

# THE PSYCHOSOCIAL IMPACT OF HIV AND AIDS ON CHILD DEVELOPMENT IN LESOTHO: A HUMAN RIGHTS CALL FOR ACTION

By

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# **DECLARATION**

I hereby declare that this mini dissertation	n which I submit for the
Masters in International Human Rights Law	and HIV in Africa is my
own work and has not previously been subn	nitted by me or any other
person at another university. Both primary an	nd secondary sources have
been acknowledged.	
Mamello Phekani	Date

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# LIST OF ABBREVIATIONS



ACHPR African Charter on Human and Peoples' Rights

ACRWC African Charter on the Rights and Welfare of the Child

AHRLR African Human Rights Law Report

AIDS Acquired Immune Deficiency Syndrome

AU African Union

AYC African Youth Charter

CEDAW Convention on the Elimination of All Forms of

Discrimination against Women

CERD Convention on the Elimination of all Forms of Racial

Discrimination

CESCR International Convention on Economic, Social and Cultural

**Rights** 

CRC Convention on the Rights of the Child

ECOSOC Economic and Social Council

ESA Eastern and Southern Africa

HAART Highly Active Antiretroviral Therapy

HIV Human Immunodeficiency Virus

HRC Human Rights Committee

ICCPR International Covenant on Civil and Political Rights

MDGs Millennium Development Goals

NSP National AIDS Strategic Plan

OAU Organisation of African Unity

OHCHR Office of the High Commissioner for Human Rights

OVC Orphaned and Vulnerable Children

PLWHA People Living with HIV and AIDS

UDHR Universal Declaration of Human Rights

UN United Nations

UNDP United Nations Development Programme



WHO World Health Organisation

WFP World Food Programme

#### 1.1 INTRODUCTION



Eastern and Southern Africa (ESA) continue to be the epicentre of the HIV epidemic. The Southern Africa region, in particular, experiences the most severe HIV epidemics in the world, with one third (34%) of all people with HIV globally residing in the 10 countries of Southern Africa. It is more saddening to face the reality that the most affected population category within the region is children. Nearly half (47%) of the world's 3.4 million children under the age of 15 living with HIV were found in the ESA at the end of 2010.

The virus has caused untold trauma, pain and suffering to vast numbers of children in Africa. Their plight is made that much more poignant by their inability to articulate their suffering.<sup>3</sup> Our shared humanity and global duty to protect the rights of the most vulnerable people make the suffering of children in the wake of the AIDS pandemic the responsibility of all.<sup>4</sup>

However, for a very long time, the relationship between HIV and AIDS and human rights was only understood to involve people infected with HIV and AIDS and the discrimination to which they were subjected.<sup>5</sup> Overtime, the call for human rights and for compassion and solidarity with people living with HIV and AIDS became explicitly embodied in the

<sup>&</sup>lt;sup>1</sup> www.unicef.org/esaro/5482 HIV AIDS.html (accessed 11 May 2013)

<sup>&</sup>lt;sup>2</sup> As above

<sup>&</sup>lt;sup>3</sup> C Kisoon et al 'Whose right' (2002) AIDS Review 46

<sup>&</sup>lt;sup>4</sup> LM Richter et al; 'Strengthening families to support children affected by HIV and AIDS' (2009) 21 AIDS Care 3

<sup>&</sup>lt;sup>5</sup> S Gruskin & D Tarantola 'Human rights and HIV/AIDS' hivinsite.ucsf.edu (accessed 08 June 2013)



first World Health Organisation (WHO) global response to AIDS.<sup>6</sup> By framing this public health threat in human rights terms, it became anchored in international law. As a result, this made governments and intergovernmental organisations publicly accountable for their actions toward people living with HIV and AIDS<sup>7</sup> for issues relating to their health and well-being. This link is apparent in the disproportionate incidence and spread of the disease among certain groups depending on the nature of the epidemic and the prevailing social, legal and economic conditions,<sup>8</sup> particularly for children living in poverty.

The economic and social effects of HIV infection and AIDS on children include malnutrition, migration, homelessness and reduced access to education and healthcare. It is therefore important that the protection and promotion of human rights in countries is geared towards reducing vulnerability to HIV infection by addressing its root causes such as poverty, lack of access to education, information and non-discrimination. Thus an effective international response to the pandemic must be grounded in respect for all civil, cultural, economic, political and social rights and the right to development in accordance with international human rights standards, norms and principles. 10

<sup>&</sup>lt;sup>6</sup> As above; World Health Organisation, World Health Assembly, Resolution WHA 40.26, Global Strategy for the prevention and control of AIDS, Geneva, WHO 5 May 1987

<sup>&</sup>lt;sup>7</sup> Gruskin & Tarantola (n 5 above)

<sup>8</sup> www2.ohchr.org/English/issues/hiv/introhiv.htm (accessed 08 June 2013)

<sup>&</sup>lt;sup>9</sup> G Foster 'Safety nets for children affected by HIV/AIDS in Southern Africa' <u>www.issafrica.org</u> (accessed 17 June 2013) 65

<sup>&</sup>lt;sup>10</sup> n 8 above



Nevertheless, the issue of children and HIV and AIDS is perceived mainly as a medical or health problem, although in reality it involves a much wider range of issues.<sup>11</sup> In this regard, the right to health, embodied in various international, regional and national human rights instruments, is central. The Committee on the Rights of the Child (Children's Committee) has noted that the concept of health and development must be understood more broadly than being strictly limited to the provisions relating to the right to life, survival and development and right to health.<sup>12</sup> However, there must be an understanding of the main human rights that need to be promoted and protected in order to ensure that adolescents do enjoy the highest attainable standard of health, develop in a well-balanced manner, and are adequately prepared to enter adulthood and assume a constructive role in their communities and in society at large.<sup>13</sup>

# 1.1.1 Concept of health

As far back as 1948, WHO defined health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.<sup>14</sup> Through its definition, WHO embraced psychology and sociology as core concepts in determining health. Therefore the right to health means that states must generate conditions in which everyone can

<sup>&</sup>lt;sup>11</sup> General Comment No 3 HIV/AIDS and the rights of the child CRC/GC/2003/3 in *General comments of the Committee on the rights of the child* (2006)

 $<sup>^{12}</sup>$  Committee on the rights of the child, General Comment No 4 'Adolescent health and development CRC/GC/2003/4 para 4

<sup>13</sup> As above

<sup>&</sup>lt;sup>14</sup> WHO Constitution 1948 preamble



be as healthy as possible. It does not mean the right to be healthy. <sup>15</sup> Since then, health and government responsibility for health, have, in various ways, been codified in different human rights instruments. <sup>16</sup>

However, the general content of all these instruments points to the fact that health is a fundamental human right indispensable for the exercise of other human rights.<sup>17</sup> The UN Committee on Economic, Social and Cultural Rights acknowledged in General Comment No 14 that formerly unknown diseases such as HIV and AIDS and others have become widespread and have created obstacles for the realisation of the right to health.<sup>18</sup> Therefore these diseases have to be taken into account in interpreting the law as well as state responsibility as appears in human rights instruments.

# 1.1.2 Understanding HIV and AIDS and its psychosocial impact

There are features of the HIV and AIDS epidemic that call to attention the core concepts of health as defined by WHO, namely mental and social well-being. Although the Third Committee of the United Nations General Assembly did not adopt the definition of health contained in the preamble to the Constitution of WHO when drafting article 12 of the

<sup>15</sup> www.who.int (accessed 23 July 2013)

<sup>&</sup>lt;sup>16</sup> For example, arts 3, 6, 19, & 23 of the International Covenant on Civil and Political Rights 1966 (ICCPR), arts 3, 9, 10, 12 & 15 of the International Covenant on Economic, Social and Cultural Rights 1966 (CESCR), art 5 of the Convention on the Elimination of all Forms of Racial Discrimination 1969 (CERD), arts 3 & 12 of the Convention on the Elimination of all Forms of Discrimination Against Women 1981 (CEDAW), arts 3, 6, 20, 24 & 39 Convention on the Rights of the Child 1989 (CRC), art 25 of the Universal Declaration of Human Rights 1948 (UDHR), art 14 of the African Charter on the Rights and Welfare of the Child 1999 (ACRWC) et cetera

<sup>&</sup>lt;sup>17</sup> General Comment No. 14(2000) 'The right to the highest attainable standard of health (Art 12 of ICESCR)'

<sup>&</sup>lt;sup>18</sup> As above, para 10.



International Covenant on Economic, Social and Cultural Rights (CESCR), the reference in article 12 (1) of the Covenant to 'the highest attainable standard of physical and mental health' is not confined to the right to health care.<sup>19</sup>

HIV/AIDS is often associated with a range of psychosocial sequelae that must be addressed throughout all stages of the disease.<sup>20</sup> Initially, an HIV diagnosis impacts on a patient through common responses such as shock, disbelief, denial, fear, anxiety, depression and guilt. Moreover, a patient experiences worry about health deterioration and despair becomes common. This is the first stage of a psychological impact defined by receiving 'the bad news' and is often caused by little knowledge or a distorted picture of HIV. From a social angle, ill health resulting from HIV-infection is likely to affect the working capacity of newly diagnosed patients.<sup>21</sup> Consequently, financial difficulties and constraints often arise at this stage especially because HIV infected patients are often those in economically productive age groups who are possibly the breadwinners or the major caretakers of their families.

Admittedly, patients may show a variety of reactions upon receiving the bad news. Although some patients may not experience psychological trauma from the onset, long term adherence to the highly active antiretroviral therapy (HAART) is a real challenge.<sup>22</sup> With the advent of

<sup>&</sup>lt;sup>19</sup> n 17 above para 4

<sup>&</sup>lt;sup>20</sup> WS Chan & WY Chung Meeting psychosocial needs of HIV patients <u>www.info.gov.hk</u> (accessed 18 July 2013)

<sup>&</sup>lt;sup>21</sup> As above

<sup>&</sup>lt;sup>22</sup> n 19 above



HAART, HIV infection has become a manageable disease that requires near perfect drug adherence, that is, 95% or above for maximum viral suppression.<sup>23</sup> Non-adherence to HAART often results in treatment failure. On the other hand, patients with good drug adherence may also be challenged by either transient (diarrhoea and nausea) or longer lasting side effects such as lipodystrophy, dyslipidaemia, and neuropathy.<sup>24</sup>

Some of side effects, though distressing, can be treated and are reversible, for example, fatigue, insomnia, diarrhoea, nausea and stomach upset.<sup>25</sup> Other side effects, for example, lipodystrophy, often cannot be completely removed. Physical manifestations vary, which typically include fat accumulation on the upper back and neck (buffalo hump) and under the muscles of the abdomen. There may also be lipomass, breast enlargement, and peripheral fat wasting in face, legs, arms and buttock.<sup>26</sup> These severe changes in physical appearance, coupled with the psychological trauma that some patients experience often cause patients to be in despair and constant fear of exposure of their HIV status.

Throughout the whole process, children are often something of an epiphenomenon; a tragic by product, relegated to mitigation efforts that

<sup>25</sup> KH Nott & K Vedhara *Psychosocial and Biomedical interactions in HIV infection* (2000) 278

<sup>&</sup>lt;sup>23</sup> DL Paterson et al 'Adherence to protease inhibitor therapy and outcomes in patients with HIV infection' (2000) 133 *Annals of Internal Medicine Journal* 21-30

<sup>&</sup>lt;sup>24</sup> n 19 above

 $<sup>^{26}</sup>$  UNAIDS. Caring for carers: managing stress in those who care for people with HIV and AIDS. Geneva: UNAIDS, 2000.



fall somewhere between child survival and child development.<sup>27</sup> Young children find themselves living with withdrawn, preoccupied and ill caregivers that eventually die. Such loss and instability is maximally injurious to their health and well-being.<sup>28</sup> Therefore for children to enjoy sustainable physical, mental and social well-being, a number of areas in their lives require persistent effort in providing HIV and AIDS related treatment especially the psychosocial impact that HIV has on their lives as expounded above.

