an average member of society can[90] and that people with cognitive disabilities have trouble learning new things, making generalizations from one situation to another, and expressing themselves through spoken or written language.[91]

One of the reasons why this vulnerable category of persons living with disabilities has been marginalised in various matters concerning HIV prevention is due to the common but incorrect assumption that they are less vulnerable to HIV infection because they are unlikely to be sexually active or engage in high-risk behaviours.[92] However, there has been a growing body of literature which indicates that these assumptions are far from true and that persons living with cognitive disabilities face all sorts of vulnerabilities to HIV and AIDS, and are at equal or increased risk of infection.[93]

One of the main challenges faced by persons living with cognitive disabilities is the high incidences of sexual abuse which further increases their vulnerability and risk of exposure to HIV. Generally, they are

[87]Mandesi (n 83 above) 3.
[88]UNAIDS Disability and HIV Policy Brief http://www.who.int/disabilities/jc1632_policy_brief_disability_en.pdf (accessed 23 September 2012).
[89]UNAIDS Disability and HIV Policy Brief (n 88 above).
[90]Marini (n 52 above) 18.
[91](n 52 above) 18.
[92]S Kamga 'A call for a protocol to the African charter on Human and Peoples' Rights on the rights of persons with disabilities in Africa' (2011).
[93]'The forgotten: HIV and disability in Tanzania' http://www.gtz.de/de/dokumente/gtz2009-en-hiv-and-disability-tanzania.pdf (accessed 23 September 2012).

regarded an easy target for sexual abuses due to the fact that they are often unable to fight off, recognise, or report their perpetrators.[94] Women and girls who are intellectually challenged and those in special school and care facilities are particularly at risk.[95] In Africa, the 'cleansing myth' of 'virgin rape' which is the notion that one can pass his own HIV infection on if one sleep with a virgin has also contributed to the increasing levels of HIV infection among girls with intellectual or cognitive disabilities.[96]

Another challenging factor for persons living with cognitive disabilities is that they require information on HIV and AIDS, and access to programmes, services, and resources. However, there is not enough data on HIV prevalence among persons living with cognitive disabilities and not much is being done to meet their specific needs in that regard.[97] Reaching persons with cognitive disabilities with education on healthcare services is a challenge as resources are considered to be scarce; they often need special services for information and other interventions. In other words, very few of them have access to basic services or even know the existing resources.[98] The requirement for special attention due to the multiple challenges that persons living with cognitive disabilities face in the context of HIV in Africa cannot be over emphasised.

The United Nations has acknowledged inadequacies of National AIDS Strategic Plans for persons living with disabilities as not explicit or clear and failing to address specific needs of the vulnerable group.[99] Despite the high link between HIV and disability and the likelihood of being both the cause and consequence for each other, the CRPD makes no adequate provision for issue of HIV in the context of disability and vice versa.

It has been observed that the majority of the persons living with disabilities in Africa are at a higher risk of HIV exposure.[100] Therefore, in as much as persons living with disabilities can be identified as a vulnerable group, the various categories or types of disabilities expose the individuals living with them to peculiar challenges and one of the common challenges is the risk of exposure to HIV. There is an urgent need to create regional and national responses to these challenges and promote access to preventive measures which include information and HIV and AIDS education.

[94]K Hughes *Human Rights Protected: Nine southern African country reports on HIV, AIDS and the law* (2007) 22.
[95]UNAIDS Disability and HIV Policy Brief (n 88 above).
[96]Hughes (n 94 above) 30.
[97]UNAIDS (n 81 above.).
[98]Forgotten HIV and disability in Tanzania (n 93 above).
[99]UNAIDS (n 81 above).
[100]Gerntholtz (n 6 above) 4.

3.3 Obligations of states under international human rights law

The obligations of states under international human rights law include the obligation to respect, protect and fulfil.[101] The obligation to respect concerns what government does through its organs, agents and structures of law to ensure that human rights are enjoyed.[102] This means that the state must ensure that persons living with cognitive disabilities for example, must not suffer unjustified state intervention in the enjoyment of their human rights and where the state needs to take positive actions such as develop policies or laws, they ought to do so according to the resources available.

The obligation to protect requires the state to take measures to prevent other individuals or groups from violating the integrity, freedom of action and other human rights of the individual.[103] This means that in the context of HIV and with respect to persons living with cognitive disabilities, the state must take positive action to prevent acts of direct and indirect discrimination against them and to prevent or punish any other form of violation of their human rights that puts them at risk of exposure to HIV.

Finally, the obligation to fulfil requires states to take measures to ensure for each person within its jurisdiction, the opportunity to obtain satisfaction of their needs, recognised in human rights instruments, which cannot be secured by personal efforts.[104] This means that the state must adopt legislative, administrative, judicial and all necessary practical measures to ensure the rights of persons living with cognitive disabilities in relation to HIV services are implemented. For example, ensure that HIV and AIDS training and vocational specialists as well as teachers in schools receive training on how to transfer information to persons who have cognitive or learning disabilities to ensure that they too are made to understand how to avoid or prevent high risk behaviours.

3.4 The CRPD and the development of soft law

The adoption and entry into force of the CRPD in 2006 was a crucial step towards the protection of the rights of persons living with disabilities. The values and principles of non-discrimination and equality of opportunity are at the core of the CRPD. There are essentially eight guiding principles of the CRPD namely; respect for inherent dignity and individual autonomy; full and effective participation and inclusion in society; equality of opportunity; equality between men and women; respect for the evolving capacities of children with disabilities; respect for difference and acceptance of persons living with disabilities as part of human diversity and humanity; non-discrimination and, full and effective

[101] 'Amnesty International, Respect Protect Fulfil, AI Index: IOR 50/01/00' http://www.amnesty.org (accessed 18 September 2012).
[102] AI Index (n 101 above).
[103] As above.
[104] As above.

participation and inclusion in society.[105] By the beginning of September 2012, 153 states have become party to the CRPD, 115 have ratified[106] and 27 African states have ratified.[107]

The CRPD is the primary international instrument that addresses discrimination, physical and systematic barriers and legal challenges faced by persons living with disabilities. This international instrument aims to promote inclusion of persons living with disabilities in all aspects of society. Highly acclaimed human rights scholars have proclaimed that the CRPD 'ensures accountability and adherence of legal obligations by states'.[108] This is true, due to the fact that all states that are party to the convention are bound by the terms of the Convention and failure to adhere is monitored as well as addressed.

The Committee on the rights of persons with disabilities is a body of independent experts which monitors implementation of the Convention by state parties.[109] One of the obligations of state parties who have ratified the Convention is to submit the initial report within two years of ratification and a periodic report every four years thereafter.[110] The Committee has the mandate to examine each report and make suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the state party concerned.[111] This system of monitoring promotes accountability by ensuring that each state party reports on its adherence to and implementation of the rights and guarantees set out under the CRPD.

