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# The right to health care in the specific context of access to HIV/AIDS medicines: What can South Africa and Uganda learn from each other?

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# Summary

Unlike many other African countries, which either exclude socio-economic rights from their constitutions or include them in the Preamble or the section on Directive Principles of State Policy, the South African Constitution is well known for its inclusion of this category of rights in its Bill of Rights. For example, while the right to health care services is specifically provided for in the South African Constitution, the Ugandan Constitution merely requires the state to 'take all practical measures to ensure the provision of basic medical services to the population'. In the specific context of access to HIV/AIDS medicines, it is interesting to note that, in spite of the disparity in the measure to which the right to health care is constitutionally protected, Uganda is renowned for having taken the lead in the roll-out of anti-retroviral treatment. South Africa has been widely criticised for its initial disastrous approach towards HIV/AIDS treatment, an approach that led to the loss of millions of lives that could have been saved

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with the early roll-out of anti-retroviral treatment. The article looks at the different approaches adopted by the two countries in terms of access to HIV/AIDS medicines and the implications for the right to health care. Apart from identifying the lessons Uganda and South Africa can learn from each other, the article explores the important question of accountability for the violation of the right to health care occasioned by inadequate access to HIV/AIDS medicines.

## 1 Introduction

Although the first cases of AIDS were recorded in Uganda and South Africa around the same time (1982), the early spread of the disease was much more rapid and severe in Uganda than in South Africa. By 1987, Uganda was the epicentre of the disease with prevalence rates of up to 29 per cent in urban areas. South Africa, on the other hand, had a lower initial rate of infection, with prevalence rates among pregnant women at 12,2 per cent in 1996, but rising to 24,8 per cent in 2001 and 30,2 per cent in 2005. By that time, HIV prevalence in Uganda had fallen dramatically from an estimated 30 per cent among pregnant women in 1991 to around 5 per cent in 2001.

Today, while South Africa is seen as one of the countries most severely affected by HIV/AIDS, Uganda is held up as a model in the fight against the epidemic. According to the 2008 UNAIDS Report on the Global AIDS Epidemic, an estimated 5,7 million South Africans are living with HIV, making it the largest HIV epidemic in the world.<sup>4</sup> The prevalence of HIV/AIDS in the adult population is about 18,8 per cent.<sup>5</sup> In Uganda, on the other hand, adult HIV prevalence has stabilised at 5,4 per cent, representing less than one million Ugandans.<sup>6</sup>

Although there are fears of a possible resurgence of the AIDS epidemic, there are a number of reasons why Uganda is hailed as a rare success story in spite of being one of the first countries on the African continent to experience the devastating impact of the disease. These reasons revolve around strong government leadership which, at the time, showed high-level political commitment to HIV prevention and care. This was coupled with broad-based partnerships and extensive

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See 'HIV and AIDS in Uganda' http://www.avert.org/aidsuganda.htm (accessed 14 July 2009).

See 'HIV and AIDS in South Africa' http://www.avert.org/aidssouthafrica.htm (accessed 14 July 2009).

As above.

See UNAIDS 2008 Report on the Global Aids Epidemic http://www.unaids.org/en/ KnowledgeCentre/HIVData/GlobalReport/2008/2008\_Global\_report.asp (accessed 14 July 2009).

As above.

<sup>6</sup> As above.

public education campaigns involving all sectors of society. On the other hand, a number of factors have been blamed for the severity and devastation of the HIV/AIDS epidemic in South Africa; a situation, many argue, that could have been avoided or at least minimised. Although some have argued that the severity of the AIDS epidemic in South Africa has its genesis in the pre-1994 apartheid policies and the subsequent major political changes which distracted the country from the disease, it is widely acknowledged that government's failure to act promptly and decisively was largely responsible for the HIV/AIDS devastation seen in the country at the turn of the century.8 The government's attitude was reflected in the extremely unorthodox views held by the then President Thabo Mbeki and his Minister of Health, Manto Tshabalala-Msimang, who in 2006 led the United Nations (UN) Special Envoy for HIV/AIDS in Africa to refer to South Africa as 'the only country in Africa whose government continues to propound theories more worthy of a lunatic fringe than of a concerned and compassionate state'. The current state of the HIV/AIDS epidemic in both Uganda and South Africa will be discussed in more detail below. Suffice here to say that HIV medicines, also known as anti-retroviral drugs (ARVs), have played a significant role in the varying trends and impacts of the disease as experienced by the two countries.

The introduction of life-saving ARVs in 1996 gave people living with HIV worldwide new hope as the virus no longer was a death sentence. Although ARVs were very expensive at the time, by the turn of the century, living with HIV had been transformed, particularly for people in Europe and the United States. Because of ARVs people with HIV could now live longer and lead productive lives. For such people, HIV/AIDS suddenly became a manageable medical condition rather than a fatal certainty.

Anti-retroviral drugs were introduced in Uganda in clinical trials as early as 1998. In 2004, Uganda began to offer free ARV medication to people living with HIV as part of a pilot programme and by 2006, 56 per cent of all those in need were receiving free HIV treatment. In South Africa, only the small minority who could afford to pay for private health care had access to ARV treatment before 2004. It was

See 'Uganda reverses the tide of HIV/AIDS' http://www.who.int/inf-new/aids2.htm (accessed 14 July 2009).

The latter argument is the thrust of a recent Harvard study in P Chigwedere et al 'Estimating the cost benefits of anti-retroviral drug use in South Africa' (2008) 49 Journal of Acquired Immune Deficiency Syndrome 410, while the former argument is contained in AIDS in South Africa: Treatment, transmission and the government http://avert.org/aids-south-africa.htm (accessed 15 July 2009).

See Kaiser Network 'Remarks by Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa, to the closing session of the XVI International AIDS Conference, Toronto, Canada' quoted in AIDS in South Africa: Treatment, transmission and the government http://.avert.org/aids-south-africa.htm (accessed 15 July 2009).