The right to health, like all human rights, imposes on state parties three types of obligations: to respect, protect and fulfil this right.<sup>29</sup> It is the lack of respect for human rights that fuels the spread and exacerbates the impact of the disease, while at the same time, HIV and AIDS undermines progress in the realisation of human rights.<sup>30</sup>

While many countries have adopted different methods of treatment and prevention of HIV, it is argued that a broad based approach that looks into the psychosocial aspect of the virus as a treatment and prevention method can go a long way in putting an end to the spread of HIV and AIDS. Knowledge regarding psychosocial factors related to HIV disease and their associations with health behaviours can be translated into more effective treatment protocols that address these factors, which may

<sup>&</sup>lt;sup>27</sup> G Foster et al 'Where the heart is: meeting the psychosocial needs of young children in the context of HIV/AIDS' (2006) Call to action: Toronto 8

<sup>&</sup>lt;sup>28</sup> As above

<sup>&</sup>lt;sup>29</sup> n 15 above

<sup>&</sup>lt;sup>30</sup> n 8 above



subsequently decrease poor adherence and reduce the spread of disease.<sup>31</sup>

# 1.1.3 HIV and AIDS prevalence and the socio-economic profile of Lesotho

Located in Southern Africa, Lesotho is a landlocked country with an estimated population of 2.2 million people.<sup>32</sup> Despite being one of the smallest and poorest countries in the region, Lesotho has the third highest HIV and AIDS prevalence in the world, with an estimated adult prevalence rate of 23.6 %.<sup>33</sup> One of the social repercussions of the high rate of HIV prevalence and infection is the high number of orphans and vulnerable children (OVC).<sup>34</sup> Fifteen % of children below the age of 18 are orphans in Lesotho.<sup>35</sup> This has resulted in depleting family structures thus leaving many children without caregivers. Despite the strength of extended family structures, the sheer number of OVC coupled with high levels of poverty have negatively impacted extended family care for OVC in Lesotho.<sup>36</sup>

<sup>&</sup>lt;sup>31</sup> K Whetten et al 'Trauma, mental health, distrust and stigma among HIV positive persons: implications for effective care' (2008) 70 Psychosomatic Medicine 531

<sup>32</sup> www.worldbank.org (accessed 20 May 2012)

<sup>&</sup>lt;sup>33</sup> 2013 CIA world fact book <u>www.theodora.com</u> (accessed 19 October 2013)

<sup>&</sup>lt;sup>34</sup> T Tamasane 'Analysis of services for orphans and vulnerable children in Lesotho – a desktop review' (2011) Human Sciences Research Council 34

<sup>35</sup> As above

<sup>&</sup>lt;sup>36</sup> Tamasane (n 7 above)12



Studies that have been conducted on the situation of children affected and infected by HIV paint a gloomy picture. These studies indicate challenges that OVC face and one of the challenges, of interest to the current study, is the psychosocial trauma caused by loss of a parent or a caregiver.<sup>37</sup> Children who have lost parents to AIDS also suffer psychological scarring, and are vulnerable to physical, psychological and sexual abuse, exploitation and violation of their basic human rights<sup>38</sup> yet the Government of Lesotho in its response to HIV especially for children, provides services to OVC focused overwhelmingly on material assistance; there is little by way of psychosocial and emotional support.<sup>39</sup>

In the light of the above highlighted factors, it is imperative that Lesotho adopts an HIV treatment approach integrating psychosocial support for children infected and affected by HIV. The duty placed on the government of Lesotho to respect, protect and fulfil the rights of children pertaining to the provision of the highest attainable standard of health arises from both international and regional treaties.

To mention but a few, article 24 of the Convention on the Rights of the Child (CRC),<sup>40</sup> article 12 of CESCR,<sup>41</sup> articles 11(1) (f) and 12 of the Convention on the Elimination of all Forms of Discrimination Against

<sup>&</sup>lt;sup>37</sup> Ministry of Health and Social Welfare, 1999, 2001; Sechaba Consultants, 1993; UNICEF, 1999; UNAIDS, UNICEF, USAID & WFP, 2004

<sup>&</sup>lt;sup>38</sup> Tamasane (n 7 above) 14-15

<sup>&</sup>lt;sup>39</sup> Tamasane (n 7 above) 35

<sup>&</sup>lt;sup>40</sup> Lesotho signed the Convention on the 21 August 1990 and became party on the 10 March 1992

<sup>&</sup>lt;sup>41</sup> Lesotho became party to the Covenant on the 09 September 1992



Women (CEDAW),<sup>42</sup> article 5(e) (iv) of the Convention on the Elimination of all Forms of Racial Discrimination (CERD)<sup>43</sup> and article 16 of the African Charter on Human and Peoples' Rights (ACHPR)<sup>44</sup> all place a responsibility on the government of Lesotho, as a member state, to make provision of health to accord to international and regional standards. The notion of the highest attainable standard of health in all these articles takes into account both the individual's biological and socio-economic preconditions and a state's available resources.<sup>45</sup>

The Constitution of Lesotho makes provision for health under Chapter III, titled principles of state policy, which are not enforceable by any court but subject to the limits of the economic capacity and development of Lesotho. However, the right to health is closely related to and dependent upon the realisation of other human rights, *inter alia*, the right to life, human dignity, equality, freedoms of association, assembly and movement, all of which are provided for under Chapter II of the Constitution of Lesotho as fundamental human rights and freedoms. The obligations attached to this right are fundamental to guiding the action of states to place children at the centre of the response to the pandemic and to adopt strategies that are sensitive to children's rights and needs in relation to HIV and AIDS.46 This study therefore examines the states'

 $<sup>^{</sup>m 42}$  Lesotho signed the Convention on the 17 July 1980 and ratified it on the 22 August 1995

<sup>&</sup>lt;sup>43</sup> Lesotho ratified the Convention in 1971

 $<sup>^{44}</sup>$  The Charter entered into force on 21 October 1986. Lesotho signed the Charter on the 07 March 1984 and ratified it on the 10 February 1992

<sup>&</sup>lt;sup>45</sup> n 16 above para 9

<sup>&</sup>lt;sup>46</sup> n 11 above 15



obligation to provide the aforementioned support and service to Lesotho's children.

#### 1.2 PROBLEM STATEMENT

The overwhelming frustration and strain that HIV and AIDS has caused politically, socially and individually, no doubt, negatively affects child development and adjustment in society. As human beings, our neurophysiological functioning, emotional regulation and co-operative learning, are tailored to function optimally in stable, secure and affectionate relationships and *environments*<sup>47</sup> with others.<sup>48</sup> This is especially critical for children. In the absence of these social conditions, regardless of the material environment, children grow poorly, fail to thrive, show delayed language, cognitive and motor development and display inappropriate emotional and interpersonal behaviour.<sup>49</sup>

The current Constitution of Lesotho has a section on protection of children and young persons<sup>50</sup>, however, it is very ambiguous. It can be argued that it leaves room for different and broad interpretations of the term protection which should embody all aspects of the child's well-being. Despite this, the long awaited Children's Protection and Welfare Act of 2011 does little to offer assistance on this dilemma.

<sup>&</sup>lt;sup>47</sup> My emphasis

<sup>&</sup>lt;sup>48</sup> Richter (n 4 above) 3

<sup>&</sup>lt;sup>49</sup> Richter (n 4 above) 4

<sup>&</sup>lt;sup>50</sup> 1993, sec 32



The Children's Protection and Welfare Act is a culmination of over five years of extensive consultations, advocacy, lobbying, technical and financial support.<sup>51</sup> While the Act in Part XXV, dealing with measures relating to health of children, recognises emerging child protection and welfare challenges faced by Lesotho as a result of the HIV and AIDS epidemic in the country; the third highest HIV prevalence in the world; it is lacking in how this problem can be best addressed. It is contended that section 23(2) (b)<sup>52</sup> was a step in the right direction but should have gone further to state how the challenge can be addressed especially in the light of the HIV and AIDS epidemic and the harmful effects it has on children's psychosocial development.

This study will therefore analyse Lesotho's international, regional and national obligations to put in place comprehensive and effective HIV and AIDS treatment and prevention methods. This analysis will stem from a study of the UN treaty instruments, African Union (AU) instruments as well as Lesotho national health laws and policies. It will further look into the underlying effects of HIV such as the psychosocial impact on child development. Psychosocial impact weakens social ties and values, and makes children that grow into adults that are susceptible to abuse, exploitation, discrimination and crime.<sup>53</sup>

<sup>&</sup>lt;sup>51</sup> www.aclr.info (accessed 08 June 2013)

<sup>&</sup>lt;sup>52</sup> It provides: For the purposes of this Act, a child is emotionally and psychologically injured if there is impairment of the child's mental and emotional functioning that is evidenced by, among other things, a mental or behavioural disorder, including anxiety, depression, withdrawal, aggression or delayed development

<sup>&</sup>lt;sup>53</sup> n 1 above



#### 1.3 RESEARCH QUESTIONS

In the light of the preceding background, the following questions shall be the basis of the study:

- 1. What is meant by psychosocial in the context of HIV and AIDS treatment and prevention and how can it be used as a tool in the fight against the spread and stigma associated with the disease?
- 2. What is the nature and content of Lesotho's international, regional and national human rights obligations to provide psychosocial support for children affected and infected by HIV and AIDS in response to a global call for action to curb the spread of the disease?
- 3. Is there adequate psychosocial support and mechanisms that the government of Lesotho has put in place to address the holistic effect of HIV not only from a resource perspective but also psychologically and socially to enable proper child development despite the devastation of HIV and AIDS?
- 4. Is there existing legislation and are there policies in place which can be used to build on treatment and prevention methods already in place, to include psychosocial support for children? Does the said legislation conform to international standards? Where can it be improved to ensure comprehensive treatment and support on HIV for children beyond resource constraints?



#### 1.4 SIGNIFICANCE OF THE STUDY

The findings of this study will help fill in the gaps in the existing law as well as provide guidance and information to legislators, policy makers and relevant stakeholders on a human rights-based approach to child development in the light of the HIV and AIDS pandemic. It will not only be beneficial to Lesotho but to other countries where the psychosocial impact of HIV on child development has been regarded as totally unrelated to comprehensive treatment of HIV and AIDS and the subsequent respect for the human rights of children.

#### 1.5 DEFINITION OF TERMS

In this study, unless the context indicates otherwise, the following terms have the following meanings:

## 1.5.3 Psychosocial

It refers to a range of intervention tools, processes and programmes for children in difficult circumstances to address their non-material, especially their social and emotional needs.<sup>54</sup> Psychosocial interventions are different from the (psychosocial) care and support that children receive from affectionate caregivers in their everyday lives, it is the day-by-day, consistently nurturing care that constitutes the building blocks of children's psychosocial well-being, including how children learn,

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<sup>&</sup>lt;sup>54</sup> Foster et al (n 26 above) 8



develop and adapt, and governments need to provide the facilitating environment, with services and legislative protection.<sup>55</sup>

#### 1.5.4 Child

The CRC<sup>56</sup> and the African Charter on the Rights and Welfare of the Child (ACRWC)<sup>57</sup> define a child as any human being under the age of 18. The Lesotho Child Protection and Welfare Act<sup>58</sup> also define a child as a person under the age of eighteen years. This study adopts all the three definitions.