Furthermore, in respect of promoting accountability, the Optional Protocol to the CRPD provides for individual complaints to be submitted to the Committee by individuals, groups of individuals or a third party on behalf of individuals and groups of individuals, alleging that their rights have been violated under the Convention. To date, the Committee has only dealt with one individual complaint.[112] The Optional Protocol creates a mechanism for individuals and organisations to bring complaints to the Committee on the Rights of Persons with Disabilities.[113] This allows for persons whose rights are directly or indirectly violated by acts or omissions by the state or its agents, to complain and ensure they are answerable for it.

Countries that have ratified the Optional Protocol recognise the competence of the Committee "to

[105]Article 3 of the United Nations Convention on the Rights of Persons with Disabilities.
[106]'The CRPD' http://www.un.org/disabilities/countries.asp?navid=12&pid=166 (accessed 12 September 2012).
[107](n 106 above) Djibouti ratified the convention on 18 June 2012.
[108]F Viljoen *International Human Rights Law in Africa* (2012) 140.
[109]Article 34 of the CRPD.
[110]Article 35 of the CRPD.
[111]Article 36 of the CRPD
[112]Communication 3/2011, *HM v Sweden*, CRPD/C/7/D/3/2011 http://www.ohchr.org/EN/HRBodies/CRPD/pages (accessed 19 September 2012).
[113]Article 2 of the Universal Declaration.

receive and consider communications on alleged violations of the provisions of the CRPD by State parties. Individuals and organisations may take their complaints to the Committee once they have exhausted all local remedies. The mechanism created by the Optional Protocol is an important addition to existing domestic remedies, and it enhances access to justice for persons living with disabilities as guaranteed under article 13 of the CRPD.

The protection of the rights of persons living with disabilities has been a gradual process and before the adoption and entry into force of the CRPD, most matters concerning disability rights were contained in soft law. Although persons living with disabilities form the largest minority afflicted with serious human rights violations, they did not initially form part of the UN concept of minority due to the fact that the recognised minorities were ethnic, linguistic and religious.[114] The adoption and entry into force of the CRPD now shows that persons living with disabilities have recognised by the UN as a minority group needing special protection.

The UN General Assembly and the Economic and Social Council (ECOSOC) have adopted a number of resolutions since the 1950s which deal mostly with prevention and rehabilitation, such as the 1950 resolution dealing with social rehabilitation of the physically handicapped.[115] In the 1970s two resolutions were adopted by the UN General Assembly; firstly, there was the Declaration on rights of mentally retarded persons[116] which provides in article 1 that mentally retarded persons enjoy the same rights as all other human beings and further outlines the human rights which persons living with disabilities are entitled to.

Some of the specific rights referred to in the declaration are the right to education, training and rehabilitation. The declaration further provides that in protecting these rights there is need to appoint guardians for persons with disabilities in order to provide the necessary care for those who cannot do so for themselves as a way to protect them. This declaration was a positive step towards the protection of the rights of persons living with disabilities. However, it had the drawback of being too narrow and too specific due to the fact that it only focussed on persons with mental disabilities. In addition to this, it was a declaration, and thus non-binding.

Following the 1970 declaration, the Declaration on the rights of disabled persons was adopted.[117] It provided that persons living with disabilities have the same civil and political rights as all other human beings. In addition to this, the Declaration identifies a number of economic and social rights

[114]Declaration on the Rights of Persons belonging to National or Ethnic, Religious or Linguistic Minorities: Adopted by General Assembly Resolution 47/135 of 18 December 1992.
[115]Quinn & Degener (n 40 above) 11.
[115]Hahn (n 41 above) 39.
[116]Declaration on the Rights of Mentally Retarded Persons, General Assembly Resolution 2856 (XXVI) (20 December 1971).
[117]Declaration on the Rights of Disabled Persons, General Assembly Resolution 3447 (XXX) 9 December 1975 Para 4.

which play a major role in mainstreaming persons living with disabilities in society.[118]

Furthermore, this Declaration provided for the protection against exploitation and abusive treatment of a degrading nature and that persons living with disabilities must participate in matters that affect their lives.[119] The principles laid out in this Declaration are crucial in respect of persons living with cognitive disabilities because the very essence of the need to include their special needs in HIV related matters is a way of mainstreaming their rights and promoting equality.

As advocacy for the rights of persons with disabilities progressed, the UN started to incorporate these rights in its action plans. The slogan 'nothing about us without us' gained momentum and began to be given effect. Unfortunately, soft law was still dominant in respect of the rights of persons living with disabilities. Thus, the year 1981 was proclaimed by the United Nations as the International Year of the Disabled with the theme full participation and equality and the International Decade was launched.[120]

Following this, the World Programme of Action was launched with the aim of preventing exclusion and marginalisation of persons living with disabilities; ensure rehabilitation and equalisation of opportunities.[121] It is clear that at this point, the rights based approach towards persons living with disabilities was adopted. The focus is on ensuring that by all means possible, persons living with disabilities are not excluded in or marginalised but rather that they are socially integrated in all matters that affect their lives and such matters include HIV related issues.

The World Programme of Action is soft law and was therefore not binding on states and it could only be enforced through a monitoring mechanism. Through this mechanism, the WPA was reviewed periodically at national, regional and international levels, the first of which was undertaken in 1987[122] and the second was undertaken in 1992 from which it was found that not much progress had been made.[123]

It is following the second review that a meeting was held recommending the drafting of a Convention on the human rights of persons living with disabilities.[124] A report by a group of experts at this point revealed that discrimination against persons living with disabilities still continued despite all the efforts made with respect to the development of soft law that many member states had not enacted legislation to give effect to the rights of persons living with disabilities and where such legislation existed, it was

[118](n 117 above) Paragraph 6.
[119](n 117 above) Paragraphs 10 and 12.
[120]Hahn (n 41 above) 40.
[121]General Assembly Resolution 37/52 (3 December 1982).
[122]'The Stockholm Global Meeting of Experts to Review the Implementation of the World Programme of Action concerning Disabled Persons' http://www.ohcr.org (accessed 20 September 2012).
[123]Hahn (n 41 above) 42.
[124]As above.

not within the broader socio-economic sphere and there was still no consensus to adopt a disability specific treaty.[125]

With respect to the topic of HIV and how persons with disabilities are at risk of exposure, there was no direct address or reference to it. More significantly, the Standard Rules on the Equalisation of Opportunities for persons with disabilities were adopted in 1993. The main purpose of the Rules was to achieve positive and full inclusion of persons living with disabilities in all aspects of society.[126]

This approach to ensure that persons living with disabilities exercise the same rights and obligations as others[127] promotes equality of opportunity for persons living with cognitive disabilities in matters that concern HIV services, infrastructure and preventive information. It is noteworthy that nowhere in the abovementioned instruments were matters concerning HIV and disability addressed. However, many of the principles and guidelines referred to are relevant in the discourse regarding the incorporation of the specific needs of persons with cognitive disabilities in HIV related matters.

3.5 Provisions under the CRPD relevant to the protection of the rights of persons living with cognitive disabilities in the context of HIV and AIDS

The CRPD does not contain any express provision that directly refers to the challenges arising from matters of HIV and any form of disability; however, it contains various provisions which serve as guiding provisions in the interpretation the requirements for addressing the specific needs of persons living with cognitive disabilities in HIV related matters. The CRPD guarantees the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.[128] This means that persons living with cognitive disabilities ought to have equal access to the highest attainable standard of health even in the context of HIV.