<sup>&#</sup>x27;HIV and AIDS in Uganda' (n 1 above). See also Uganda: Summary Country Profile for HIV/AIDS Treatment Scale-Up http://www.who.int/3by5/june2005\_uga.pdf (accessed 21 November 2009).

only after enormous pressure, legal challenges and an unprecedented public outcry that the government reluctantly started to supply the drugs in 2004. By the end of 2007, only about 28 per cent of the people who needed treatment were receiving it.<sup>11</sup>

The different approaches adopted by Uganda and South Africa in terms of access to HIV/AIDS medicines form the basis of the discussion in this article. The concept of 'access' is critical to the discussion, for it is not just about the existence of medicines, but the ability to access them. It has been held that accessibility means physically available and financially affordable. 12 In other words, 'access to medicines can only be assured if a sustainable supply of affordable medicines can be guaranteed – that is, a regular ongoing supply of affordable medicines'. 13 It has further been pointed out that, from a public health perspective, 'access to essential drugs depends on (1) rational selection and use of medicines; (2) sustainable adequate financing; (3) affordable prices; and (4) reliable health and supply systems'. 14 And as with other health care facilities and services, access to medicines has to be realised on a non-discriminatory basis, taking into account the most vulnerable and marginalised sections of the population. 15 It is against this background that the progress in the realisation of the right of access to HIV/AIDS medicines has to be seen. It also has to be seen not only in a general human rights context, but also in the specific context of the right to health care. Accordingly, apart from the lessons Uganda and South Africa can learn from each other, there is the important guestion of accountability for the violation of the right to health care occasioned by inadequate access to HIV/AIDS medicines. It is to this specific aspect of the right to health care that we first turn our attention.

# 2 The right to health care

# 2.1 The nature of the right

The World Health Organisation (WHO) broadly defines 'health' as 'a state of complete physical, mental and social well-being'. <sup>16</sup> It is in that context that the UN Committee on Economic, Social and Cultural

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See L Garbus & E Marseille 'HIV/AIDS in Uganda' http://hivinsite.ucsf.edu/doc/ariug.doc (accessed 21 November 2009).

See A Hassim et al Health and democracy: A guide to human rights, health law and policy in post-apartheid South Africa (2007) 438.

<sup>13</sup> As above.

<sup>&</sup>lt;sup>14</sup> AE Yamin 'Not just a tragedy: Access to medications as a right under international law' (2003) 21 Boston University International Law Journal 325 327.

See para 12 of General Comment 14 The Right to the highest attainable standard of health (UN DocE/C 12/2000/4) http://www.unhchr.ch/tbs/doc.nsf/(symbol)/ E.C.12.2000.4.En (accessed 18 July 2009).

See the Constitution of the World Health Organisation *Basic documents* (2007) 1.

Rights (ESCR Committee) has interpreted the right to health, as defined in article 12(1) of the International Covenant on Economic, social and Cultural Rights (ICESCR), as<sup>17</sup>

an inclusive right extending not only to timely and appropriate health care, but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.

The 'right to health care' can specifically be defined as 'the prevention, treatment and management of illness and the preservation of mental and physical well-being through the services offered by the medical and allied health professions'. There is no necessary conflict in the use of the terms 'right to health' and 'right to health care', as long as we understand that the 'right to health' is not possibly intended to guarantee a person's good health, but rather as 'a more convenient shorthand to cover the detailed language and references that are found in international treaties'. There is no doubt, however, that the right to health care, however defined, includes the right of access to medical treatment, including HIV/AIDS medicines.

Like all rights concerning health, the right to health care belongs to the category of human rights known as socio-economic rights. By their nature, these rights have important social and economic dimensions as most of them reflect specific areas of basic needs or delivery of particular goods and services. They also tend to create entitlements to material conditions for human welfare and, as such, a duty is placed on the state to actively implement them. It is in that context that the right to health care, which includes the right of access to HIV/AIDS medicines, has to be understood. It is also against that background that the international context of the right to health care in the context of HIV/AIDS medicines has to be discussed — an aspect to which we now turn our attention.

#### 2.2 The international context

There is no shortage of international human rights instruments and documents dealing with the right to health care. Most of these instruments are not choosy in their terminology and generally refer to the right to health as defined by the WHO.<sup>21</sup> It is that prevailing interna-

General Comment 14 (n 15 above) para 11.

See 'Definition of health care' http://www.answers.com/topic/health-care (accessed 18 July 2009).

See C Ngwena & R Cook 'Rights concerning health' in D Brand & C Heyns (eds) Socio-economic rights in South Africa (2005) 107.

See JC Mubangizi The protection of human rights in South Africa: A legal and practical quide (2004) 118.

See n 16 above.

tional terminological usage that will be adopted in this section. The discussion will also be divided into global instruments, on the one hand, and regional and sub-regional instruments on the other.

#### 2.2.1 Global instruments

In the global context, the point of departure is perhaps the Universal Declaration of Human Rights (Universal Declaration), article 11 of which proclaims that '[e]veryone has the right to a standard of living adequate for the health and well-being of himself and his family including ... medical care and necessary social services'.<sup>22</sup>

Furthermore, article 12(1) of ICESCR recognises the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Article 12(2) also lays down broad guidelines regarding the necessary steps to be taken by the member states in order to achieve the full realisation of this right.

Other UN treaties that directly address the right to health include the Convention on the Rights of the Child (CRC),<sup>23</sup> the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)<sup>24</sup> and the International Convention on the Elimination of All Forms of Racial Discrimination (CERD).<sup>25</sup> In addition to these, there are other instruments whose provisions indirectly or implicitly impact on the right to health. A good example is the International Covenant on Civil and Political Rights (ICCPR), article 6(1) of which guarantees the right to life and article 7 of which prohibits medical or scientific experimentation on anyone without his free consent. It is important to note that Uganda has either ratified or acceded to all the above-mentioned international human rights instruments and although South Africa is yet to ratify ICESCR, its Constitution includes an extensive catalogue of socio-economic rights that are contained in ICESCR.