## 1.5.5 Vulnerable children

The government of Lesotho defines a vulnerable child as<sup>59</sup>

Any person who is below the age of 18, who has one or both parents who have deserted or neglected him or her to the extent that he or she has no means of survival and as such is exposed to dangers of abuse, exploitation and or criminalisation and is, therefore, in need of care and protection

In this study, reference to vulnerable children will be made in line with the aforementioned definition but to also include children that are made vulnerable by HIV and AIDS.

 $^{\rm 56}$  Art 2 thereof, entered into force on 2 September 1990

<sup>55</sup> As above

<sup>&</sup>lt;sup>57</sup> Art 2 thereof, entered into force on 29 November 1999

<sup>&</sup>lt;sup>58</sup> Sec 3 of Act no. 7 of 2011

<sup>&</sup>lt;sup>59</sup> Ministry of Health and Social Welfare 'National orphans and vulnerable children strategic plan: 2006-2011 (2005) Department of Social Welfare, Maseru Lesotho 6



#### 1.5.6 Orphan

The UN defined an orphan as a child under the age of 18 who has lost either or both parents, and who lives in difficult conditions, which includes a lack of food and access to services and support.<sup>60</sup> Although this definition is adopted by this study, it takes into account that children orphaned by AIDS face particular challenges in their lives because of the stigma that is attached to the disease but, admittedly, there are shared concerns that orphaned children experience.

#### 1.5.7 Stigma

Stigma has been defined as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society.<sup>61</sup> There is perceived and direct stigma. Direct stigma is one experienced directly by an individual and perceived stigma is one where an individual's fear or concern that negative attitudes or discrimination would occur if their HIV status was known.

#### 1.5.8 Mental Health

Mental health has been defined variously by scholars from different cultures. Concepts of mental health include subjective well-being, perceived self-efficacy, autonomy, competence, intergenerational dependence, and self-actualization of one's intellectual and emotional

<sup>&</sup>lt;sup>60</sup> UNAIDS 'A review of household and community responses to the HIV/AIDS epidemic in the rural area of Sub-Saharan Africa' (1999); UNAIDS 'Report on the global HIV/AIDS epidemic' (2000); UNAIDS 'Children on the brink. A joint report on orphan estimates and program strategies' (2002); UNICEF 'Children orphaned by AIDS: frontline responses from Eastern and Southern Africa' (1999)

<sup>&</sup>lt;sup>61</sup> Whetten (n 5 above) 535



potential, among others.<sup>62</sup> Additionally, Campbell's Dictionary of Psychiatry defines mental health as a state of psychological well-being.<sup>63</sup>

# 1.5.9 Vulnerability to HIV

This is the lack of power of individuals and communities to minimize or modulate their risk of exposure to HIV infection and, once infected, to receive adequate care and support.<sup>64</sup>

#### 1.6 RESEARCH METHODOLOGY

The study will conduct a descriptive, analytical and evaluative research consisting of literature in the form of books, journal articles, internet resources, document analysis and reports of international organisations. In addition, international, regional as well as domestic legal instruments will be used as an integral part of the study.

#### 1.7 LITERATURE REVIEW

There is growing research and vast programme literature on the impact of HIV and AIDS epidemic on children. Richter notes that these impacts occur in a number of overlapping and interdependent domains,

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<sup>&</sup>lt;sup>62</sup> World Health Report Mental health: new understanding, new hope: 2001 WHO

<sup>&</sup>lt;sup>63</sup> JM Bertolote 'The roots of the concept of mental health' (2008) 7 World Psychiatry Journal 115

<sup>&</sup>lt;sup>64</sup> Gruskin & Tarantola (n 5 above)



including children's psychosocial development.<sup>65</sup> She identifies nine factors as well as three determinants of poor adjustment in children. Of interest to this study, only two factors from this literature will be discussed.

The first impact that Richter identifies is the psychosocial impact. She argues that affected and orphaned children are often traumatised and suffer a variety of psychosocial reactions to parental illness and death.<sup>66</sup> Common problems experienced by children affected and orphaned by HIV and AIDS include loss of homes, dropping out of school, separation from siblings and friends, increased workloads and social isolation.<sup>67</sup> All these problems have a negative impact on the current and future mental health of children. Moreover, the combination of these effects on children increases their vulnerability to a range of consequences, including HIV infection, illiteracy, poverty, child labour, exploitation and the prospect of unemployment.<sup>68</sup>

A general survey showed that the level of mental health problems detected among HIV positive individuals is substantially higher than that of the general population.<sup>69</sup> Existing studies of children's reactions suggest that children tend to show internalising rather than externalising

<sup>&</sup>lt;sup>65</sup> L Richter 'The impact of HIV/AIDS on the development of children' in R Pharoah (ed) A generation at risk? : HIV?AIDS, vulnerable children and security in Southern Africa (2004) Monograph series No109 9

<sup>&</sup>lt;sup>66</sup> n 26 above, 11

<sup>&</sup>lt;sup>67</sup> As above

<sup>&</sup>lt;sup>68</sup> Foster (n 9 above) 65

<sup>&</sup>lt;sup>69</sup> Whetten (n 5 above) 532



symptoms in response to such impacts – depression, anxiety and withdrawal – as opposed to aggression and other forms of antisocial behaviour.<sup>70</sup>

Secondly, Richter identifies the long-term psychological effect of emotional deprivation that children affected and orphaned by HIV and AIDS suffer. She notes that children who grow up without the love and care of adults devoted to their well being are at higher risk of developing psychological problems<sup>71</sup> as they develop. But to this end, Foster provides a solution. He argues that the psychological, social and material needs of young children during their development are best met by a constant group of dedicated people, related to one another, in lifelong family-type groups.<sup>72</sup>

Family care is our species-specific cultural adaptation to ensure children's growth, learning and socialisation.<sup>73</sup> The most appropriate and sustainable sources of psychosocial well-being for young children come from caring relationships in the home, school and community because supportive families and communities nurture and sustain children's resilience.<sup>74</sup> However, we have not seen the same emphasis on family re-unification, placement and support in efforts to support children affected by HIV and AIDS especially as a result of adult

<sup>&</sup>lt;sup>70</sup> Richter (n 27 above) 12

<sup>&</sup>lt;sup>71</sup> As above

<sup>&</sup>lt;sup>72</sup> Foster (n 18 above) 8

<sup>&</sup>lt;sup>73</sup> Richter ( n 4 above) 3

<sup>&</sup>lt;sup>74</sup> Foster (n 18 above) 6



mortality.<sup>75</sup> Instead, there has been a proliferation of orphanages, many funded through the faith sector.<sup>76</sup>

The Joint Learning Initiative on Children and AIDS calls for a complete turnaround in this approach, accentuating the need to reinforce families' long-term caring capacities as the basis of a sustainable response to children affected by HIV and AIDS and the need for family centred services integrating health, education and social support.<sup>77</sup> If excessive emphasis is placed on externally provided, stand-alone *HIV and AIDS intervention*<sup>78</sup> programmes, there is a danger of discounting the importance of everyday love, support and reassurance that children receive from families and communities.<sup>79</sup>

#### 1.8 STRUCTURE

This study will consist of four chapters. The first chapter is the introductory chapter which is comprised of the background to the study, the problem statement, research questions, significance of the study, definition of terms, research methodology and literature review. The second chapter will provide insight on the psychological and social aspect of HIV and AIDS and its impact on children. It will further

<sup>&</sup>lt;sup>75</sup> Richter (n 4 above) 4

<sup>&</sup>lt;sup>76</sup> As above

<sup>&</sup>lt;sup>77</sup> Richter (n 4 above) 4

<sup>&</sup>lt;sup>78</sup> My emphasis

<sup>&</sup>lt;sup>79</sup> Foster (n 18 above) 9



highlight how the psychosocial effects manifest. The third chapter will be an analytical study of laws and policies in place which Lesotho has enacted and those that its party to internationally and regionally to evaluate whether they address the problem and if not, why and how this gap can be filled. Chapter 4 consists of the recommendations and conclusions.



#### Chapter 2

# 2. The psychosocial aspect of HIV and AIDS and its impact on children

#### 2.1 Introduction

Children affected by HIV and AIDS have critical psychosocial needs:<sup>80</sup> that are the *sine qua non* of optimal human development. Therefore, support for children's psychosocial well-being is crucial.<sup>81</sup> Children have a right to develop to their full potential because it will help them contribute to the prevention of HIV in the next generation and the long-term advancement of society.<sup>82</sup> With millions of children made vulnerable by the epidemic, care and support to help them survive and stay safe has never been more crucial than now.<sup>83</sup>

Since the evolution of the HIV and AIDS epidemic, the disease has triggered quick-fix interventions because it was a unique disease. While short-term interventions may be ameliorative, they do not address the

Foster et al (n 27 above) 29. Children affected by HIV and AIDS are defined as children who have HIV, who have AIDS, whose parents are sick or have died of AIDS, whose siblings, relative or friends have the disease or have died, whose households are stressed by children from another family who have been orphaned by AIDS and who are at high risk of infection such as those who live on the street. HIV/AIDS and policies affecting children Interagency Coalition on AIDS and Development <a href="https://www.icad.cisd.com">www.icad.cisd.com</a> (accessed 08 June 2013)

<sup>&</sup>lt;sup>81</sup> Foster et al (n 27 above)13, 25

<sup>&</sup>lt;sup>82</sup> As above. The following provisions of law make reference to the rights of children to develop in an environment that is conducive for their development into adults that can take substantial part in the progression of their communities: art 5 of the ACRWC & arts 6, 19, 24 & 27 of the CRC

<sup>&</sup>lt;sup>83</sup> n 1 above



core problems of children's ongoing development and the needs of their families.<sup>84</sup> HIV and AIDS have not one, but two, forms of impact; one being on the individual and the other being on the society.<sup>85</sup> The crisis of children left behind by AIDS became, and still is, a humanitarian, development and human rights challenge of unprecedented proportions.<sup>86</sup> The challenge in responding to the pandemic lies in addressing not just the infection itself, but also the conditions that make infection possible.<sup>87</sup>

It is common knowledge that for the virus to be able to infect a person, it needs certain physiological and biological conditions. In addition, the psychological and social aspects of human development are known to be pivotal in determining a person's vulnerability to the infection. When these physiological, biological and psychosocial conditions are negatively affected and persist unchanged for most of a person's life, especially in a child's early years, they have permanent effects on a child's developmental, cognitive and social capacities.<sup>88</sup>

The need for a focus on these physiological, biological and psychosocial factors and a modification of treatment practices to adequately address them is particularly compelling because of their relationship with HIV-related behaviours including medication adherence and HIV risk

<sup>&</sup>lt;sup>84</sup> Foster et al (n 27 above) 32

<sup>85</sup> Kisoon et al (n 3 above) 9

<sup>&</sup>lt;sup>86</sup> Foster (n 9 above) 65

<sup>&</sup>lt;sup>87</sup> Kisoon et al (n 3 above) 16

<sup>88</sup> Foster (n 27 above) 8



behaviours.<sup>89</sup> However, a human rights-based approach in dealing with these factors is important because human rights are inextricably linked with the spread and impact of HIV and AIDS on individuals and communities around the world.<sup>90</sup> The protection and promotion of human rights are essential in preventing the spread of HIV and to mitigating the social and economic impact of the pandemic.<sup>91</sup>

#### 2.2 Child development

The Children's Committee has noted that childhood is a period of continuous growth from birth to infancy, through the preschool age to adolescence.<sup>92</sup> The stages of a child's development are cumulative and each stage has an impact on subsequent phases, influencing the children's health, potential, risks and opportunities.<sup>93</sup> Therefore understanding children's development is essential in order to appreciate how health problems in childhood can affect their entire life course and assist in formulating intervention strategies that will address all areas of impact.