This necessarily entails that policies and plans pertaining to HIV should provide for non-discriminatory, accessible and appropriate HIV health service for persons living with cognitive disabilities, as well as services for people living with HIV who experience disablement.[129] There are many other provisions in the CRPD which can be interpreted in a manner which incorporates responses to HIV and the challenges that arise as a result of disability.

[125]Hahn (n 41 above) 40.
[126]General Assembly Resolution 48/96 of 20 December 1993.
[127]Standard Rules on the Equalisation of Opportunity, 1993 para 15.
[128]Article 25 of the CRPD.
[129]Gerntholtz (n 6 above) 18.

Firstly, article 8 of the CRPD,[130] provides for awareness-raising regarding the capabilities and contributions of persons living with disabilities. This provision makes no reference to matters concerning HIV. The omission of an express provision concerning HIV and disability has a probable consequence of translating itself into national policies, legislations and programmes, which currently prove inadequate in the African context in terms of their recognition and support in facilitating access to HIV services for persons living with disabilities. Article 8 essentially requires states to take measures to raise awareness of and combat stereotypes, prejudices and harmful practices against the rights of persons living with disabilities in the context of HIV.[131] Such measures include putting in place national policies, legislation and programme to achieve this objective.

Secondly, states are required to undertake or promote research and development of universally designed goods, services, equipment and facilities which meet the specific needs of a person with disabilities and that require the minimum possible adaptation and the least cost.[132] This provision is relevant in the context of HIV because it requires that HIV related goods and services, equipment and facilities are universally designed so that they can meet the specific needs of persons with disabilities. It has been noted in the interpretation of this provision that HIV testing and counselling services for instance should be universally designed to ensure that they are able to meet the needs of people with physical, sensorial, cognitive/intellectual and mental disabilities.[133] Therefore, HIV testing and counselling services must incorporate the specific needs of persons living with cognitive disabilities.

Thirdly, the CRPD protects the rights of all persons to equality, prohibits discrimination on the basis of disability and guarantees equal and effective legal protection against discrimination on all grounds.[134] In addition to this, states are required to ensure reasonable accommodation for people with disabilities.[135] With respect to HIV and protection of the rights of persons living with cognitive disabilities, this means that states must ensure equal access to HIV related services with the aim to reduce discrimination against those affected.

Fourthly, article 9 of the CRPD guarantees accessibility. It requires state parties to take measures to ensure access to the physical environment, transportation, information and communications, and to facilities and services.[136] This means that states have a duty to ensure accessibility for persons living

[130]Convention on the Rights of Persons with Disabilities, 2006.
[131]Article 8 of the CRPD.
[132]Article 4 of the CRPD.
[133]Hanass-Hancock (n 2 above) 23.
[134]Article 5 of the CRPD.
[135]Reasonable accommodation in article 2 of the UN Convention on the Rights of Persons with Disabilities is defined as 'necessary and appropriate modification and adjustment 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.'
[136]Article 9 of the CRPD.

with cognitive disabilities to services which reduce their vulnerability to HIV and mitigate the impact of HIV on their lives.[137] This requires that health care facilities which relate to HIV matters should make specific provision for persons with cognitive disabilities to enable them access the facilities equally.

Further, persons living with cognitive disabilities are entitled to equal rights and to recognition as persons with legal capacity before the law.[138] The state in this respect is required to provide persons living with cognitive disabilities the legal capacity to participate in decisions that affect their rights, where this is possible and practical. This means that HIV laws, policies and programmes should provide persons with cognitive disabilities the legal capacity to consent to HIV testing and treatment services except for situations where it is impossible for such consent to be provided.

Furthermore, state parties have an obligation under the CRPD to ensure effective access to justice for persons living with disabilities.[139] This means that where HIV related human rights violations such as rape or other sexual abuse is committed against persons living with cognitive disabilities, such victims must have effective access to justice. This can only best be achieved through the incorporation of the specific needs of persons with cognitive disabilities in HIV related awareness, education and training of all relevant persons such as medical practitioners and law enforcement agents. It is also important that legal services are accessible to persons living with cognitive disabilities.

In addition, persons living with disabilities are guaranteed protection from cruel, inhuman or degrading treatment or punishment, including being subjected to medical or scientific experiments without free consent.[140] This is further supported by article 17 which protects their rights to physical and mental integrity. This means that states should protect people living with cognitive disabilities from cruel, inhuman or degrading treatment in the context of HIV and from being subjected to HIV related medical research and health services without their free consent.

States ought to implement HIV laws, policies and research guidelines which protect persons with cognitive disabilities from cruel, inhuman or degrading treatment such as forced sterilization or exploitative research.[141] Persons living with cognitive disabilities are also protected from violence, exploitation and abuse.[142] In the context of HIV it entails protecting them from violence or abuse that exposes them to the risk of contracting HIV or that occurs as a result of their HIV or perceived HIV status.[143] It is also worth noting that article 22 protects their right to privacy and this means that they

[137]Hahn (n 41 above) 25.
[138]Article 12 of the CRPD.
[139]Article 13 of the CRPD.
[140]Article 15 of the CRPD.
[141]J Comaroff *Modernity and its malcontents. Ritual and power in postcolonial Africa* (1993) 11.
[142]Article 16 of the CRPD.
[143]Gerntholtz (n 6 above) 18.

have the right to confidentiality.

Additionally, state parties are required to take appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life.[144] This means that states should take measures to ensure that persons living with cognitive disabilities achieve full inclusion and participation in all aspects which consequently reduces their vulnerability to HIV and mitigates the impact of HIV and AIDS on their lives.[145] Practically, this requires that social assistance policies and laws should provide social assistance to persons living with cognitive disabilities in order to support their inclusion and participation in all aspects of life, thereby reducing their marginalisation and vulnerability to HIV.

Further, state parties guarantee political rights for persons living with disabilities to ensure that they can participate in political and public life[146]. This means that persons living with cognitive disabilities can participate in the design, development, implementation and monitoring of national HIV programmes, allowing them to bring out their specific needs which can then be incorporated into such programmes.

Finally, state parties are obliged to collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the convention.[147] With respect to HIV related matters, this means that states should collect information and data on disability and HIV to ensure appropriate national responses to matters that affect the lives of persons living with disabilities in the context of HIV. For instance, epidemiological surveillance should collect data on the numbers of people living with disabilities and affected by HIV, and the number of people living with HIV who experience disablement.[148] All of these provisions if effectively implemented can substantially improve the lives of persons living with cognitive disabilities and mostly the challenges they face with respect to their vulnerability to HIV exposure.