In the specific context of the right of access to HIV/AIDS medicines, a number of UN declarations and similar documents are relevant. Perhaps the most pertinent of these is the United Nations General Assembly Declaration of Commitment on HIV/AIDS (2001) which recognises that<sup>26</sup>

access to medication in the context of pandemics such as HIV/AIDS is one of the fundamental elements to achieve progressively the full realisation of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

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<sup>22</sup> Art 11 Universal Declaration.

<sup>&</sup>lt;sup>23</sup> Art 24.

<sup>&</sup>lt;sup>24</sup> Art 12.

<sup>&</sup>lt;sup>25</sup> Art 5(e)(iv).

See art 15 of the United Nations General Assembly Declaration of Commitment on HIV/AIDS (2001).

The Declaration also urges member states to have developed, by 2003, national strategies 'to strengthen health care systems and address factors affecting the provision of HIV-related drugs, including antiretroviral drugs. The Member states were also urged to make every effort 'to provide progressively and in a sustainable manner, the highest attainable standard of treatment for HIV/AIDS, including the prevention and treatment of opportunistic infection, and effective use of quality-controlled anti-retroviral therapy'. The systems are developed, by 2003, national strategies and address factors affective use of quality-controlled anti-retroviral therapy'.

In 1996, the Office of the UN High Commissioner for Human Rights (UNHCHR) and the Joint UN Programme on HIV/AIDS prepared guidelines for UN member states on the application of international human rights law in the context of HIV/AIDS. The International Guidelines on HIV/AIDS and Human Rights, as they are officially known, were first published in 1998, revised in 2002 and consolidated in 2006. The 2002 revision and 2006 consolidation of the Guidelines was intended to ensure that they reflect new standards and developments in HIV-related treatment and evolving international law norms on the right to health generally, and the right of access to HIV-related prevention, treatment, care and support specifically.

Subsequent to the initial adoption of the International Guidelines on HIV/AIDS and Human Rights, a series of UNHCHR resolutions have been adopted to promote and monitor the guidelines. These include the Resolution on the Protection of Human Rights in the Context of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) (1997, 1999 and 2001)<sup>29</sup> and the Resolution on Access to Medication in the Context of Pandemics such as HIV/AIDS.<sup>30</sup> The latter Resolution, *inter alia*, calls upon member states 'to address factors affecting the provision of drugs related to the treatment of pandemics such as HIV/AIDS ... in order to provide treatment and monitor the use of medications, diagnostics and related technologies'.<sup>31</sup>

One of the recent relevant UN instruments is the Political Declaration on HIV/AIDS (2006). Adopted by the General Assembly after a review of the progress achieved in realising the targets set out in the 2001 Declaration of Commitment on HIV/AIDS, the Political Declaration on HIV/AIDS, inter alia, reaffirms that prevention, treatment, care and support for those infected and affected by HIV/AIDS are mutually reinforcing elements of an effective response.<sup>32</sup> It also commits member states to overcoming legal, regulatory or other barriers that block access to

<sup>&</sup>lt;sup>27</sup> Art 55.

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

<sup>&</sup>lt;sup>29</sup> UN Commission on Human Rights Resolutions 1997/33, 1999/49 & 2001/51.

UN Commission on Human Rights Resolution 2002/32.

<sup>31</sup> Art 4.

Art 23 of the UN Political Declaration on HIV/AIDS (2006).

effective HIV prevention, treatment, care and support, medicines, commodities and services.<sup>33</sup>

The length and depth of this paper do not lend themselves to a detailed discussion of all global human rights instruments and documents that have a bearing on the right to health care generally and access to HIV/AIDS medicines specifically. Suffice to say that there are numerous other instruments, such as WHO Resolutions, ESCR Committee General Comments, ILO instruments and WTO documents, all of which urge, call upon or oblige member states to ensure access to health care and HIV/AIDS medicines or recognise and set standards for the access thereto.

# 2.2.2 Regional and sub-regional instruments

The African Charter on Human and Peoples' Rights (African Charter) is the founding African regional human rights instrument. Article 16 of the African Charter provides that state parties 'shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick'. Another African regional treaty that has a bearing on health care is the Constitutive Act of the African Union (AU) (2000) which states as one of its objectives 'to work with relevant international partners in the eradication of preventable diseases and the promotion of good health on the continent'.<sup>34</sup> Furthermore, both the Protocol to the African Charter on the Rights of Women in Africa (2003) (African Women's Protocol) and the African Charter on the Rights and Welfare of the Child (1990) (African Children's Charter) oblige state parties to provide adequate, affordable and accessible health services and to ensure the provision of necessary medical assistance and health care to women and children.<sup>35</sup>

In addition to the above regional treaties, there are a number of AU declarations and similar documents dealing specifically with HIV/AIDS. The Abuja Declaration and Plan of Action on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases (2001) acknowledged HIV/AIDS as an emergency on the continent and urged African leaders to place the response to HIV at the forefront and as the highest priority in their respective national development plans. Two years later, African leaders adopted the Maputo Declaration, <sup>36</sup> which reaffirmed the commitment enshrined in the Abuja Declaration.

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<sup>&</sup>lt;sup>33</sup> Art 24.

<sup>&</sup>lt;sup>34</sup> Art 3(n).

See art 14(2)(a) of the African Women's Protocol and art 14(2)(b) of the African Children's Charter

See the Maputo Declaration on HIV/AIDS, Tuberculosis, Malaria and Other Related Infectious Diseases (2003).