<sup>&</sup>lt;sup>89</sup> Whetten et al (n 31 above) 555

<sup>90</sup> n 8 above

<sup>&</sup>lt;sup>91</sup> n 17 above para 30

<sup>&</sup>lt;sup>92</sup> General Comment No. 15 (2013) The right of the child to the enjoyment of the highest attainable standard of health (article 24) para 20

<sup>93</sup> As above



Child development is a process that evolves in an orderly progression through well established successive stages which always occur in the same order. Heach phase is more complex and differentiated from the one preceding it. Had each phase is significant as important developmental changes occur in terms of physical, psychological, emotional and social development, expectations and norms. He advent of HIV and AIDS poses a serious threat to child development and proper growth. Studies show, for example, that the HIV encephalopathy presents with developmental delay, loss of developmental milestones, microcephaly and pyramidal tract symptoms such as spasticity.

Vandenbroeck contends that there are three phases that are critical in a child's development. The first phase, concerned with babies and toddlers, is where young children are primarily influenced by the affective attachment that they create with those people familiar to them. 98 As a rule, the affective attachments are formed with people from their own cultural or ethnic groups. These attachments provide for appropriate socialization and development of relationships. 99 As a normal evolution in their development, they develop fear of strangers and this has little to do with cognitive stereotypes, but solely with an

<sup>&</sup>lt;sup>94</sup> CZ Ndiaye Psychosocial care and counselling for HIV infected children and adolescents: a training curriculum (2009) 33 <a href="https://www.crsprogramquality.org">www.crsprogramquality.org</a> (accessed 08 June 2013)

<sup>95</sup> As above

<sup>&</sup>lt;sup>96</sup> n 91 above para 20

<sup>&</sup>lt;sup>97</sup> Ndiave (n 91 above) 44

<sup>&</sup>lt;sup>98</sup> M Vandenbroeck *The view of the Yeti: bringing up children in the spirit of self-awareness and kindredship* (1999) 85

<sup>&</sup>lt;sup>99</sup> Ndiaye (n 93 above) 37



emotional feeling of uneasiness.<sup>100</sup> Nothing can replace the need of all children, especially those who are very vulnerable, for affectionate and stable family care.<sup>101</sup>

However, the breakdown of families due to HIV is denying opportunities to develop these relationships which are important to children's quality of life and healthy development.<sup>102</sup> In this phase, young children, before they enrol in school, are more likely to be moved from one household to another during the crisis of parental illness and death, leading to instability in care giving, with adverse effects on their development, health and well-being.<sup>103</sup> As a result, young children experience a dire human rights impact illustrated through neglect, denial and violation of their rights in the context of the HIV and AIDS epidemic.<sup>104</sup>

The second phase is where preschool children start to become extremely curious about who they are and which groups they belong to.<sup>105</sup> Here the curiosity is primarily about external differences such as gender, ethnicity and other differences.<sup>106</sup> At this stage, the social classification of people living with HIV and AIDS affects children acutely. This social classification is experienced as a result of discrimination and the stigma

<sup>100</sup> Vandenbroeck (n 97 above) 86

<sup>101</sup> Foster et al (n 27 above) 11

<sup>&</sup>lt;sup>102</sup> Ndiaye (n 93 above) 37

<sup>103</sup> Foster et al (n 27 above) 26

<sup>104</sup> Chan & Chung (n 20 above)

<sup>105</sup> Vandenbroeck (n 97 above) 86

<sup>&</sup>lt;sup>106</sup> As above



that is attached to the HIV. The Children's Committee has noted that discrimination is responsible for heightening the vulnerability of children to HIV and AIDS, as well as seriously impacting the lives of children who are affected by HIV and AIDS or are themselves HIV infected.<sup>107</sup> To them, people who are deemed different are automatically not as welcome. They are highly receptive to the social views held by others about them. This phase of crude stereotypes is fed by the children's self-centred affective processes.<sup>108</sup>

The likelihood of maladjustment is increased when these adverse social views endure overtime, when stresses are cumulative and when fewer opportunities for recovery and hope exist.<sup>109</sup> Therefore interventions targeted narrowly at children, in isolation from their social and communal environment may in fact undermine protective resources in operation in families and communities thus presenting additional threats to children's basic security.<sup>110</sup>

The third phase is where children aged seven to eight go through major intellectual development, during which they not only have an eye for the group someone belongs to but also to the individual.<sup>111</sup> It is the shift from pre-operational to concrete operational thinking and it is for this reason

<sup>&</sup>lt;sup>107</sup> n 11 above para 7

<sup>&</sup>lt;sup>108</sup> Vandenbroeck (n 97 above) 86

<sup>&</sup>lt;sup>109</sup> R Pharoah A generation at risk? *HIV/AIDS, vulnerable children and security in Southern Africa* (2004) 109 Monograph 23

<sup>&</sup>lt;sup>110</sup> TS Betencourt et al Children affected by HIV/AIDS: SAFE, a model for promoting their security, health and development www.tandfonline.com (accessed 08 June 2013)

<sup>&</sup>lt;sup>111</sup> Vandenbroeck (n 97 above) 86



that this period is called the 'golden age' as it is one in which adults have a significant role to play.<sup>112</sup> All young children require protection and nurturing that meets their needs and ensures their health, affectionate relationships with stable caregivers that support their developing psychological and social capacities, and ongoing interactions with encouraging adults that promote their language and cognitive development.<sup>113</sup>

Care and support enable children to have a sense of self-worth and belonging and are essential for children to learn, to develop life skills, to participate in society and to have faith for the future.<sup>114</sup> The heart of psychosocial care is to be found in the home yet the HIV and AIDS epidemic is felt most acutely at the level of families. Barolsky summarised this as follows:<sup>115</sup>

Parents who are living with HIV and AIDS need to come to terms with the fact that they may die and leave young children who need to be cared for by extended family and community networks. Older people will need to accept that they may be responsible for the care and support of young children and often traumatised grandchildren, and that their children, upon whom they have expected to rely for support through their old age, will die before them.

The illness of people living with HIV and AIDS, the death of parents and the orphaning of children all place an enormous burden on the ability of the family to operate as an agent of socialisation, economic support,

<sup>113</sup> Foster et al (n 27 above) 8

<sup>&</sup>lt;sup>112</sup> As above

<sup>114</sup> Foster et al (n 27 above) 14

<sup>&</sup>lt;sup>115</sup> V. Barolsky (Over) Extended AIDS Review 2003 Centre for the Study of AIDS University of Pretoria 10



nurturance and care for children.<sup>116</sup> Consistent with their obligations under article 27 of the CRC, the Children's Committee has thus called on state parties to support and strengthen the capacity of families and communities of children orphaned by AIDS to provide them with a standard of living adequate for physical, mental, spiritual, moral, economic and social development, including access to psychosocial care, as needed.<sup>117</sup>

## 2.3 Psychosocial impact of HIV and AIDS

The psychosocial impact of HIV and AIDS is the dynamic relationship between the social and psychological experiences where the effects of one continually influences the other. For now, it is known that HIV and AIDS have the potential to affect healthcare and social security to the point of almost crippling them with the burden it inflicts. For example, a study made by the World Food Programme (WFP) in Lesotho found that extended families and households caring for OVC were found to have suffered from vulnerability and food insecurity compared to those without OVC. 120

<sup>&</sup>lt;sup>116</sup> Barolsky (n 110 above) 14

<sup>&</sup>lt;sup>117</sup> n 11 above para 33

<sup>&</sup>lt;sup>118</sup> Ndiaye (n 93 above) 65

<sup>119</sup> Kisoon et al (n 3 above) 9

<sup>&</sup>lt;sup>120</sup> World Food Programme *Response of community safety nets to the needs of OVC in Lesotho* (2007) World Food Programme: Lesotho



The devastation of the social structure in Lesotho from the AIDS epidemic has left a huge cohort of children increasingly vulnerable and alone, especially in rural Lesotho.<sup>121</sup> They lack essential psychosocial support and life skills training required to develop into responsible adults.<sup>122</sup> A recent study by the United Nations Development Programme (UNDP) indicated that the contribution of poverty and lack of support to health deprivations in Lesotho is 18.9%.<sup>123</sup> Therefore when using the term psychosocial, it is important to be clear about the meanings of psychosocial needs and psychosocial well-being.<sup>124</sup>

Psychosocial needs are the needs that all people have, especially young children, whose brains, bodies and social lives are developing. These include the need to be happy, creative, to belong in social groups, and to have hope for the future. 125 It is important that these needs are identified and addressed in a holistic manner because if these needs are not addressed, it can lead to psychological dysfunction in the child. When children face difficulties and deprivations, particularly when these are chronic or repetitive, they are especially in need of stability, affection and reassurance. 127

www.helplesotho.org (accessed 11 July 2013)

<sup>122</sup> As above

<sup>&</sup>lt;sup>123</sup> UNDP Human Development Report 2013 'The rise of the South: human progress in a diverse world

<sup>124</sup> Foster et al (n 27 above) 14

<sup>&</sup>lt;sup>125</sup> As above

<sup>&</sup>lt;sup>126</sup> Ndiaye ( n 93 above)63

<sup>127</sup> Foster et al (n 27 above) 14



Well-being is generally defined as the prevalence of positive attributes.<sup>128</sup> Thus aspects of psychosocial well-being include self acceptance, positive relations with others, autonomy, environmental mastery, purpose in life and personal growth.<sup>129</sup> It is determined by a combination of children's capacities and their social and material environment.<sup>130</sup> The emphasis on the best interests of the child therefore has a special significance in the context of HIV and AIDS issues for children.<sup>131</sup>

## 2.3.1 Levels of Impact

HIV and AIDS affect children at three fundamental levels. At an individual level, the causes of psychosocial problems are poor parenting, caring for both parents and other siblings, separation from brothers and sisters, chronic illness, death or sickness of a parent and loss of home. As a result of death or illness and moving between kin households to achieve the most optimum care arrangements for all concerned, children are frequently relocated. In Lesotho, extended families and households as well as traditional safety nets have attempted to absorb OVCs in the process of relocation but studies show that these safety nets are suffering significantly from vulnerability and food security.

<sup>&</sup>lt;sup>128</sup> nwia.idwellness.org (accessed 16 September 2013)

<sup>&</sup>lt;sup>129</sup> CD Ryff 'Happiness is everything, or is it? Explorations on the meaning of psychological wellbeing' (1989)57 *Journal of Personality and Social Psychology* 1069

<sup>130</sup> Foster et al (n 27 above) 14

<sup>131</sup> Kisoon et al (n 3 above) 49

<sup>&</sup>lt;sup>132</sup> Ndiaye (n 93 above) 66

<sup>&</sup>lt;sup>133</sup> Pharoah (n 104 above) 10

<sup>&</sup>lt;sup>134</sup> n 114 above



Caregivers change and siblings may be split up. Separation from siblings has not only been found to be a predictor of emotional distress in children and adolescents, but children become more vulnerable when they are cared for by people they are not used to having around, especially aged relatives due to the conditions of mutual dependency that often exists between extended families.<sup>135</sup>

However, the capacity of families to take in children affected by HIV and AIDS is severely limited by their already severely constrained economic conditions. The poorest families have absorbed the greatest force of impact by diversifying their livelihoods; including through migration to compensate for lost income and labour, by reducing consumption, that is, eating less and spending less on education and healthcare, all of which affects the immediate and long-term well-being of children. This impact is felt strongly by rural populations in Lesotho where a vast majority of the population is found to be affected by HIV and AIDS.