3.6 Conclusion

Apart from soft laws that evolved in earlier times, the CRPD is the first international treaty to comprehensively address the needs of persons living with disabilities and it sets the global standard on disability rights. It goes beyond protecting people with disabilities from discrimination and focuses on the broader protection and promotion of all human rights integral to ensuring the full participation of people living with disabilities in society. Unfortunately, it does not strictly define disability, but bases

[144] Article 26 of the CRPD.
[145] Quinn and Degener (n 40 above) 22.
[146] Article 29 of the CRPD.
[147] Article 30 of the CRPD.
[148] Quinn and Degener (n 40 above) 26.

its understanding on the human rights and social approach to disability; the preamble recognises that "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others".[149]

The CRPD affirms the right of all persons living with disabilities to the full enjoyment of all their human rights and freedoms and pays particular attention to the human rights of women with disabilities. The preamble emphasises the need to integrate a gender perspective in all efforts to promote the rights of people with disabilities, while also recognising that women and girls with disabilities are at a higher risk of violence and abuse, both inside and outside the home. The Convention recognises that women and girls with disabilities face multiple forms of discrimination and obliges States to take steps to empower them.[150] The complexity of the concept of disability requires more specific references and address of the various challenges faced by the many types or categories of disability as the type of disability often determines the intensity of the marginalisation.

As has already been noted, many of the rights and key concepts within the instruments discussed are relevant to the protection of the rights of people living with cognitive disabilities from exposure to HIV, particularly for persons living with cognitive disabilities it is in respect of information and education concerning HIV prevention. If the relevant provisions are effectively implemented, they can substantially reduce the marginalisation of persons living with cognitive disabilities and consequently translate into regional instruments and national HIV laws, programmes and policies, thereby mainstreaming the specific needs of persons living with disabilities and more specifically persons living with cognitive disabilities.

[149]Preamble of the CRPD.
[150]'International Norms and Standards Relating to Disability' http://www.un.org/esa/socdev/enable/comp500.htm (accessed 20 September 2012).

CHAPTER FOUR

4.1 Introduction

Regional and international instruments were generally intended to have general application to all human beings.[151] This means that although some regional instruments may not have specific reference to the situation of persons living with cognitive disabilities, it does not preclude application to them because they too are entitled to these rights which are indivisible and inherent in every human being. It is the intention of the author to emphasise that notwithstanding the applicability of human rights to all individuals, there are some vulnerable groups that need special and specific attention in order to achieve a balanced level of equality in the enjoyment of human rights at regional and national level.

The challenges faced by persons living with cognitive disabilities with regard to HIV related services are very different from those faced by the average man, moreover, in order to put them at equal footing with the general population, there is often need to provide special attention by addressing their peculiar needs. For instance, one successful model for integrated care developed at the Luthando Neuropsychiatric HIV Clinic in Soweto, South Africa which has provided care to more than 500 patients to improve HIV care among persons with mental or cognitive disabilities. This has been achieved by providing therapy and special care to those who are unable to immediately understand the modes of prevention and treatment for HIV.[152]

Thus, although there are various human rights instruments with provisions that can be interpreted to include protection of the rights of persons living with cognitive disabilities, there are still some peculiar challenges which they face and with respect to HIV relates matters, there is need to make provision for the special needs of persons living with cognitive disabilities in that context. This chapter aims to highlight some of the shortcomings in the regional and national strategies with respect to protecting the rights of persons living with cognitive disabilities in relation to HIV and AIDS, and to emphasise the need to have regional strategies to address the limited protection of these rights.

4.2 National responses to HIV and AIDS in relation to persons living with cognitive disabilities

Persons living with cognitive disabilities generally face various challenges in respect of HIV related matters. They face manipulations into risky sexual conduct due to their limited capacity to comprehend

[151] Article 1 of the Universal Declaration: 'all human beings are born free and equal in dignity and in rights'.
[152] 'Human rights, mental illness and HIV: The Luthando Neuropsychiatric HIV Clinic in Soweto, South Africa' http://www.hhrjournal.org/index.php/hhr/article/view/434/671 *Health and human rights international journal* (accessed 4 October 2012).

information, they are prone to sexual abuse, they do not easily understand information regarding prevention methods of HIV and experience challenges comprehending what they see and hear as well as inferring information from social cues and body language. It has been shown that the CRPD is a very comprehensive instrument in so far as the protection of the rights of persons living with disabilities is concerned and it cannot be disputed that its drafting was a widely inclusive process.[153] It represents the desired paradigm shift toward a human rights approach to matters concerning persons living with disabilities.

However, it is not sufficient to end at the CRPD for the protection of the rights of persons living with disabilities. Regional and national plans, policies and programmes concerning HIV need to integrate the peculiar needs of vulnerable groups such as those living with cognitive disabilities and provide an effective response to the peculiar challenges faced by this vulnerable group in the context of HIV and AIDS. It cannot be disputed that there are some aspects which may not have been sufficiently addressed in the CRPD but which need specific reference in the African context due to the overwhelming effects of the pandemic in most developing countries in Africa.[154] This is even more justified by the fact that the African Charter explicitly mentions the importance of taking into account traditions and the values of African civilization in protection of human rights.[155]

There is need to narrow down the broad context contemplated by the CRPD to regional and national level in order to have matters addressed at closer proximity for easier access, accountability and reference.[156] Most national frameworks in Africa have in place instruments to address the HIV pandemic. However, very few policies or legal documents acknowledge the challenges faced by persons living with disabilities in the context of HIV, more particularly; there are no provisions for the specificities of various types of disabilities and the different challenges that arise as a result of the type of disability.

With respect to some of the national strategies in place, Botswana has in place a National Policy on Care for People with Disabilities[157] it provides, among others for education and employment benefits to be made available to persons living with disabilities. However, the policy makes no mention of matters

[153]Kanter (n 51 above) 294.
[154]Article 3 of the CRPD.
[155]M Mutua 'The Banjul Charter and the African cultural fingerprint: an evaluation of the language of duties' (1995) 35 *Virginia Journal of International Law* 339.
[156]As many African countries may opt to have specific address of the peculiar issues arising in their territories.
[157]Botswana National Policy on Care for People with Disabilities, 1996.

relating to HIV and the Botswana HIV/AIDS Policy does not mention disability either despite the fact that Botswana is one of the African countries that has recorded high rates of HIV prevalence.[158] In addition, the National Strategic framework for HIV and AIDS[159] does not make any reference to matters concerning any form of disability.

One of the African countries from which best practice can be adopted is the Democratic Republic of Congo in respect of the HIV and AIDS policy and consideration of persons living with disabilities. The Constitution provides for special measures to protect the rights and needs persons living with disabilities and to develop laws to provide for these rights.[160] In addition, the National Strategy on AIDS recognises persons living with disabilities as a key population and stresses the need to collect data on HIV and disability.[161]

With respect to addressing the protection of the rights of persons with cognitive disabilities in the context of HIV, the national strategy of the Democratic Republic of Congo provides a good platform for identifying those needing special attention in relation to HIV related matters and when identified, strategies such as therapy and special training regarding prevention and treatment can then be adopted to address the peculiar needs of persons living with cognitive disabilities.

Another African Country from which national policy has been positive with regard to matters concerning HIV and people living with disabilities is Kenya. The HIV and AIDS prevention and Control Act of 2006 provides for proxy consent to HIV testing and other health care services in the case of persons with disabilities that lack the capacity to provide individual consent. This works positively for persons with cognitive disabilities because it enables them have assistance with respect to HIV testing and health care in the event that they are unable to provide their own consent, often in cases of extreme intellectual incapacity.