More recently, and in the specific context of access to HIV/AIDS medicines, several declarations and other instruments have been adopted by the AU. These include the Gaberone Declaration on a Roadmap Towards Universal Access to Prevention, Treatment and Care (2005); the Brazzaville Commitment on Scaling Up Towards Universal Access to HIV and AIDS Prevention, Treatment, Care and Support in Africa by 2010 (2006) and the Abuja Call for Accelerated Action Towards Universal Access to HIV and AIDS, Tuberculosis and Malaria Services in Africa (2006). All these instruments either set specific timeframes or commit African leaders to the realisation of universal access to HIV/AIDS treatment, among other things. Mention should also be made of the African Commission on Human and Peoples' Rights (African Commission) Resolution on the HIV/AIDS Pandemic, 37 which declares HIV/AIDS a human rights issue and a threat against humanity. The Resolution calls upon African governments to allocate national resources in a way that reflects a determination to fight the spread of HIV/AIDS.

On the sub-regional front, there are a number of instruments and documents adopted by the Common Market for Eastern and Southern Africa (COMESA), the East African Community (EAC) and the Southern Africa Development Community (SADC) that deal with access to health care generally and HIV/AIDS treatment specifically. Besides the treaties establishing these regional formations, relevant instruments include the SADC Protocol on Health (2003). The latter Declaration, for example, reaffirms the commitment of SADC countries to the combating of AIDS as a matter of urgency by, *inter alia*, <sup>38</sup>

increasing access to affordable essential medicines, including ARVs and related technologies, through regional initiatives for joint purchasing of drugs, with the view of ensuring the availability of drugs through sustainable mechanisms, using funds from national budgets.

It is quite clear from the foregoing discussion that there is a vast array of international human rights instruments and documents dealing with health care and HIV/AIDS. What is not clear is the efficacy of such instruments and the international human rights framework in protecting health care rights generally and the right of access to HIV/AIDS medicines specifically. This is compounded by the fact that most international instruments dealing with health care and access to HIV/AIDS medicines are in the form of declarations and resolutions which, unlike treaties, are not formally binding on states. It has been argued, however, that despite not being formally binding, such instruments have become a persuasive source of guidance to states on the most appro-

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Resolution on the HIV/AIDS Pandemic – Threat Against Human Rights and Humanity (2001).

Art 2(g) of the Maseru Declaration on the Fight Against HIV/AIDS in the SADC Region (2003).

priate approach to HIV and AIDS. 39 And because access to medicine is a human right, it entails not only moral or humanitarian responsibilities, but also legal obligations. 40 These obligations have been clarified by the ESCR Committee's General Comment 14, according to which the right to health, like all human rights, imposes three types of obligations on state parties: the obligations to respect, to protect and to fulfil.<sup>41</sup> In turn, the obligation to fulfil entails obligations to facilitate, to provide and to promote. 42 The African Commission has explicitly adopted this same approach by establishing four levels of duties generated by the obligations of states under the African Charter to include the duties to respect, protect, promote and fulfil all the rights in the Charter.<sup>43</sup> It is in that context that we argue that South Africa and Uganda are both bound under international law to ensure the realisation of the right of access to HIV/AIDS medicines for those who require them. This is because the obligations of both countries under international law extend to ensuring sustained and equal access to comprehensive treatment and care, including HIV/AIDS medicines.<sup>44</sup> This has to be in the context of General Comment 14 which developed the minimum core content of the right to health.

In the case of South Africa, where the right of access to HIV/AIDS medicines has been violated even more extensively, international human rights instruments, binding or not, do play an important role in domestic law by virtue of sections 232, 231(4) and 39(1)(b) of the Constitution.<sup>45</sup> Moreover, the right to health care services is specifically protected under the national legal framework, as explained below.

D Mushayavanhu 'The realization of access to HIV and AIDS-related medicines in Southern African countries: Possibilities and actual realisation of international law obligations' in F Viljoen & S Precious (eds) Human rights under threat: Four perspectives on HIV, AIDS and the law in Southern Africa (2007) 134.

<sup>&</sup>lt;sup>40</sup> n 39 above, 135.

General Comment 14 (n 15 above) paras 33–35.

<sup>42</sup> As above

Social and Economic Rights Action Centre (SERAC) v Nigeria (2001) AHRLR 60 (ACHPR 2001) paras 43-47.

See eg General Comment 3: 'HIV/AIDS and the rights of the child' http://www. uniteforchildren.org/files/UNHCHR\_HIV\_and\_childrens\_rights\_2003.pdf (accessed 1 December 2009).

The Constitution of South Africa, 1996. Sec 232 provides that '[c]ustomary international law is law in the Republic unless it is inconsistent with the Constitution or an Act of Parliament'. Sec 231(4) provides that '[a]ny international agreement becomes law in the Republic when it is enacted into law by national legislation' and sec 39(1) (b) obliges any court, tribunal or forum to consider international law when interpreting the Bill of Rights.

# 3 Access to HIV/AIDS medicines in South Africa

#### 3.1 The constitutional framework

The right of access to health care is one of the socio-economic rights so ambitiously provided for in the 1996 South African Constitution. Section 27 provides as follows:

- (1) Everyone has the right to have access to -
  - (a) health care services, including reproductive health care;
  - (b) sufficient food and water; and
  - (c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.
- (2) The states must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.
- (3) No one may be refused emergency medical treatment.

Other constitutional provisions that directly or indirectly impact on health include section 10, dealing with human dignity; section 11, dealing with the right to life; section 28(1)(c), guaranteeing children the right to basic health care services; and section 35(2)(e), providing for the right of detainees and sentenced prisoners to conditions of detention that are consistent with human dignity, including 'the provisions, at state expense of ... medical treatment'.