For this reason, children are shuffled between homes and orphanages as they grow up. Yet, care provided in institutional settings often fails to meet the developmental and long-term needs of children because children need more than good physical care. 139 Research has shown that institutions are costly to maintain, harmful to children and draw

<sup>&</sup>lt;sup>135</sup> Pharoah (n 104 above) 10

<sup>136</sup> Richter et al ( n 4 above) 6

<sup>137</sup> Richter et al ( n 4 above) 5

<sup>&</sup>lt;sup>138</sup> C Murray Families Divided: The impact of migrant labour in Lesotho (1981) 3

<sup>139</sup> Foster et al (n 27 above) 29



attention and resources away from efforts to support families, both families of origin and foster or adoptive families, to care for children.<sup>140</sup>

At family level, the causes of psychosocial problems occur through illness of multiple family members, poverty, stigma and discrimination, multiple losses, dysfunctional relationships defined by abuse, substance abuse and domestic violence, single parenting, child-headed households, elderly caregivers, chronic illness and death and bereavement.<sup>141</sup> It is at this level that school attendance of children whose household is affected by HIV and AIDS, drops off because their labour is required for subsistence activities.<sup>142</sup>

In the face of reduced income and increased expenditure, the money earmarked for school expenses is used for basic necessities such as medication and health services. Even when children are not withdrawn from school, education often begins to compete with many other duties that affected children have to assume. The inextricable link between HIV and AIDS and poverty no doubt amplifies the impact of HIV and AIDS on children and renders its effects on them unrelenting. Prevailing conditions of poverty such as lack of access to services, poor environmental conditions, inadequate material supplies, social instability and overworked and demoralised caregivers negatively

<sup>&</sup>lt;sup>140</sup> Foster et al (n 27 above) 27

<sup>&</sup>lt;sup>141</sup> Ndiaye (n 93 above) 66

<sup>&</sup>lt;sup>142</sup> Pharoah (n 104 above)11

<sup>&</sup>lt;sup>143</sup> As above

<sup>&</sup>lt;sup>144</sup> Pharoah (n 104 above) 11



affect children's social and psychological development directly and often simultaneously.<sup>145</sup>

Finally, at community level, children experience the psychosocial impact of HIV and AIDS through lack of knowledge of HIV, lack of knowledge of children's needs, worsening poverty, stigma and discrimination, overstretched communities due to increasing numbers of OVCs and peer influence. These effects thus breed poor communal adjustment in children through the impersonal, abusive and exploitative community care. Admittedly, communities would be supportive if there was sufficient access to essential services, support and assistance, social protection, economic participation and empowerment as well as enabling policies and institutions. 147

# 2.4 Effects of the psychosocial impact of HIV and AIDS on children

Because of the psychological and social impact that HIV and AIDS has on children as discussed in the preceding paragraphs, there are resultant effects that manifest in the lives of children as they develop. Effects of psychological problems are antisocial behaviour, failing to form relationships, failure to adhere to drugs, running to the streets and exposure to risky behaviours.<sup>148</sup> There is an established link between

<sup>145</sup> Foster et al (n 27 above) 8

<sup>&</sup>lt;sup>146</sup> Ndiaye (n 93 above) 66

<sup>&</sup>lt;sup>147</sup> Foster et al (n 27 above) 26

<sup>&</sup>lt;sup>148</sup> Ndiaye (n 93 above) 69



HIV and AIDS and mental health. Many children living with HIV have difficulty with abstract reasoning and anticipating the consequences of behaviour, including non-adherence to medication, risky sexual behaviour and substance use. This is supported by a study showing that provision of mental health services for HIV affected individuals resulted in decreased treatment costs and improved health outcomes among individuals with HIV. To

Social effects manifest in several ways including avoidance and rejection by peers, due to effects of wasting and skin lesions, social withdrawal and isolation and antisocial behaviour. The behavioural symptoms of psychosocial impact of HIV in children are restlessness, hyperactivity, withdrawal and self-neglect, aggressiveness, sleep disturbances, acting out, stealing, drug abuse and sexual promiscuity. It is therefore critical to examine the situation of children through an integrated lens that effectively looks at human security and children's rights through a holistic approach to treatment and care rather than artificially limiting the scope of work to survival oriented interventions for children affected by HIV and AIDS.

## 2.5 Conclusion

<sup>&</sup>lt;sup>149</sup> Ndiaye (n 93 above) 63

<sup>&</sup>lt;sup>150</sup> K Whetten et al *Improving health outcomes among individuals with HIV, mental illness and substance use disorders in the Southeast* (2006) 18 AIDS Care 18-26

<sup>&</sup>lt;sup>151</sup> Ndiaye (n 93 above) 79

<sup>152</sup> As above

<sup>&</sup>lt;sup>153</sup> Betencourt et al (n 105 above)



With millions of children made vulnerable by the epidemic, care and support to help them survive and stay safe is nowhere near adequate.<sup>154</sup> The time has come for a strong, well founded entry by governments to ensure national responses to protect the well-being of vulnerable children.<sup>155</sup> An acceptance by governments that the pandemic affects every aspect of the individual's life and therefore makes almost every right vulnerable, is more likely to enhance optimal integrated safeguards and support.<sup>156</sup> Because the danger in a response that is not unified and integrated is that it cannot guarantee the effective and efficient prevention of human rights violations and infringements in the context of HIV and AIDS.<sup>157</sup>

<sup>&</sup>lt;sup>154</sup> n 1 above.

<sup>155</sup> Foster et al (n 27 above)9

<sup>156</sup> Kisoon et al (n 3 above) 16

<sup>&</sup>lt;sup>157</sup> As above



## **Chapter 3**

# 3. The psychosocial impact of HIV and AIDS, the law and human rights

## 3.1 Introduction

The law alone cannot stop AIDS, nor can the law alone be blamed when HIV responses are inadequate. But the legal environment can play a powerful role in the well-being of people living with HIV and those vulnerable to HIV.<sup>158</sup> Good laws, fully resourced and rigorously enforced, can widen access to prevention and health care services, improve the quality of treatment, enhance social support for people affected by the epidemic and protect human rights that are vital to survival.<sup>159</sup>

The instrumental role of law in the AIDS pandemic is perhaps the most far reaching and proactive. It seeks more than just to regulate the relationship between individuals and between the affected and society in general. It seeks an additional acceptance that law can play an instrumental role in combating AIDS and involves a recognition and acceptance of the fact that law can help to change the underlying values and patterns of social interaction that creates vulnerability to HIV and AIDS.¹60 However, law ceases to be a pivotal tool in the fight against HIV

<sup>&</sup>lt;sup>158</sup>UNDP HIV and AIDS Group Report 'Global Commission on HIV and the law: risks, rights and health' July 2012 11

<sup>159</sup> As above

<sup>160</sup> Kisoon et al (n 3 above) 12



and AIDS if it is not understood. To understand the law, it is important to first understand the role of the law.

# 3.1.1. The role of law with respect to HIV and AIDS

Hamblin has argued that law can play three distinct roles in the approach to any issue: a proscriptive role; a protective role and an instrumental role.<sup>161</sup> In its proscriptive role, law is essentially concerned with proscribing certain forms of conduct and imposing sanctions as a consequence of non-compliance.<sup>162</sup> This was the primary role played by the law in the initial stages of the pandemic wherein AIDS sparked social panic and resulted in the enactment of harsh laws by states.

This approach was almost entirely premised on the idea that placing restrictions on people with HIV and AIDS or people thought to be especially at risk of HIV infection would prevent the spread of the virus. <sup>163</sup> For example, in 1986, Thailand had a law titled Announcement No. 11 which prohibited foreigners with HIV and AIDS from entering the country or becoming residence. More modern examples of where law has intervened in a proscriptive way are laws requiring compulsory HIV testing and compulsory disclosure in certain circumstances. <sup>164</sup>

 $<sup>^{161}</sup>$  J Hamblin 'The role of law in the HIV and AIDS policy' HIV and development programme UNDP Issue paper No 11

<sup>&</sup>lt;sup>162</sup> As above

<sup>163</sup> Hamblin (n 146 above)

<sup>&</sup>lt;sup>164</sup> Kisoon et al (n 3 above) 12. Currently, the Ugandan legislators on the parliamentary HIV/Aids committee are considering the HIV/Aids and Control Bill 2010, which is now in its final stages. Mandatory HIV testing is one of the clauses in the Bill. Other clauses in the bill include: disclosure of one's HIV status to third parties, discretion by medical personnel to disclose one's HIV status to one's sex partner, and the criminalization of intentional



In its protective role, law protects individuals and classes of individuals against adversity, harmful and undesirable occurrences they face as a result of their HIV status. These laws include those protecting against discrimination, invasions of privacy and respect for ones dignity. The instrumental role of the law is its ability to promote values and behavioural patterns that lead to reduced susceptibility to HIV infection. Although this is the most controversial model for legal intervention and also the most difficult to interpret and apply, this approach looks beyond the rights of the individuals to endeavour to change the underlying values and patterns of social interaction to reduce the risk of HIV to the most vulnerable. HIV to the

Having defined the role of the law in the fight, prevention and treatment of HIV and AIDS, it is now beyond dispute that the pandemic is no longer an issue that is squarely within the parameters of health nor a

and attempted transmission of HIV/Aids. Despite protests from HIV and AIDS activists in Uganda, the legislators on the parliamentary HIV/Aids committee have stuck to their guns, insisting that mandatory testing is for the benefit of all Ugandans and will allow the government of Uganda to plan better for persons living with the virus. <a href="https://www.newvision.co.ug">www.newvision.co.ug</a> (accessed 24 September 2013)

<sup>165</sup> For example, the Sexual Offences Act No. 3 2003 of Lesotho, sec 30 thereof, provides protection for women and girls from malicious HIV infection. The section provides for a mandatory testing in cases of rape to establish the status of the offender to determine the severity of the offence for purposes of sentencing. In addition, the Lesotho Labour Code (Amendment) Act No. 5 of 2006 prohibits discrimination in the workplace on the basis of one's HIV status. Other countries such as Botswana, have laws that prohibit discrimination against persons with AIDS and HIV testing as a requirement for employment such as the National Industrial Relations Code of Good Practice 2000; the Gambian Labour Act No. 5 of 2007 prohibits discrimination based on actual, perceived, or suspected HIV status; the Kenyan Employment Act No. 11 of 2007 prohibits discrimination based on HIV status; and Mozambique's Law No. 5/2002 deals with non-discrimination in the workplace against workers or candidates for employment who are HIV/AIDS carriers.

<sup>&</sup>lt;sup>166</sup> J Payne-James et al *Medicolegal essentials in healthcare* (2004) 212



bio-medical issue. A study of the provisions of the law is therefore imperative to determine its coverage of the human rights impact of HIV and AIDS on children, especially on their psychosocial well-being and development.