In addition to this, the National Council for Persons with Disabilities in Kenya[162] can recommend that the Attorney General takes appropriate legal action in the case of discrimination against persons living

[158]J Pfumorodze & C Fombad 'Protecting the disabled in Botswana: an anomalous case of legislative neglect' in I Grobbelaar-du Plessis and T Van Reenen (eds) *Aspects of Disability Law in Africa* (2011) 85.
[159]Botswana National Strategic Framework for HIV and AID, 2010 to 2016.
[160]Article 49 of the Constitution de la Republique Democratique du Congo, 2006.
[161]Democratic Republic of Congo, Plan Strategique National de lute contre le SIDA 2010-2014 (NSP).
[162]Established under the Persons with Disability Act of Kenya, 2003.

with disabilities. This promotes addressing abuses against persons with cognitive disabilities which have the risk of exposing them to HIV such as involuntary sexual intercourse or inability to access health care due to presumed insanity. The National Strategic Plan on HIV/AIDS in Kenya does not mention disability. However, the Draft National Policy on Disability 2005 also specifically mentions matters around HIV and disability such as mainstreaming disability in health and HIV/AIDS services.[163] These are progressive steps towards mainstreaming matters concerning persons living with cognitive disabilities in national laws and policies on HIV.

Further, among some of the Southern African Countries, Zambia has in place the Persons with Disabilities Act[164]. However it makes no reference to HIV although the Act is very firm on the concept of equality and non-discrimination. It provides that contravention with the provisions of the Act amounts to an offence.[165] More positively, the National HIV/STI/TB Policy of 2005 recognises persons living with disabilities as a vulnerable group and provides for free access to VCT for persons with disabilities and inclusion of persons living with disabilities in all HIV-related interventions. In addition, the National Strategic Plan in Zambia refers to the need to provide health and social services for persons with disabilities.[166] This can effectively encourage special interventions for persons living with cognitive disabilities in all matters that affect them in the context of HIV and AIDS such as the modes adopted when spreading information on prevention.

Some countries such as Zimbabwe make no mention of disability matters in the National Policy on HIV and AIDS although the National Strategic Plan recognises persons with disabilities as a vulnerable group.[167] Inadequacies such as these tend to promote the limited protection which persons who need special attention receive. There is need to promote a holistic approach to the peculiar challenges faced by vulnerable groups in relation to HIV matters such as persons living with cognitive disabilities who are often unable to immediately perceive information regarding HIV prevention and AIDS treatment and also in respect of health care and support.

Uganda and Namibia have also made positive efforts towards achieving substantive inclusion of legal and administrative safeguards to incorporate the peculiar needs of persons living with different types of disabilities at national level. The National Policy on HIV/AIDS in Namibia includes persons with

[163]Kenya Draft National Policy on Disability, 2005.
[164]The Zambia Persons with Disabilities Act 33 of 1996.
[165](n 164 above) Section 32.
[166]The Zambia National HIV and AIDS Strategic Framework 2006 - 2010 (NSP).
[167]Gerntholtz (n 6 above).

disabilities as a vulnerable group and requires that HIV related prevention information must be tailored to meeting the specific needs of people with disabilities.[168] In addition, the National Plan provides for targeted prevention services for persons with disabilities and provides for impact mitigation services for persons with disabilities that are affected by HIV.[169] This is very important for persons living with cognitive disabilities because it ensures that preventive information is tailored to meet the specific needs of persons living with cognitive disabilities.

In Uganda, persons with disabilities are identified as a key group at higher risk of HIV exposure and the National Strategic Plan provides for HIV prevention and impact mitigation services for persons with disabilities.[170] In addition, the National Policy[171] in Swaziland recognises persons living with disabilities as a vulnerable group and provides for the need to protect and empower persons living with disabilities in order to minimize the impact of HIV on them. The Constitution also provides for discrimination on the grounds of disability and appropriate measures, including legislative to allow for persons living with disabilities to achieve their full mental and physical potential.[172] It cannot be disputed that these national responses through policy are a very progressive step towards incorporating persons living with disabilities in the context of HIV and AIDS.

However, given the special needs of groups such as persons living with cognitive disabilities, it is not enough to simply identify them as a vulnerable group or to make provision for data collection. There is need to promote specific address of the dynamic and very peculiar needs of persons living with disabilities and more particularly persons living with cognitive disabilities in the context of HIV and AIDS.

Unfortunately, most policies in many African countries do not go into detail about the measures to be adopted in order to address the peculiar challenges faced by various categories of persons living with disabilities particularly with respect to matters such as accessibility, availability and health care support for specific categories of persons living with disabilities.

[168]The Namibia National Policy on HIV and AIDS, 2007.
[169]The Namibia Third Medium-Term Plan on HIV/AIDS 2004 - 2009.
[170]Uganda National HIV and AIDS Strategic Plan 2007/8 - 2011/12 (NSP).
[171]The Kingdom of Swaziland HIV/AIDS Policy, 2006.
[172]The Constitution of the Kingdom of Swaziland, 2005.

4.3 The African human rights system

Several instruments in the African human rights system are relevant to the discussion of the rights of persons living with cognitive disabilities in Africa and the mainstreaming of their rights in everyday life, particularly HIV related matters. Such instruments include the African Charter on Human and Peoples' Rights (African Charter),[173] the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women (African Women's Protocol)[174] and the African Charter on the Rights and Welfare of the Child (African Children's Charter).[175]

The African human rights system has progressed positively over the years. The proclamation of the African Decade of Disabled Persons occurred at a time when the process of transforming the Organisation for African Unity (OAU) to the African Union (AU) was in progress.[176] The AU, unlike the OAU, has a clearly defined human rights mandate. The AU Constitutive Act states that one of one of the objectives of the AU is to 'promote and protect human and people's rights and other relevant human rights instruments[177].

Africa does not have a specific treaty which addresses the protection of the rights of persons living with disabilities. On the other hand, the Inter-American system has in place the Inter-American Disability Convention which specifically provides for the protection of rights of persons living with disabilities in the region.[178] The African Commission has to date only adjudicated upon one communication which deals with the rights of persons living with disabilities.[179] However, Africa still records substantive levels of human rights violations against persons living with disabilities more so in respect of the current focus by governments to combat deadly diseases such as HIV and AIDS.[180]

4.3.1 The African Charter

The AU adopted the African Charter in 1981.[181] It is the principal instrument upon which the African human rights system is founded. It has been described as a unique catalogue of substantive rights that

[173]Article 2 of the African Charter on Human and Peoples' Rights (ACHPR).
[174]Article 23 of the Protocol to the ACHPR on the Rights of Women in Africa.
[175]Article 13 of the African Charter on the Rights and Welfare of the Child.
[176]I Grobbelaar-du Plessis and T Van Reenen (eds) *Aspects of Disability Law in Africa* (2011) 85.
[177]Article 3(h) of the Constitutive Act of the African Union.
[178]UNAIDS (2009) (n 167 above) 4.
[179]The *Purohit* Case.
[180]F Armstrong and L Barton *Disability, Human Rights and Education: Cross Cultural Perspectives* (1999) 11.
[181]OAU Doc CAB/LEG/67/3 adopted on 26 June 1981 and entered into force 21 October 1986.