In so far as access to HIV/AIDS medicines is concerned, however, our focus should be on section 27, as it is within the ambit of 'health care services' that HIV/AIDS treatment falls. In that regard, although the Constitution does not define 'health care services', it has been suggested that such services should include proper medical care, prevention and diagnosis of diseases and vaccination. The definition of health care services could also be seen in the context of CRC, which defines such services to include 'facilities for the treatment of illness and rehabilitation of health'. The definition of health'.

The constitutional right of access to health care services in South Africa has to be seen in the context of the legacy of the gross inequality that characterised South African society before 1994. By conferring on everyone a right of access to health care services, section 27(1) of the Constitution attempts to provide a legal foundation for an egalitarian and equitable health care system. The section therefore not only obliges the state to provide access to health care services, but it also places a duty on the state and on private health care providers not to interfere with a person's access to existing services. The constitutional duty placed on the state to respect and protect the right of access to

<sup>&</sup>lt;sup>46</sup> See J de Waal et al A Bill of Rights handbook (2001) 448.

<sup>&</sup>lt;sup>47</sup> Art 24(1) CRC.

<sup>40</sup> Ngwena & Cook (n 19 above) 131.

See S Khoza (ed) Socio-economic rights in South Africa (2007) 280.

health care services has been articulated and interpreted through various Constitutional Court judgments, the most important of which is *Minister of Health and Others v Treatment Action Campaign and Others*, so in which the Court not only demonstrated a willingness to impugn executive policy making, but also showed a commitment to enforcing the right of access to HIV/AIDS medicines and health care services specifically, and socio-economic rights generally.

# 3.2 The legislative and policy framework

As mentioned earlier, there is no doubt that the introduction of anti-retroviral drugs and other HIV/AIDS medicines have enabled HIV-positive people in many parts of the world to live productive lives for many years. In some countries (like South Africa), however, a lack of access to these life-saving and sustaining medicines has led to an extensive loss of life and caused untold pain and devastation.

While many countries in the world (particularly the Western world) began to use ARVs to treat HIV as far back as 1996, in South Africa such treatment was only available to people who had access to private medical care. It was not until 2003 that the South African government began to provide anti-retroviral therapy through the public health sector. A study by the Harvard School of Public Health estimated that about 330 000 people died of AIDS in South Africa between 2000 and 2005 because of the government's failure to implement an effective HIV/AIDS treatment programme.<sup>51</sup> The study concluded as follows:<sup>52</sup>

Access to appropriate public health practice is often determined by a small number of political leaders. In the case of South Africa, many lives were lost because of a failure to accept the use of available ARVs to prevent and treat HIV/AIDS in a timely manner.

This lack of political will explains the slow pace at which the legislative and policy framework for dealing with HIV/AIDS has been developed in South Africa. The genesis of the legislative framework is to be found in the Medicines and Related Substances Control Act.<sup>53</sup> Originally enacted in 1965, the Act has been amended several times, leading to the Medicines and Related Substances Control Amendment Act.<sup>54</sup> that is most significant in dealing with access to essential medicines. A further amendment resulted in the Medicines and Related Substances

<sup>2002 10</sup> BCLR 1030 (CC). Other cases in which the constitutional right of access to health care was given content include Republic of South Africa v Grootboom 2001 1 SA 46(CC); Soobramoney v Minister of Health, KwaZulu-Natal 1998 1 SA 765 (CC) and EN & Others v Government of the Republic of South Africa & Others 2007 1 BCLR 84 (D).

See Chigwedere et al (n 8 above) 410.

Chigwedere et al (n 8 above) 414.

Act 101 of 1965.

<sup>&</sup>lt;sup>54</sup> Act 90 of 1997.

Amendment Act<sup>55</sup> and the full reform package (inclusive of all the amendments) finally came into force in May 2004, almost seven years after the 1997 Amendment was signed into law.

Constraints of space do not allow for a detailed discussion of the Medicines and Related Substances Control Act and all its amendments. Suffice to say here that the 1997 amendment included a set of regulations<sup>56</sup> and both the amendment and regulations deal with a number of issues relating to access to medicines, including measures to ensure the supply of cheaper medicines, a transparent pricing system, the introduction of a fee-for-service system, promoting the use of generic medicines and fast-tracking procedures for the registration of essential medicines.

Mention should also be made of the National Health Act.<sup>57</sup> This legislation, which replaced the Health Act of 1977, is regarded as the single, most important piece of legislation for the health sector. The Act<sup>58</sup>

provides a framework for a structured uniform health system in order to unite the various elements of the national health system in a common goal to improve universal access to quality health services, taking into account the obligations imposed by the Constitution.

As such, its importance lies mainly in the fact that it places emphasis on aligning the national health care services to the imperatives of the Constitution and the Bill of Rights, an aspect that is significant to the right of access to medicines for HIV/AIDS and other diseases.

In so far as the policy framework is concerned, several policies and guidelines purporting to support the implementation of HIV/AIDS strategies in South Africa have been developed since 1994. In the context of HIV/AIDS treatment, these include the National Drug Policy for South Africa (1996) and the Guidelines on the Adequate Treatment of Opportunistic Infections (2002), among others. However, it was not until 2003 that the government came up with a comprehensive plan in the form of the National Operational Plan for Comprehensive HIV and AIDS Management, Treatment, Care and Support (2003), supplemented by the National Anti-retroviral Treatment Guidelines (2004).

The Operational Plan committed the government to providing ARV treatment to all those who needed it (believed to be about 1 650 000 people) by March 2008.<sup>59</sup> However, due to denialist and obstructionist attitudes at national and provincial leadership levels, the roll-out was so slow that by the end of 2008, fewer than 600 000 people were

<sup>&</sup>lt;sup>55</sup> Act 59 of 2002.

<sup>56</sup> Sec 35 of the Act.

<sup>&</sup>lt;sup>5/</sup> Act 61 of 2003.

See 'National Health Act proclaimed by the President' http://www.info.gov.za/speeches/2005/05042013451004.htm (accessed 7 December 2009).