# 3.2 The psychosocial impact of HIV and AIDS and human rights laws

## 3.2.1 Human rights norms expanded

In a very ironic sense, HIV and AIDS are a sentinel of human rights.<sup>167</sup> It can be argued that the disease has managed to reach the proportion of a pandemic worldwide for the simple reason that human rights are being violated. The strength of a rights-based approach as a primary tool in the fight against HIV and AIDS lies in the recognition that all individuals have inherent rights by virtue of their humanity.

Beyond this recognition, there needs to be a process of locating the needs of those affected by HIV and AIDS in human rights that can be claimed and asserted. In the past, the human rights framework contained little reference to HIV and AIDS. The challenge for the international community, was, therefore, to identify relevant rights, shape their meaning for use in HIV and AIDS debates and set about conceptualising the manner in which these rights were to be implemented.<sup>168</sup> However, more recently there have been developments at international, regional

<sup>167</sup> Kisoon et al (n 3 above) 9

<sup>168</sup> Kisoon et al (n 3 above) 29



and domestic levels to develop a human rights legislative framework specifically for PLWHA.

# 3.2.2 Interpreting human rights norms in the context of HIV and AIDS: the global level

In international human rights law, there are three key documents which tend to be described collectively as the international bill of rights. Hey consist of the Universal Declaration of Human Rights (UDHR), the International Covenant on Civil and Political Rights (ICCPR) and CESCR. The UDHR provides a starting point in understanding the codification and development of international human rights. It has entrenched both civil and political rights, as well as social and economic rights. However, these rights were all expressed in the language of aspirations and ideals and rendered them legally unenforceable against states. Nonetheless, the UDHR had a ripple effect in the development of human rights over time.

There has been definite progress globally on articulating through the existing human rights documents, rights which are interpreted to apply with equal vigour to HIV and AIDS.<sup>170</sup> There is a general acceptance that these documents on their own, provide a basis for a right that can be asserted and an adequate remedy in the context of HIV and AIDS.

<sup>169</sup> Kisoon et al (n 3 above) 25

<sup>170</sup> Kisoon et al ( n 3 above) 34



Firstly, the primary right that gives birth to all other rights is the right to life. The ICCPR recognises the right to life as an inherent right that should be protected and not arbitrarily taken.<sup>171</sup> In its general comment on the right to life, the Human Rights Committee (HRC) noted that the right to life must not be interpreted narrowly. It contended that it creates positive obligations on states to protect life, especially through adopting measures, *inter alia*, to eliminate epidemics;<sup>172</sup> and HIV and AIDS are the most serious epidemics to plague the present generation.

Interpreting the right to life, the HRC has recommended that Namibia pursue efforts to protect the population from HIV and AIDS and adopt comprehensive measures encouraging greater numbers of persons suffering from HIV and AIDS to obtain adequate antiretroviral treatment and facilitate such treatment. It has also called for equal access to treatment in Kenya and for Uganda to allow greater number of persons suffering from HIV and AIDS to obtain adequate antiretroviral treatment. It has also called for equal access to treatment in Kenya and for Uganda to allow greater number of persons suffering from HIV and AIDS to obtain adequate antiretroviral treatment.

In addition to the international bill of rights, there are specialised treaties that deal with particular issues.<sup>175</sup> These include the ACRWC and the Protocol to the African Charter on Human and People's Rights

<sup>&</sup>lt;sup>171</sup> Art 6(1) thereof. Also art 4 of the ACHPR

<sup>&</sup>lt;sup>172</sup> General Comment 6 on the Right to Life (1994) para 5

<sup>&</sup>lt;sup>173</sup> www.equalpartners.info (accessed 24 August 2013)

<sup>&</sup>lt;sup>174</sup> As above

<sup>175</sup> Kisoon et al (n 3 above) 26



on the Rights of Women in Africa (Women's Protocol).<sup>176</sup> The Women's Protocol bears particular importance in the context of HIV in Africa because of the high susceptibility of women and girls to HIV infection. Article 14 (1) (d) and (e) addresses the issue of HIV by providing for self-protection and protection against sexually transmitted infections, including HIV and AIDS as well the right to be informed of one's health status and on the health status of one's partner, particularly if affected with sexually transmitted infections, including HIV/AIDS, in accordance with internationally recognised standards and best practices. Expanding on this provision, the African Commission has noted that in Sub-Saharan Africa, young women aged 15 to 24 years are as much as eight times more likely than men to be living with HIV.<sup>177</sup> As a result, the Commission has explicitly recognised that women in Africa have a right to the highest attainable standard of health which includes sexual and reproductive health and rights.<sup>178</sup>

In the light of the fact that women and children are among two of the groups of people whose position and treatment in society makes them most vulnerable to HIV and AIDS, the covenants of particular relevance to HIV and AIDS at international level are the CRC and the CEDAW. A particular issue that is covered by both conventions is the right to health, which is central to the HIV and AIDS pandemic. But HIV and AIDS impacts so heavily on the lives of all children that it affects all their rights

 $<sup>^{176}\,\</sup>mbox{Adopted}$  in July 2003 and came into force in November 2005

<sup>&</sup>lt;sup>177</sup> General Comment on Article 14 (1) (d) and (e) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa 2012 para 3. See also n 11 above para 2.

<sup>&</sup>lt;sup>178</sup> As above para 5. See also art 27 of the SADC Protocol on Gender and Development 2008



– civil, political, economic, social and cultural.<sup>179</sup> The right to access to health and the right to health are broadly stated rights embodied in different international and regional documents, which impose duties on states to promote, fulfil and enforce basic standards of health.<sup>180</sup>

With HIV and AIDS becoming a global health problem, it brought change in thinking about health and human rights. There was a fundamental paradigm shift and the recognition that health was more than just the absence of disease and infirmity; it was a state of complete physical, mental and social well-being.<sup>181</sup> The Children's Committee interprets children's right to health, as defined in article 24 of the CRC, as an inclusive right extending not only to timely and appropriate prevention, health promotion, curative, rehabilitative and palliative services, but also a right to grow and develop to their full potential, and live in conditions that enable them to attain the highest standard of health by implementing programmes that address the underlying determinants of health.<sup>182</sup> With this interpretation, the Children's Committee admittedly noted that not only is children's right to health important in and of itself, but also the realisation of the right to health is indispensable for the enjoyment of all the other rights in the CRC.<sup>183</sup>

<sup>&</sup>lt;sup>179</sup> n 11 above para 5

<sup>180</sup> Kisoon et al (n 3 above) 55

<sup>&</sup>lt;sup>181</sup> Preamble to the Constitution of the World Health Organisation, adopted 19 June – 22 July 1946, New York

<sup>&</sup>lt;sup>182</sup> n 91 above para 2

<sup>&</sup>lt;sup>183</sup> n 91 above, para 7



The Economic and Social Council (ECOSOC) noted that the right to health is not to be understood as a right to be healthy.<sup>184</sup> This right imposes both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation.<sup>185</sup> By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.<sup>186</sup>

The right to health is guaranteed in various international instruments. These include the UDHR,<sup>187</sup> CESCR<sup>188</sup>, CRC,<sup>189</sup> CEDAW<sup>190</sup> and CERD.<sup>191</sup> Similarly, the right to health has been proclaimed by the Commission on Human Rights,<sup>192</sup> as well as in the Vienna Declaration and Programme of Action of 1993.

As noted earlier, the right to health is closely related to and dependent upon the realization of other human rights including the right to food,

<sup>&</sup>lt;sup>184</sup> n 17 above para 8

<sup>&</sup>lt;sup>185</sup> As above. Also para 24 of General Comment 15 (n 91 above).

<sup>&</sup>lt;sup>186</sup> n 17 above para 8

<sup>&</sup>lt;sup>187</sup> Art 25 (1)

<sup>&</sup>lt;sup>188</sup> Art 12

<sup>&</sup>lt;sup>189</sup> Art 24

<sup>&</sup>lt;sup>190</sup> Art 11 (f) and 12

<sup>&</sup>lt;sup>191</sup> Art 5 (e) (iv)

<sup>&</sup>lt;sup>192</sup> In its Resolution 1989/11



housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement.<sup>193</sup> These and other rights are integral components of the right to health. For people to be able to enjoy all these rights, they have to be in a state of good mental and physical health. Therefore Lesotho, as a state that has signed and ratified all the above mentioned international instruments<sup>194</sup>, has an obligation and a duty to ensure that the right to health is ensured in the lives of ordinary Basotho men and women.

These rights have to be realised through the eradication of stigma, discrimination and poverty in particular because poverty makes the right to health a distant goal and this is becoming increasingly rampant in Lesotho as indicated by the 2013 Human Development Index. Poverty has particular implications in the prevention and treatment of HIV and AIDS. These include inadequate access to nutritious food affecting medication adherence due to side effects, inadequate access to water, sanitation and housing as well as the psychological burden it inflicts. By addressing this social enigma, the psychosocial impact of HIV and AIDS as a result of poverty in Lesotho would be curbed.

The CRC deserves particular mention because it addresses issues pertaining to children and their development. The CRC is a result of the

<sup>&</sup>lt;sup>193</sup> n 17 above para 3

 $<sup>^{194}</sup>$  Lesotho ratified the CESCR on 09/09/1992, the ICRC on 10/03/1992, CEDAW on 22/08/1995 and CERD on 04/11/1971

<sup>&</sup>lt;sup>195</sup> n 117 above



global acknowledgement of the need to specifically protect and promote the rights of the child. The provisions of the Convention were not created at the time when HIV and AIDS were considered a threat to humanity, although, many of them can now be interpreted to include an implicit protection of the rights impacted by the pandemic. The CRC compels states to make an effort to realise the goals set out in the Convention and because of the importance of the rights contained in the Convention, they have acquired the force of international customary law and as such are considered binding on state parties.

The notion of the highest attainable standard of health as provided by the CRC as well takes into account both the individual's biological and socio-economic preconditions. Thus, genetic factors, individual susceptibility to ill health and the adoption of unhealthy or risky lifestyles may play an important role with respect to an individual's health.<sup>197</sup> Consequently, the right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health.<sup>198</sup>

Undeniably, the psychosocial aspect of human development determines a person's well being therefore its tenable to conclude that the right to

<sup>196</sup> Kisoon et al (n 3 above) 48

<sup>&</sup>lt;sup>197</sup> n 17 above para 9

<sup>&</sup>lt;sup>198</sup> As above. The Children's Committee has called on states to take all possible measures to ensure that children have uninterrupted access to health services, and to protect them not only with physical support such as food and clean water but also to encourage special parental or other psycho-social care to prevent or address fear and traumas (n 91 above para 40)



health encapsulates a persons' psychosocial being. Indeed, it has been argued that treatment of HIV and AIDS should be understood in a holistic manner and should ideally combine integrated support and care and therefore include nutrition, emotional and psychological care.<sup>199</sup>

With time, the international response to the HIV and AIDS pandemic has grown more sophisticated in its recognition of the range of issues that need to be addressed<sup>200</sup> with respect to HIV and AIDS. In 1996, the Office of the High Commissioner for Human Rights (OHCHR) in collaboration with the Joint United Nations Programme on HIV and AIDS published the International Guidelines.<sup>201</sup> This was an initiative at an international level to conceptualise an integrated, holistic and coordinated approach to HIV and AIDS. The guidelines were produced primarily to assist states in creating a positive; rights based response to HIV and AIDS and are consistent with human rights and fundamental freedoms.<sup>202</sup>

The Guidelines contend that the content of the right to health has been increasingly defined and now explicitly includes the availability and accessibility of HIV prevention, treatment, care and support for children and adults.<sup>203</sup> The recommendations contained in the Guidelines are already in accordance with the commitments that states have already

<sup>199</sup> Kisoon et al (n 3 above) 54

<sup>&</sup>lt;sup>200</sup> Kisoon et al (n 3 above) 30

<sup>&</sup>lt;sup>201</sup> International Guidelines on HIV/AIDS and Human Rights 2006 Consolidated Version.