belong to individuals and peoples in Africa as it embodies the African cultural conception.[182] It also includes both civil and political rights and socio-economic rights. Above all, it includes and promotes the concept of peoples' rights. It is not disputed that all rights in the African Charter also belong to and can be enjoyed by persons living with disabilities. The Preamble of the African charter emphasises the need to eliminate all forms of discrimination on the basis of race, ethnic group, colour sex, language, religion or political status but does not mention disability as a ground.[183] It has however been noted that disability can be read into the category of 'other status' and this is the view adopted by the Committee on ESCR.[184]

It is one thing to guarantee formal equality in the enjoyment of rights as article 2 does, and another thing to ensure the substantive and equal enjoyment of those rights in practice. The existence of vulnerable groups such as women, children and persons living with disabilities requires that individuals belonging to these groups are not discriminated against, but rather that positive action is taken to ensure that they have the capacity to enjoy the rights guaranteed under the Charter.

Article 16 of the African Charter protects the right to enjoy the best attainable state of physical and mental health and although no express mention is made of persons living with disabilities, the provision was adequately interpreted in the *Purohit* case to also include the rights of persons living with disabilities, more so those living with mental disabilities. The most direct reference to disability in the African Charter is in article 18(4) which provides that persons living with disabilities have the right to special measures of protection in keeping with their physical or moral needs.[185] Article 18(4) is couched in general terms and does not guarantee any specific right. The provision puts the need to protect the rights of persons living with disabilities together with elderly persons and yet they belong to two distinct groups.

Unfortunately, the African human rights system does not have a specialised monitoring body for the rights of persons living with disabilities although the Commission plays this role. On the other hand, the Organisation of American States has a specific convention for disability, the Convention on Elimination of all forms of Discrimination against persons living with disabilities (the OAS Disability Convention) and a specialised body for disability rights.[186] In addition to this, the OAS Disability Convention

[182]Mutua (n 155 above) 339.
[183]Armstrong (n 180 above) 7.
[184]Armstrong (n 180 above) 7.
[185]Article 18(4) of the African Charter on Human and People's Rights.
[186]Article 6 of the Organisation of American States Disability Convention.

requires state parties to take all necessary measures, including making laws to promote the integration of persons living with disabilities into society in order to promote equality.[187]

Further, state parties under the OAS convention undertake to increase public awareness campaigns to eliminate stereotypes, prejudices and discrimination which are some of the key hindrances to the enjoyment of human rights by persons living with disabilities.[188] In this regard, a vital lesson that can be seen from the practice in other regions is that there is need to make specific provision for the rights of persons living with disabilities because in the same manner that women and children need special attention, this vulnerable group need specific legislative address of their human rights.

Therefore, there is need to specifically spell out the rights, or at least create provisions that clearly indicate practical ways in which persons living with disabilities can enjoy their rights. For instance, no provision is made for the specific needs of persons with cognitive disabilities in relation to HIV and AIDS related matters, this, among many other shortcomings does not promote responses to the peculiar needs of persons living with disabilities in order to ensure equality of enjoyment.

For instance, in order for persons living with cognitive disabilities to effectively perceive information, there is need for a person relaying the information to have specific teaching skills in order to effectively relay information to them.[189] If regional instruments clearly provide for the substantive rights to be protected and the specific measures to be taken in order to mainstream persons living with cognitive disabilities in society, a better level of equality will be achieved. Matters concerning disability rights are very complex and the relevant attention ought to be given to addressing their peculiar challenges.

4.3.2 African Women's Protocol

The African women's Protocol [190] contains a provision which has a bearing on the rights of women living with disabilities. The overall aim of this Protocol was to respond to the ineffective protection of the rights of women in Africa.[191] The Protocol makes specific reference to the rights of women with

[187] Armstrong (n 180 above) 18.
[188] As above.
[189] 'International Classification of Impairments, Disabilities and Handicaps (ICIDH), Geneva: World Health Organisation, 1980' http://www.disabled-world.com/disability/types/ (accessed on 16 September 2012).
[190] Adopted on 11 July 2003 in Maputo, Mozambique and entered into force on 25 November 2005.
[191] African Women's Protocol, preamble, paragraph 11 'despite the ratification of the African Charter on Human and Peoples' Rights and other international human rights instruments by the majority of state parties, and their solemn commitment to

disabilities under article 23 which is a step forward from the substantive provisions of CEDAW.[192] Some of the issues covered in the African women's Protocol and not in the CEDAW include polygamy, medical abortion, domestic violence, and HIV and AIDS.

It is generally accepted that women with disabilities suffer double discrimination: first as women and secondly as women with disabilities.[193] Other challenges faced by women with disabilities in Africa include poverty, joblessness, misery, and social exclusion.[194] It is without doubt that article 23 of the Protocol is aimed at addressing the extreme vulnerability of women living with disabilities by requiring states to ensure their freedom from violence, discrimination based on disability and the right to be treated with dignity.[195]

Unfortunately, article 23 is the only provision in the Protocol which makes specific provision for women with disabilities despite the fact that the concept of disability is broad and complex. With respect to the specific categories of disability, women living with physical disabilities do not exactly need the same interventions as women living with cognitive disabilities in the context of HIV and AIDS related matters. The former may require that ramps are available in health centres while the latter needs specialised personnel to be available within the centres in order to effectively interact with them on matters concerning HIV and AIDS.

The fact that the Protocol sets apart a provision regarding women with disabilities shows that there is acknowledgment that although the entire instrument can apply to this vulnerable group, there is need to acknowledge women living with disabilities and the double discrimination they face. Therefore, making provision for their specific needs would not exactly be duplicating protective provisions but rather an acknowledgement of the multiple and peculiar challenges they face as a result of the varying types and categories of disability in the context of HIV related matters.

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eliminate all forms of discrimination and harmful practices against women, women in Africa still continue to be victims of discrimination and harmful practices'.

[192]F Viljoen 'An introduction to the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa' (2009) 16 *Washington & Lee Journal of Civil Rights and Social Justice* 11.

[193]S Kamga 'the rights of women with disabilities: Does the protocol on the rights of women in Africa offer any hope?' (2011) *Barbara Faye Waxman Fidducia Papers on Women and Girls with Disabilities* 1.

[194]C McClain'The triple oppression: Disability, race and gender' http://www.disabilityworld.org/women/southafrica.shtml (accessed 4 October 2012).

[195]Kamga (n 193 above) 5.

4.3.3 The African children's charter

The African children's charter[196] identifies children with disabilities as a category in need of special protection[197] and addresses the plight of the African child whose needs and interests were not adequately catered for and reflected in the Charter on the Rights of a Child (CRC) although both contain provisions on disability rights.[198] Unfortunately, article 13 of the African children's charter does not recognize the impact of cultural beliefs on children born with cognitive or other disabilities who may suffer human rights violations simply because their birth is associated with witchcraft or punishment from gods.