See 'HIV/AIDS in South Africa' http://www.aids.org.za/hiv.htm (accessed 10 August 2009).

being treated.<sup>60</sup> This in spite of the approval in 2007 of a new HIV/AIDS and STI Strategic Plan which was seen as a major breakthrough in the response to HIV/AIDS.

The 2008/2009 changes in government that saw the end of the Thabo Mbeki era, however, seem to have brought renewed hope for a turnaround in the government's commitment to dealing effectively with the HIV/AIDS epidemic. At the 5th International Aids Society (IAS) Conference on HIV Pathogenesis, Treatment and Prevention held in Cape Town in July 2009, the IAS applauded the South African government for moving quickly to dramatically scale up the provision of anti-retroviral therapy for people with HIV/AIDS across the country. <sup>61</sup> This is all very well, but for the turnaround to be sustainable, a new approach towards the implementation of the National Strategic Plan and the Operational Plan will be required as there are still many issues to be resolved regarding access to HIV/AIDS treatment, including the availability of ARVs, the high cost of the drugs and limited access to generic medicines. <sup>62</sup>

# 3.3 The role of the courts and civil society

Any discussion on the current situation regarding access to HIV/AIDS medicines in South Africa would be incomplete without reference to the role played by the courts and that of certain sectors of civil society. In so far as the courts' role is concerned, the Constitutional Court has not only been innovative in interpreting and giving content to the right of access to health care contained in the Constitution, <sup>63</sup> but it has also been assertive in reminding the state of its obligation to take reasonable steps to create and implement a legal framework that facilitates access to health care services, including HIV/AIDS medicines. In the specific context of HIV/AIDS medication, the earliest case to come before the South African courts was *Van Biljon and Others v Minister of Correctional Services and Others*, <sup>64</sup> in which the Court held that the state had a constitutional duty to provide anti-retroviral therapy to two prisoners for whom it had been medically prescribed.

The most relevant and prominent case, however, is undoubtedly *Minister of Health and Others v Treatment Action Campaign and Others*, <sup>65</sup> in which the Constitutional Court upheld the decision that the state had violated the constitutional rights of expectant HIV-positive mothers by not supplying them with Nevirapine – a drug that could reduce by half the rate of HIV transmission from mothers to babies. The Court further

<sup>&</sup>lt;sup>60</sup> As above.

See 'IAS applauds SA commitment to treatment scale up' http://www.ias2009.org/ (accessed 10 August 2009).

HIV/AIDS in South Africa (n 59 above).

<sup>63</sup> See eg Grootboom & Soobramoney (n 50 above); Minister of Health & Others v Treatment Action Campaign & Others 2002 5 SA 721 (CC).

<sup>1997 4</sup> SA 441 (C).

<sup>65 2002 5</sup> SA 721 (CC).

held that the government's policy fell short of compliance with sections 27(1) and (2) of the Constitution and that the government had not reasonably addressed the need to reduce mother-to-child transmission of HIV. The government was ordered to permit and facilitate the use of Nevirapine and to remove the restrictions that prevented the drug from being made available at public hospitals and clinics that were not research or training sites. In making this order, the Court took into account, among other things, the implications of the roll-out on limited resources and the associated budgetary implications, but pointed out that it was constitutionally bound to require the state to take reasonable measures to meet its constitutional obligations and to subject the reasonableness of these measures to evaluation. 'Such determinations of reasonableness may in fact have budgetary implications, but are not in themselves directed at rearranging budgets,' the Court said.<sup>66</sup>

The above so-called Nevirapine case is particularly important, not only in demonstrating the role of the courts, but also the importance of advocacy in realising the right of access to HIV/AIDS medicines. The case was brought by the Treatment Action Campaign (TAC), a nongovernmental organisation (NGO) whose main function is to campaign for affordable treatment for people living with HIV and AIDS. Although the TAC has been the most prominent and effective civil society organisation (CSO) in advocating and campaigning for HIV/AIDS treatment, there are several other NGOs that have played and continue to play an important role. These include the AIDS Foundation of South Africa, the AIDS Consortium, Wits University AIDS Law Project, the AIDS Legal Network of South Africa, the Centre for HIV/AIDS Networking (HIVAN), Lovelife and the Health Systems Trust. While the work of these NGOs has been unco-ordinated and often strongly resisted by government, they have nevertheless played a critical role in improving access to HIV/ AIDS medicines in South Africa. It is too early to predict the new government's approach towards the role of NGOs in the fight against HIV/ AIDS, but it is submitted that nothing short of a broad-based partnership between the state and civil society will achieve the universal access to HIV/AIDS medicines envisaged in the 2003 Operational Plan and the 2007 Strategic Plan mentioned earlier.

# 4 Access to HIV/AIDS medicines in Uganda

#### 4.1 The constitutional framework

Unlike South Africa, Uganda pays minimal attention to socio-economic rights in its Constitution. <sup>67</sup> Except for the right to education, <sup>68</sup> the rights

<sup>&</sup>lt;sup>66</sup> Para 38.

The Constitution of the Republic of Uganda (1995).

<sup>&</sup>lt;sup>68</sup> Art 30.

of women,<sup>69</sup> the rights of children,<sup>70</sup> the right to a clean and healthy environment<sup>71</sup> and economic rights, <sup>72</sup> which are explicitly recognised in the Bill of Rights, other socio-economic rights are laid down in a preliminary section entitled National Objectives and Directive Principles of State Policy. This section contains a set of objectives and principles intended to guide all organs of the state (including the judiciary) and non-state actors 'in applying or interpreting the constitution or any other law and in taking and implementing any policy decisions for the establishment and promotion of a just, free and democratic society'. 73 There is therefore no explicit provision for the right of access to health care in the substantive Bill of Rights section of the Ugandan Constitution. Because of this, skeptics may ask: Legally, is there a right to health care in Uganda? As pointed out above, Uganda is party to international and regional human rights instruments that spell out the right to health care. The Constitution provides that the rights and freedoms, which are specifically mentioned in the Bill of Rights 'shall not be regarded as excluding others not specifically mentioned [such as the right to health care]'. 74 It can thus be argued that the right to health care, though not specifically mentioned, is legally recognised and can be enforced in a competent court.<sup>75</sup> The right can also be protected through a creative interpretation of other constitutionally-recognised rights such as the right to life. Though the right to life can be taken away in cases of

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<sup>69</sup> Art 33.