<sup>&</sup>lt;sup>202</sup> Kisoon et al (n 3 above) 30

<sup>&</sup>lt;sup>203</sup> n 181 above 6



made under individual human rights instruments to promote, protect and respect civil and political rights, as well as social, economic and cultural rights. Therefore by incorporating the rights contained in the Covenants, the Guidelines revitalise the ICCPR and CESCR for application in the context of HIV and AIDS.<sup>204</sup>

The 2001 UN General Assembly Special Session Declaration of Commitment on HIV and AIDS also marked the beginning of significant change in the scope of the HIV and AIDS response.<sup>205</sup> This declaration was followed by a substantial increase in political commitment, social mobilisation and financial resources, witnessed in 2003 by the launch of the WHO's 3 by 5 initiative<sup>206</sup> and the announcement of the US President Emergency Plan for AIDS Relief (PEPFAR).<sup>207</sup> International mobilization to combat HIV and AIDS grew further with the establishment of the Millennium Development Goals (MDGs) in 2000. MDG 6 sets a goal for governments to halt and reverse the spread of HIV and AIDS as a primary target. Goal 6 therefore places a particular responsibility on the government of Lesotho to take into account all the factors that begets the spread of HIV and AIDS such as the psychosocial implications of the pandemic in order to reverse the spread.

# 3.2.3 Regional level

<sup>&</sup>lt;sup>204</sup> As above

<sup>&</sup>lt;sup>205</sup> MD Vitoria et al 'The global fight against HIV/AIDS, Tuberculosis and Malaria' (2009) 131 American Society for Clinical Pathology 844

<sup>&</sup>lt;sup>206</sup> WHO Treating 3 million by 2005: making it happen: the WHO strategy Geneva, Switzerland, WHO 2003

<sup>&</sup>lt;sup>207</sup> Vitoria et al (n 185 above) 844-845



As part of the international human rights landscape, there are also regional instruments that have provisions on HIV and AIDS and have also been interpreted in the context of HIV and AIDS. The most relevant instruments for our purpose are the ACHPR, the ACRWC and the African Youth Charter.<sup>208</sup>

#### a) ACHPR

The ACHPR is considered a key document regarding human rights in Africa. The ACHPR includes many of the general rights also contained in the International Bill of Rights such as the rights to equality, dignity and respect for life. However, it also includes specific rights such as the right to the enjoyment of the best attainable state of physical and mental health and the obligation placed on states to take the necessary measures to protect the health of their people and ensure that they receive the required medical attention.<sup>209</sup>

In *Purohit and Moore v The Gambia*,<sup>210</sup> the African Commission expounded on the right health as articulated in the ACHPR. In this case, the applicants alleged, amongst other things, that the legislative regime in Gambia for mental patients violated the right to enjoy the best attainable state of physical and mental health and the right of the disabled to special measures of protection in keeping with their physical and moral needs. Holding that The Gambia fell short of satisfying the

<sup>&</sup>lt;sup>208</sup> Adopted in July 2006 and entered into force in August 2009

<sup>&</sup>lt;sup>209</sup> Art 16 thereof

<sup>&</sup>lt;sup>210</sup> (2003) AHRLR 96 (ACHPR 2003)



requirement of article 16 and 18(4) of the African Charter, the Commission stated that the enjoyment of the right to health is crucial to the realisation of other fundamental rights and freedoms and includes the right of all to health facilities, as well as access to goods and services, without discrimination of any kind.

The Children's Committee has resonated with the sentiments of the African Commission by contending that special attention must be given to certain categories of people, especially children and adolescents with psychosocial disabilities.<sup>211</sup> Moreover, the Charter has unique features when contrasted with the two covenants in that it contains both civil and political rights, as well economic, social and cultural rights in a single charter. From the view of the Charter, both categories of rights are subject to the same mechanisms for enforcement and justifiability. Thus this framework offers huge potential to the continent in the fight against HIV and AIDS.<sup>212</sup>

## b) ACRWC

In 1990, African leaders responding to the need for a region specific instrument protecting the rights and welfare of children in the continent adopted the ACRWC.<sup>213</sup> The Charter is explicit about the duty of states to protect and advance children's basic rights to well being and health, privacy and education, nutrition and the requisite rights ensuring that

<sup>&</sup>lt;sup>211</sup> n 91 above para 15

<sup>&</sup>lt;sup>212</sup> Kisoon et al (n 3 above) 26-27

<sup>&</sup>lt;sup>213</sup> Kisoon et al (n 3 above) 49



the best interests of the child prevail.<sup>214</sup> It also contains provisions embodied in the CRC and other international instruments relating to the rights of the child and thus creates responsibility for states to implement the provisions into their domestic legal framework.

The emphasis on the best interest of the child has special significance in the context of HIV and AIDS issues for children in Africa. This notion has to be understood with the acceptance that children hold inherent fundamental rights and through this acceptance, the commitment of key actors to protect, enforce and advance the rights of children both internationally and regionally can be brought into question.

Undoubtedly, the aftermath of colonialism in most African countries has resulted among other things, in an emphasis on civil and political rights at the expense of socio-economic rights. The reality of this is that the real underlying causes and propellants of HIV and AIDS are increasingly being viewed as socio-economic issues and are seldom dealt with adequately or in a consistent fashion. These social and economic factors which contribute to HIV infection are vast and often have the effect of inflicting fear, extreme and at times irrational emotion, panic and even denial which have the combined effect of almost paralysing a society's ability to take action until it is too late. 216

<sup>&</sup>lt;sup>214</sup> As above

<sup>&</sup>lt;sup>215</sup> Kisoon et al (n 3 above) 21

<sup>&</sup>lt;sup>216</sup> Kisoon et al (n 3 above) 13



Admittedly, the reach of international and regional agreements is limited in Africa as evidenced by the catastrophic impact of HIV and AIDS on the most disempowered and vulnerable groups in societies. For example, the 2009 Health and Demographic Survey of Lesotho indicated that rural populations had significantly less knowledge about HIV and AIDS, nutrition and family planning. The study further showed that out of 200 grandmothers participating in the survey, 95% of them did not know what HIV and AIDS were, although most of them had lost their children to the disease. At the time, the CESCR, the CRC, the ACRWC and the ACHPR provided for access to information and education.<sup>217</sup>

Moreover, AIDS orphans in Lesotho accounted for 65% of all orphans in the country<sup>218</sup> and this resulted in unique social effects for these children including an inability to pursue their education, stigma, discrimination and psychological trauma due to the abrupt change in their lives. It then becomes critical to any effective response to HIV and AIDS through the impetus of human rights law, that human rights be firmly entrenched within domestic frameworks, where the potential for implementation and protection of the most vulnerable in society is greatest.

## c) African Youth Charter<sup>219</sup>

Africa holds the largest population of the world's young people.<sup>220</sup> However, the passage from childhood to adulthood in Africa is often

<sup>&</sup>lt;sup>217</sup> Art 13 of the CESCR; arts 13, 17, 19, 28 & 29 of the CRC; art 11 of the ACRWC & arts 9, 17 & 25 of the ACHPR

<sup>&</sup>lt;sup>218</sup> Children orphaned by HIV and AIDS www.avert.org (accessed 28 August 2013)

<sup>&</sup>lt;sup>219</sup> Lesotho signed the Charter on 18/05/2010 and ratified on 31/05/2010



fraught with dangers. Poverty, unemployment, violence, sexual coercion and exploitation, substance abuse, crime and other risky behaviours pose major challenges to youth throughout the region.<sup>221</sup> These desperate circumstances render the youth vulnerable to conditions that place them at risk of HIV infection such as early child bearing, unintended pregnancies, unsafe abortions and early sexual debuts.

In view of the above-mentioned situation, the African Union adopted the African Youth Charter. This instrument deals with various issues pertaining to youth within the region. Of particular importance is article 16 which provides for the best attainable state of physical, mental and spiritual health of all youths. It further prescribes ways in which state parties are to pursue the full implementation of this rights with specific reference to HIV and AIDS as well.<sup>222</sup>

Reference to HIV and AIDS is pivotal because young people, who represent 33 % of the African population, have great potential in the battle against HIV and AIDS.<sup>223</sup> This acknowledgment is particularly important in light of newly available evidence suggesting that changing the sexual behaviour of youth through appropriate social influences is critical to tackling the pandemic.<sup>224</sup> This acknowledgment is also very

<sup>&</sup>lt;sup>220</sup> Africa regional consultation with youth on HIV/AIDS and sexual reproductive health <u>www.siteresources.worldbank.org</u> (accessed 1 October 2013)

<sup>&</sup>lt;sup>221</sup> As above

<sup>&</sup>lt;sup>222</sup> Art 16(1) & 2(d), (e), (g) & (h)

<sup>&</sup>lt;sup>223</sup> n 219 above

<sup>&</sup>lt;sup>224</sup> As above



crucial in Lesotho because some HIV infection in children has been attributed to early sexual debuts and some of these acts are forced and the majority of them are unprotected.<sup>225</sup>

## 3.2.4 National level

Since the adoption and promotion of the International Guidelines as a standard measure for national and international responses to the pandemic, Lesotho has adopted a national AIDS strategic plan and national policies to provide a framework for a national response to the HIV and AIDS pandemic. HIV and AIDS have been spreading at phenomenal rates in Lesotho since the first AIDS case was reported in 1986.<sup>226</sup> Today, Lesotho is among the worst affected Southern African countries. Worried by this development, the Lesotho government announced in 2000 its anti-HIV and AIDS policy and the strategies for implementing it.<sup>227</sup>

The key elements of the plan were the commitment of all stakeholders; accountability to the nation and transparency at all levels; effective communication among all sectors; empowerment and involvement of all stakeholders; sensitivity to culture; networking and exchange of

<sup>&</sup>lt;sup>225</sup> Lesotho HIV prevention response and modes of transmission analysis Lesotho National AIDS Commission Epidemiological Review 2009

<sup>&</sup>lt;sup>226</sup> FK Makoa 'Aids policy in Lesotho: implementation challenges' (2004) 1 African Security Review 13

<sup>&</sup>lt;sup>227</sup> Government of Lesotho National AIDS Strategic Plan (NSP) 2000/2001-2003/2004: A rolling plan for the national response to the HIV and AIDS epidemic in Lesotho



experiences.<sup>228</sup> However, the strategic plan was fraught with some inadequacies as it did not fully address the needs of HIV and AIDS sufferers, even though they were supposedly among the targeted beneficiaries.<sup>229</sup>

Thereafter, there was the 2006-2011 NSP which was further revised in 2009. The NSP was developed through an extensive participatory process and was meant to provide a coordinated and strategic approach to HIV and AIDS response. It had the aim of halting the epidemic and providing comprehensive care and support to those affected by the disease. It was also influenced by a number of national and international factors related to HIV and AIDS responses.<sup>230</sup>

The NSP has three primary aims: to stop the epidemic from growing by reducing the incidence rates to below 2% threshold; to provide comprehensive treatment, care and support to PLWHA and those with the co-infection of TB; and to mitigate the socio-economic impact of the epidemic on society and in particular, OVC, PLWHA and vulnerable households. From the above stated goals, it can be deduced that the overall goal of the NSP is to prevent the spread of HIV and to mitigate the impact of AIDS in Lesotho. This objective does cover all aspects of the potential impact that HIV and AIDS has in Lesotho, including the stated psychosocial impact of the pandemic as such it can be inferred

N Zungu-Dirwayi et al 'An audit of HIV and AIDS policies in Botswana, Lesotho, Mozambique, South Africa, Swaziland and Zimbabwe' Social aspects of HIV and AIDS and health research programme Research Monograph 2004 24

<sup>&</sup>lt;sup>229</sup> Makoa (n 198 above) 5

<sup>&</sup>lt;sup>230</sup> Section 2, para 21 of the NSP



that there is legislative and policy basis in Lesotho for addressing the psychosocial impact of HIV and AIDS for vulnerable people especially children.