Under article 13 of the African children's charter, the rights of children with disabilities are subject to progressive realization and availability of resources and yet they are very crucial rights for children with disabilities which often need immediate realisation. This article provides protection for children with mental and physical disabilities and article 13(2) mentions a disabled child generally, it does not specifically recognize that disability is a multifaceted concept which is not only limited to mental and physical disability as there are other complex disabilities such as living with albinism.

Finally, for children living with cognitive disabilities, the educational set up is a very important aspect for them, there is need to acknowledge that more special schools need to be developed to eliminate the lack of education and to eliminate the perception that children with cognitive disabilities are insane but merely have learning, intellectual or developmental disabilities. Special schools improve their development and works positively in future to enable them perceive information more effectively including information regarding HIV and AIDs.

4.3.4 The African Youth Charter

Africa recognizes that vulnerable groups to which special attention is drawn constitutes of youth with disabilities. They are covered under the African Youth Charter which highlights the situation of African youth and sets out their rights and duties. According to article 24 of the Charter, youth with disabilities are, firstly, guaranteed the right to special care and to equal and effective access to education, training, health care services, employment, sport, physical education and cultural and recreational activities. This

[196]The African Children's Charter OAU Doc CAB LEG/24.9/49, adopted on 11 July 1990 and entered into force on 29 November 1999.
[197]Article 13 of the African children's charter.
[198]D Chirwa 'The merits and demerits of the African Charter on the Rights and Welfare of a Child' (2002) 10 *International Journal of Children's Rights* 157.

is very relevant for youth living with cognitive disabilities as it promotes special care to be provided to them through education, health care and employment. Secondly, state parties are obliged to work towards eliminating any obstacles that may have negative implications for the full integration of youth with disabilities.

Unfortunately, the African youth charter only refers to youth with disabilities as 'physically and mentally challenged youth'. This means that there is still need to acknowledge the dynamic nature of disability and to acknowledge the various categories of disability. This can be achieved if regional strategies are adopted in order to address the peculiar needs of persons living with cognitive disabilities with respect to HIV related services in order to provide a holistic approach to the specific challenges faced by the various categories and types of disabilities.

4.4 Conclusion

Many African countries have ratified the CRPD with Djibouti being the most recent in July 2012 and countries like Angola, Botswana and Zimbabwe have not signed the CRPD although most African countries have signalled their intention to be bound by the CRPD by signing it.[199] It is noteworthy that, people living with HIV may develop cognitive and physical disabilities as a result of lack of treatment of HIV and AIDS. Studies show that there is a high HIV prevalence rate among persons living with disabilities.[200] Therefore, the challenges faced by persons living with cognitive disabilities in the context of HIV/AIDS require specific address which cannot be adequately covered through an international instrument but rather, in order to eliminate all preventable risks which persons living with cognitive disabilities are exposed to by virtue of their vulnerability to HIV infection there is need to develop regional measures.

Given the various African instruments discussed above, it is clear that the African human rights system acknowledges that although the various instruments can apply to persons living with disabilities, there is need to acknowledge that disability is a very complex issue and making provision for their specific needs would therefore not be a duplication of protective provisions but rather an acknowledgement of the complex nature of the subject and the need to identify the specific needs of the various categories and types of disability.

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[199] The United Nations Convention on the Rights of persons with disabilities available at http://www.un.org/disabilities/countries.asp?navid=12&pid=166 (accessed 12 September 2012).

[200] D Olowu 'Protecting children's rights in Africa: A critique of the African Charter on the Rights and Welfare of the Child' (2002) 10 *International Journal of Children's Rights* 127.

CHAPTER FIVE

5.1 Conclusion

It is without doubt that persons living with cognitive disabilities in Africa are sexually active and therefore at risk of HIV infection. This paper has shown that persons with cognitive disabilities have not been adequately included in the African human rights system and in national policies, plans and programs on HIV. This has affected their to access appropriate information regarding HIV and AIDS due to their inability to make generalisations or immediately perceive information.

Persons living with cognitive disabilities are a vulnerable group who merit special attention regarding their human rights. Cognition refers to understanding, the ability to comprehend what one sees and hears, and to infer information from social cues and body language.[201] This means that people living with cognitive disabilities have trouble learning new things, making generalizations from one situation to another, and expressing themselves through spoken or written language. It is essentially a learning, intellectual and developmental challenge.[202] Generally, most persons living with cognitive disabilities are unable to access effective information regarding HIV prevention because it is presumed that they are not sexually active or are at lower risk and this constitutes a human rights issue which requires attention.

A number of African countries provide some form of protection of disability rights either through the constitutional framework, national policies or plans. However, national plans and policies as well as legislation need to go beyond merely recognising persons living with disabilities as a key population at higher risk of exposure to HIV.[203] Due to their challenging communication skills, persons with cognitive disabilities are often disadvantaged because they experience lack of opportunities for both formal and informal education which then makes them more vulnerable to abuse, physical, psychological and sexual. They commonly suffer from discrimination and limited access to services and information.

It is therefore proposed that regional and national provisions regarding persons living with disabilities and HIV in Africa should make provision for the creation of mechanisms to ensure that public awareness programmes on HIV are accessible to all persons living with disabilities no matter the form

[201] 'Defining Disability, types and categories' (n 10 above).
[202] Marini (n 52 above) 4.
[203] Hannass-Hannock (n 2 above) 34.

or category of disabilities. This can best be achieved by making such regional instruments, plans, policies and legislation more specific both with regard to the peculiar features of the region and more importantly with regard to the national requirements. This entails ensuring that legal instruments and policies tackle the peculiar challenges faced by as many categories or types disability in order to achieve holistic and more specific form of protection. In addition, this promotes specific address of the varying challenges, whether physical, mental or psychosocial, to mention a few.

There is an urgent need for African regional instruments as well as national strategies to acknowledge the complexities of the concept of disability and ensure that as much attention is paid to addressing the peculiar needs of this vulnerable group. With respect to persons living with cognitive disabilities, the following recommendations are proposed in order to ensure equal access to services and information on HIV for persons living with cognitive disabilities;

5.2 Recommendations

The ultimate objective is to improve the lives and health of persons living with cognitive disabilities in relation to HIV and AIDS in Africa.

5.2.1 Specific instrument in Africa concerning disability

The key principles of the CRPD[204] which include equality of opportunity, accessibility and non-discrimination, full and effective participation and inclusion in society together with the notion of reasonable accommodation and affirmative action (positive measures) are so crucial to guarantee basic human rights and freedoms for persons living with disabilities in Africa as a continent.[205] Undoubtedly, these principles are very relevant to promote equality for persons living with cognitive disabilities. However, there are some very crucial factors or challenges such as HIV and AIDS which is so prevalent in Africa that there is need to have specific address of the various consequences in has on the lives of persons living with disabilities in clear, elaborate and specific terms rather than a general approach.