<sup>&</sup>lt;sup>70</sup> Art 34.

<sup>&</sup>lt;sup>71</sup> Art 39.

<sup>&</sup>lt;sup>72</sup> Art 40.

<sup>73</sup> NODPSP I(i).

<sup>&</sup>lt;sup>74</sup> Art 45

On the enforcement of rights and freedoms by the courts in Uganda, see art 50 of the Constitution. It should be noted that there has been a debate as to whether the Constitutional Court of Uganda is a 'competent court' for the purpose of handling the enforcement of human rights. In James Rwanyarare & Another v Attorney-General (Constitutional Petition 11/1997), the Constitutional Court held that it lacked jurisdiction to entertain a petition alleging a violation of human rights under art 50. However, in Attorney-General v Tinyefuza (Constitutional Appeal 1/1997), the Supreme Court held that arts 50 and 137 (on the interpretation powers of the Constitutional Court) must be read together since the Constitutional Court is bound to hear cases involving the enforcement of human rights and freedoms in the course of interpreting the Constitution. In Serugo v Kampala City Council & Another (Constitutional Appeal 2/1998), it was held that the jurisdiction of the Constitutional Court is exclusively derived from art 137, but the court can, if it deems it appropriate, deal with matters of redress and compensation, which are matters of enforcement of human rights under art 50 of the Constitution. In Alenyo George William v Attorney-General & Others (Constitutional Petition 5/2000), the Constitutional Court also held that it can handle cases of enforcement of human rights in the course of interpretation of the Constitution. It is therefore now settled that if a matter does not involve the interpretation of the Constitution as stipulated under art 137, any other court is a 'competent court' for the purpose of redressing violations of human rights.

capital punishment,<sup>76</sup> the state has a duty to take positive measures to protect and ensure the right through the prevention of death. Indeed, some judges have creatively interpreted the right to life. For example, in *Salvatori Abuki and Another v Attorney-General*,<sup>77</sup> the petitioner challenged the constitutionality of an exclusion order that was made under section 7 of the Witchcraft Act. He argued that the order deprived him of his property and the right to a livelihood. The court held that the exclusion order was unconstitutional since it threatened the right to life through deprivation of shelter, food and essential sustenance. Courts in Uganda can also learn from other jurisdictions where it has been observed that the right to life should not be understood in a restrictive manner and should be interpreted broadly to include other dimensions, such as health care.<sup>78</sup>

The relative success with which Uganda has been able to create the necessary framework for providing access to HIV/AIDS treatment, in comparison to South Africa's dismal record, may therefore not only be sought in the constitutional protection or lack thereof. Various other factors and role players have been significant in the progress towards the current situation regarding access to HIV/AIDS medicines in both countries, as explained below.

# 4.2 Policy framework: An overview

International human rights law accentuates the adoption of legislative, executive/administrative and judicial measures for the realisation of the right to health. The ESCR Committee recognises that each state has a margin of discretion in assessing the apposite feasible measures for implementing the right to health generally, and the right to health care in particular. In Uganda, there is no legislation that specifically deals with the right to health and its components, such as the right to health

Art 22(1). In Susan Kigula & 416 Others v Attorney-General (Constitutional Petition 2/1997), the petitioners challenged the constitutionality of the death penalty on the grounds that it violated the right to life and subjected them to cruel, inhuman and degrading punishment. The Court held that the death penalty is an exception to the right to life under the Constitution and therefore constitutional. However, it was held that a prolonged stay on death row subjected the prisoners to cruel, inhuman and degrading punishment

Constitutional Petition 2/1997.

See, eg, the Indian case of Paschim Banga Khet Mazdoor Sanity & Others v State of West Bengal & Another (1996) 4 SCC 37 and the Venuezelean case of Cruz Bermudez & Others v Minsterio de Sanida y Asistencia Social (1999) Case 15789.

See eg art 2(2) of ICESCR.

General Comment 14 (n 15 above) para 53.

care of persons living with HIV/AIDS.81 None of the international and regional human rights instruments that recognise the right to health care have been directly incorporated into the domestic legal system. However, most of the issues concerning the promotion and protection of the right to health care of persons living with HIV/AIDS are covered under policies, which are important because they dictate what level of health care provision is guaranteed, and what kinds of goods and services will be offered. The policy framework also helps in explaining how priorities may be established between competing claims and where to concentrate resources. Uganda has an elaborate policy framework, critical for the promotion of the right to health care of persons living with HIV/AIDS. The policy framework, developed in collaboration with civil society and donors, recognises the impact of poverty on the ability to access health care facilities, goods and services. For example, the Poverty Eradication Action Plan (PEAP)<sup>82</sup> — which is the overarching framework to guide public action to eradicate poverty — notes that poor people, who do not have the capacity to utilise private health care, should have access to the public health care system. The PEAP identifies HIV/AIDS as one of the priority areas to be tackled through a number of actions, including the provision of ARVs.83

As the lead government agency for health, the Ministry of Health has developed various policies, including a Health Sector Strategic Plan, which identify specific targets for the prevention and control of HIV/AIDS. These targets include the scale up of voluntary counselling and testing and the prevention of mother-to-child transmission (PMTCT) services at Health Centre III by 2010. The targets also include increasing the population of Health Centre IV offering comprehensive HIV/AIDS care with anti-retroviral therapy to 75 per cent by 2010. The health sector has a multi-sectoral and participatory approach, which encourages the involvement of civil society and other non-state actors in planning,