There have also been a number of AIDS specific consultations in Africa in which Lesotho has participated. To mention but a few, in 1993, the Organisation of African Unity (OAU) Summit in Cairo, Egypt confirmed the resolution on the AIDS epidemic in Africa and formally adopted the Guidelines for Action in order to implement the Programme for Action against AIDS in Africa.<sup>231</sup> In the same year, the OAU adopted the Tunis Declaration on AIDS and the child in Africa, wherein it recognised the nature and extent of the epidemic amongst children as well as the impact it has on children and their development.<sup>232</sup> A few years later, Lesotho and other African heads of state meet for the African summit on HIV and AIDS where state parties undertook to mobilize all the human, material and financial resources required to provide care and support and quality treatment to their populations affected by HIV and AIDS.<sup>233</sup>

In 2001, Lesotho further participated in the Declaration of Commitment on HIV and AIDS<sup>234</sup> wherein leaders at national level, were expected to fully promote and protect all human rights and fundamental freedoms. These included the right to the highest attainable standard of physical

<sup>231</sup> Kisoon et al (n 3 above)33

<sup>&</sup>lt;sup>232</sup> As above

<sup>&</sup>lt;sup>233</sup> African Summit on HIV/AIDS, Tuberculosis and other Related Infectious Diseases Abuja, Nigeria 24-27 April 2001

<sup>&</sup>lt;sup>234</sup> Declaration of Commitment on HIV and AIDS UNGA Special Session on HIV and AIDS 25-27 June 2001



and mental health; to address risk, vulnerability, prevention, care, treatment and support; reduction of the impact of the epidemic and to strengthen health, education and legal system capacity.<sup>235</sup> In addition, the Government of Lesotho has adopted a number of measures to address the HIV and AIDS crisis in general and its impact especially on OVCs. These include, in the main, the UN General Assembly Special Session on Children<sup>236</sup> and the Declaration of Commitment on HIV and AIDS.<sup>237</sup>

Although Lesotho does not have a specific national law enacted dealing with HIV and AIDS,<sup>238</sup> the 2003 SADC Declaration on the fight against HIV and AIDS in the SADC region was notably concluded in Maseru, the capital city of Lesotho. The Declaration recognises that upholding human rights and fundamental freedoms for all is a necessary element in the region's response to HIV and AIDS, which would encompass access to education, healthcare, social and health services, prevention, support, treatment and legal protection.<sup>239</sup> Thus states declared to evaluate the economic and social impact of the HIV and AIDS epidemic and to

<sup>&</sup>lt;sup>235</sup> As above para 37

<sup>&</sup>lt;sup>236</sup> 2002

<sup>&</sup>lt;sup>237</sup> UN General Assembly Special Session on HIV and AIDS 25-27 June 2001

The only laws in Lesotho that make mention of HIV and AIDS is the Labour Code (Amendment) Act of 2006 which provides for HIV/AIDS management in the work place. It stipulates the standards to be observed by the employers and workers which are aimed at preventing discrimination on the basis of HIV/AIDS status in the workplaces and mitigating the repercussion of the epidemic in the labour market. To ensure the smooth implementation of the provisions of this Act, enabling guidelines were developed and published. Moreover, the 2003 Sexual offences Act provides specific protection to women and girls from malicious HIV infection. The Act provides for mandatory HIV testing in cases of rape to establish the status of the offender, to determine the severity of the offence for purposes of sentencing.

<sup>&</sup>lt;sup>239</sup> Para (c) of the Recognitions



develop multi-sectoral strategies to address the impact at individual, family, community, national and regional levels.<sup>240</sup>

Although the Constitution of Lesotho<sup>241</sup> places the protection of children and youth as well as the protection of health under principles of state policy<sup>242</sup>, which are rights rendered unenforceable before the law within Lesotho, the right to life, provided for under protection of fundamental human rights and freedoms, has been sufficiently interpreted in the context of HIV and AIDS and Lesotho as state party to most of the international human rights instruments discussed above, is obliged to take all measure and steps to ensure that the adverse impact of HIV and AIDS on child development is halted and reversed in Lesotho, particularly the psychosocial impact.

## 3.3 Conclusion

There are a number of NGOs and faith-based organisation that have been making considerable strides to help those affected by HIV such as Help Lesotho. It endeavours to provide as much listening, caring and psychosocial support to all its beneficiaries to deal with grief and loss, fear and stigmatisation around HIV and AIDS, poverty-related issues, sexual violence and isolation. However, there have been tremendous challenges. These service providers provide a limited scope of activities such as access to medical care through fee waivers, provision of food and

<sup>&</sup>lt;sup>240</sup> Para 3 (e) of the Declarations

<sup>&</sup>lt;sup>241</sup> 1993

<sup>&</sup>lt;sup>242</sup> Secs 27 & 32 thereof



formula to orphaned infants and children, bursaries for secondary school students and in some cases, clothing and blankets.<sup>243</sup>

However, the discussions in the preceding chapters have shown that the impact of HIV and AIDS goes far beyond medical and financial implications. It has psychological and social implications which when not dealt with sufficiently amongst vulnerable persons such as children, can have the effect of not only tearing the social fabric of our communities, but can result in adults that are not fully developed to being effective members of their communities.

With all the laws and policies in place that can enable an effective response to HIV and AIDS in Lesotho, there are challenges at national level to implement a holistic response to the pandemic. This challenges are compounded by government bureaucracy; poor organisation of agencies and lack of support at decision-making levels of government for the multi-sectoral approach; institutional rivalry and duplication of efforts among the various NGOs and other implementing agencies.<sup>244</sup> However, the devastating impact of the pandemic is uncompromisingly testing the commitment of our leaders by attacking future electorate and the economy of the country. The true test of this commitment can realistically be measured by sound, expeditious implementation and realisation of the provisions of international and national human rights instruments into domestic frameworks.<sup>245</sup>

<sup>&</sup>lt;sup>243</sup> Tamasane (n 7 above) 23

<sup>&</sup>lt;sup>244</sup> Zungu-Dirwayi et al (n 199 above)

<sup>&</sup>lt;sup>245</sup> Kisoon et al (n 3 above) 49



# **Chapter 4**

### 4. Conclusions and Recommendations

### 4.1 Conclusions

For a long time, increasing attention has been given to children living with HIV and AIDS and those affected by the disease through healthcare provision and additional resources for their care and treatment. But a narrow approach, focused only on drug provision to those children that have been diagnosed with HIV and AIDS runs the risk of overlooking the health and psychosocial needs of large numbers of other vulnerable children living in communities affected by the pandemic.<sup>246</sup> Therefore psychosocial care, support and rehabilitation programmes evolved to counter programming that addressed only material or physical needs without taking into account the social, psychological and spiritual aspects of children's lives.<sup>247</sup>

This study undertook to examine the psychosocial impact of HIV and AIDS on child development in Lesotho. Chapter one was an introductory chapter which posed questions on the psychosocial impact of HIV and AIDS on children's development in Lesotho and how it can be addressed. Chapter 2 highlighted the concept of child development and the impact of HIV and AIDS on this process. It further noted different kinds of impact on the said development and how they manifest. The conclusion drawn in chapter 2 is that indeed HIV and AIDS has a devastating

<sup>&</sup>lt;sup>246</sup> Foster et al (n 27 above)22

Foster et al (n 27 above) 20



impact on the development of children in Lesotho and is a threat to their well-being because children are undeniably the future generation that has to be protected in order to add value to their societies and this they can only achieve if they are physically, mentally and socially fit.

Chapter 3 was an analysis of the laws in place at international, regional and national level to determine whether the law provided a basis for dealing with the psychosocial impact of the HIV and AIDS pandemic in a human rights context. The conclusion drawn from an analysis of the law at these three levels is that even though much of the laws and policies at international, regional and national level were enacted at a time when HIV and AIDS was not a threat to the world in large, provisions of law embodied in such laws are sufficient to warrant an interpretation that is inclusive of addressing the HIV and AIDS pandemic.

Indeed, some international bodies such as the HRC have interpreted fundamental rights such as the right to life to include a right to be free from the plague of HIV and AIDS and its devastating impact. However, despite these plethora of legal support and basis recognising the psychosocial aspect as an integral part of human development and the potential risk that HIV and AIDS, there is still a reluctance by governments to admit that the pandemic affects every aspect of the individuals life and therefore makes almost every right vulnerable. Even though the government of Lesotho has been making considerable strides in reversing and halting the spread of HIV and AIDS in Lesotho, most of these responses have been resource focused and provision of healthcare that addresses the medical aspect of the pandemic predominantly.



### 4.2 Recommendations

In light of the above conclusions drawn, the following recommendations are made:

1. The African conception of human rights, as reflected in the ACHPR is integrally linked with group rights. It recognises the centrality of the family and the community, as opposed to the individual. Therefore it is recommended that the government of Lesotho addresses the psychosocial impact of HIV and AIDS by strengthening the capacity of families to support children affected by HIV and AIDS.

In Lesotho, extended families and the elderly, have been carrying the heaviest load in treating, caring for and protecting children and other members directly affected by the epidemic. AIDS is best thought as a family disease therefore it is important for the government to take measures, such as provision of social grants and policies protecting the family, in order to effectively address the psychosocial impact HIV and AIDS in children. Protection of the family environment is very crucial because the best form of care for children is within their families and communities.<sup>248</sup> Children should remain in a stable environment with a familiar daily pattern and known cultural context because reliability and predictability

 $<sup>^{248}</sup>$  Psychosocial support for orphans and other children made vulnerable by HIV and AIDS: a conceptual framework UNICEF & REPSSI 14



builds trust for them.<sup>249</sup> This recommendation is supported by various provisions of the law.<sup>250</sup>

- 2. It has been indicated in the discussions in chapter 3 that even though there are NGOs and other organisations that have taken up the issue of the psychosocial well-being of children and their development in the wake of HIV and AIDS, the government has a crucial role to play, particularly in providing legislative protection in the areas of education, health and social services that meet the needs of vulnerable children. Furthermore, by developing policies that promote children's physical and psychosocial well-being, capacity and stability of their families
- 3. The national HIV and AIDS programmes and policies, such as the NSP, must take into account the needs of children and their families and address their areas of need in order to reduce the strain that families have encountered in the wake of the HIV and AIDS pandemic where parents die and often leave OVCs on already poverty stricken families.

<sup>&</sup>lt;sup>249</sup> As above

 $<sup>^{250}</sup>$  Sec 11 (1) of the Constitution of Lesotho; art 18 of the ACHPR; arts 23 & 24 of the ICCPR; arts 18 & 25 of the ACRWC & art 20 of the CRC



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