In addition, although the African Charter guarantees equality, human dignity and integrity,[206] precedent has shown that there is always need to have specific provisions that protect marginalised groups such as

[204]Article 3 of the General Principles adopted by the 8th Session of the Ad Hoc Committee on 25 August 2006 in New York.
[205]Mandesi (n 83 above) 6.
[206]Articles 3 to 5 of the African Charter.

persons living with disabilities.[207] A good example is the European Social Charter which stipulates that persons living with disabilities have the right to independence, social integration and participation in the life of the community.[208] State parties have a duty to adopt necessary measures to provide persons living with disabilities an enabling platform with guidance education and training to enable them fit into society.

It is proposed that it may be helpful to adopt a protocol to the African Charter to tackle the specific matters affecting the lives of persons living with disabilities given that they are a vulnerable group. In that respect, the instrument should specifically address the various issues such as HIV and how they affect various categories of persons living with disabilities such as persons with cognitive disabilities because the measures needed to address the challenges faced by physically disabled persons in the context of HIV may not be the same as those needed to address the challenges faced by persons living with cognitive disabilities.

The specific African protocol on disability if adopted can clearly provide for the substantive rights to be protected and the specific measures to be taken in respect of the various matters affecting the many categories of persons living with disabilities in the context of such matters as HIV. In addition, article 18(4), despite recognising the right to special measures of protection, seems to place much emphasis on needs and not the rights of persons living with disabilities and the provision is couched in very general terms.

Moreover, article 18(4) is only this provision in the African Charter which provides for the rights of persons living with disabilities. Yet disability is such a complex issue that cannot be addressed in a single provision.[209] Adoption of an African protocol will also avoid fragmentation whereby disability rights are mentioned in various African human rights instruments and create a single document to serve as the primary reference point for the protection of the rights of persons living with disabilities and thus address such matters as the challenges faced by persons living with cognitive disabilities in the context of HIV and AIDS.

[207]Examples include the adoption of the African Women's Protocol and the Children's Charter aimed at addressing the specific human rights issues affecting the respective vulnerable groups.
[208]Mandesi (n 83 above) 4.
[209]Ngwena (n 34 above) 613.

5.2.2 Domestication of key rights

African States need to ensure that laws, policies and plans recognise and address the specific HIV-related needs and rights of persons living with disabilities who also include persons living with cognitive disabilities.

It is also important that key rights, especially economic, social and cultural rights such as the right to health care, information, privacy, participation and education are domesticated within national laws, plans and policies to ensure that they can be enforced in the courts of law. In addition, all of the African human rights instruments contain provisions on disability which can be used to protect rights relating to persons living with cognitive disabilities in the context of HIV and AIDS. Therefore, it would be very useful for countries that have not yet domesticated these instruments to do so and ensure that the provisions are implemented.

5.2.3 Research and awareness raising

It is important to raise awareness on how domesticating rights especially economic, social and rights can be translated into meaningful rights and responses to HIV. This will have the effect of improving access information regarding HIV care and treatment to persons living with cognitive disabilities who are equally entitled to all human rights. Capacity building also helps to increase awareness.

In addition, there is need to improve on research and awareness raising to promote a clearer understanding of the relationship between HIV and disability, the vulnerabilities, records of prevalence within the group, the impact on them and to provide psychosocial support services in order to achieve a level of equality in respect of HIV related matters.

5.2.4 Legal protection and penalties

In order to curb or prevent human rights violations against persons living with cognitive disabilities which expose them to risk of HIV, the creation of legal protection and penalties would be very relevant. Such penalties can either be in the form of fines, imprisonment or both. For instance, the Zambia the Persons with Disabilities Act contains a provision which states that contravention with the provisions of the Act amounts to an offence which is either a fine, imprisonment or both.[210]

[210]Section 32 of the Persons with Disabilities Act number 33 of 1996, Zambia.

This ensures equality of treatment and has the effect of preventing human rights violations and abuses against persons living with disabilities that may have the effect of exposing them to HIV such as sexual violence. Another useful practice directly beneficial to persons who have mental illnesses is that in Uganda where persons who knowingly and deliberately expose a person who is mentally ill to HIV are punished for it.[211] In the same way, persons with severe cognitive disabilities are not in a position to give valid consent either to sexual intercourse or other high risk behaviours and those in a capacity to understand this have a duty to protect and not abuse them.

5.2.5 Partnership building

In order to increase the response to the challenges faced by persons living with cognitive disabilities, there is need to promote partnership building of relevant special schools and specialised health centres which are specifically trained to interact and communicate with this vulnerable group in order to effectively relay relevant information to them. This will have the effect of increasing the response to their specific needs and consequently expose them to information regarding prevention and treatment of HIV and AIDS.

5.2.6 Mental health care

Persons living with cognitive disabilities often experience psychosis, bipolar mood disorder, depression, anxiety and behavioural problems.[212] Therefore, there is need to provide for ongoing mental health care to for them which requires trained therapists and specialised hospitals within which those of extreme cases can be taken care of.

HIV-related prevention information, education, treatment, care and support strategies and materials need to be tailor made to meet the specific needs of persons living with cognitive disabilities. This ensures effective accessibility and equality. In addition, the law needs to also provide for the promotion of specialised personnel in HIV testing facilities in order to manage and take care of those who have limited cognition capacity.

5.2.7 Special interventions

Generally, sex education in Africa is often dominated by abstinence messages which might be detrimental to persons living with cognitive disabilities, who at times need special intervention,

[211] I Mulindwa *Study on reproductive health and HIV/AIDS among persons with disabilities in Uganda:* Disabled Women's Network and Resource Organisation (DWNRO) Action AID (2003) 11.
[212] (n 32 above).

demonstrations and explanations that go beyond conservative imagination[213] because persons living with intellectual or cognitive disabilities often need plain and direct instruction.

Therefore, there is need for special interventions. For example, the concept of "universal design"[214] provides for the development of programmes, products and services that are accessible to all, including people living with disabilities. By integrating this concept within regional and consequently national HIV and AIDS strategies, countries may increase access to HIV related programmes, products and services, thereby reducing the vulnerability of people living with cognitive disabilities to HIV exposure.

5.2.8 Support groups and community based projects

With respect to what can be done to improve the system for mainstreaming the needs of persons living with cognitive disabilities in the context of HIV and AIDS, the effectiveness of channels which are used to disseminate knowledge are very crucial as they depend on area specific circumstances and are disability specific. In most rural areas for instance, radios are the most used source of information while in urban areas it is predominantly from television. However, both television and radio are not sufficient modes of communication for persons living with cognitive disabilities who usually need more direct elaborations which requires that more field work is put into HIV related messages as well as less general means adopted in adverts either on television or radio.

There is need to promote implementation of community based HIV interventions. Further, to promote the creation of support groups within various communities in order to promote a collective response to the challenges persons living with cognitive disabilities face with regard to HIV related matters and information. This encourages compliance therapy and improves human rights advocacy among them.

All such matters highlighted above need a platform within which they can be achieved and this can best be achieved through a regional instrument which is disability specific as well as national responses through legislation, policy and plan in order to provide a holistic approach to addressing the peculiar needs of persons living with cognitive disabilities in the context of HIV related matters.

Word count: 19, 523

[213]Hannass-Hannock (n 2 above) 22.
[214](n 23 above).

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