However, there are proposed laws on HIV/AIDS, which are retrogressive; they promote dangerous and discredited approaches to the epidemic and, if passed in their present form, there would be a total violation of the rights of people living with HIV/AIDS. The HIV/AIDS Prevention and Control Bill requires mandatory testing for HIV and forced disclosure of HIV status and criminalises the wilful transmission of HIV. The Anti-Homosexuality Bill, which prohibits any form of sexual relations between persons of the same sex, provides for the death penalty for a homosexual who is HIV positive and has sex with a person below 18 years. The Bill also nullifies international treaties whose provisions (eg those prohibiting discrimination based on sexual orientation) are contrary to the spirit and provisions of the Bill. The laws are likely to roll back the success of Uganda in the area of HIV prevention and treatment. Their enforcement will increase stigma and discrimination against HIV-positive gays, lesbians and transgender people, who are among the marginalised and vulnerable people in the field of health care.

Ministry of Finance, Planning and Economic Development *Poverty Eradication Action Plan* (2004).

<sup>83</sup> As above.

Ministry of Health Health Sector Strategic Plan (2006).

<sup>85</sup> As above.

service delivery and monitoring. The HIV/AIDS strategy, for example, is based on government partnership with various stakeholders, including persons living with HIV/AIDS, faith-based organisations (FBOs), civil society organisations (CSOs), and parliament.<sup>86</sup>

The Ministry of Health has developed the Anti-retroviral Policy, which aims at universal access to anti-retroviral treatment to all that are clinically eligible for it. The Ministry has also developed a strategic plan on HIV/AIDS, which has a number of thematic areas, including care and treatment, the major goal of which is to improve the quality of life of persons living with HIV/AIDS by mitigating the health impacts of HIV/ AIDS by 2012.87 To this end, the strategic plan intends to increase equitable access to anti-retroviral treatment by those in need from 105 000 to 240 000 by 2012; to increase access to the prevention and treatment of opportunistic infections, including tuberculosis (TB); to scale up HIV counselling and testing to facilitate universal access to treatment by 2012; to integrate prevention into all care and treatment services by 2012; and to support and expand the provision of home-based care and strengthening referral systems to other health facilities and complementary services. 88 Another major thematic area is systems strengthening, the goal of which is to build an effective system that ensures quality, equitable and timely service delivery. The strategic plan also aims at reducing HIV transmission from mother to child by 50 per cent by 2012 through the administration and uptake of PMTCT services, including Nevirapine or other anti-retroviral treatment, combination prophylaxis and developing a home-based PMTCT programme.<sup>89</sup>

#### 4.3 The policy framework: An appraisal

It is now recognised that HIV/AIDS interventions have a number of human rights implications. Thus, although the policies on HIV prevention, treatment, care and support sound noble on the surface, it is essential to subject them to human rights scrutiny. The question is: What is the potential of these policies and strategies to enhance or negate the promotion and protection of the right to health care of persons living with HIV/AIDS? What are the challenges and prospects of the implementation of the policy framework in Uganda?

It should be noted that universality is at the core of human rights. Given that the policy framework aims at providing universal access in respect of anti-retroviral treatment, it can be said to have the potential to promote and protect the right to health care of persons living with HIV/AIDS. The goals and targets of the policy framework are in line

<sup>86</sup> As above.

<sup>&</sup>lt;sup>87</sup> Uganda AIDS Commission Moving towards universal access: National HIV/AIDS Strategic Plan (2007).

O As above.

<sup>89</sup> As above.

with the concept of the progressive realisation to the maximum level of available resources, as provided for under ICESCR.<sup>90</sup> Indeed, the implementation of the National HIV/AIDS Strategic Plan has already registered some degree of success. There has been a rapid scale-up of anti-retroviral treatment whereby over 30 000 persons living with HIV/ AIDS were initiated on anti-retroviral treatment in 2007, bringing the cumulative total on active treatment to 141 416 by June 2008, amounting to 59 per cent of the Strategic Plan's target of 240 000. 91 However, the gains made are likely to be reversed because of inadequate and irregular funding. Funding is not only critical for the provision of anti-retroviral treatment, but also physical and human infrastructure. According to the Strategic Plan, reversing the trend in the epidemic requires a massive increase in available resources, rising by over a year from about US \$263 million in 2007 to US \$513 million in 2012.92 Antiretroviral treatment accounts for 88 per cent of the resources required for care and treatment programmes. 93

Although the Abuja Declaration recommends that states should allocate at least 15 per cent of their national budgets to health,94 Uganda spends only 9 per cent on health, and certainly this has serious implications for the provision of anti-retroviral treatment. 95 The Ministry of Health relies largely on external funding for all its HIV/AIDS programmes. 96 In order to meet its targets under the policy framework, Uganda has received external support from various donors, such as the Global Fund to Fight HIV/AIDS, Malaria and Tuberculosis (Global Fund) and the United States President's Emergency Plan for AIDS Relief (PEPFAR).<sup>97</sup> It should be noted that donor funds are sometimes consumed by corruption, as evidenced by the Global Fund, where millions of dollars were swindled by state functionaries through 'fictitious' NGOs and community-based organisations (CBOs). 98 It should also be noted that external funding is not sustainable; the state must mobilise internal resources for the provision of critical components of the right to health care, such as anti-retroviral treatment.

<sup>&</sup>lt;sup>90</sup> Art 2(2) ICESCR.

<sup>&</sup>lt;sup>91</sup> Uganda AIDS Commission Report on Implementation of National HIV and AIDS Strategic Plan (2008) 23. On the progress made, see also Ministry of Health Ministerial Statement (2008) 56.

<sup>&</sup>lt;sup>92</sup> n 91 above, ix.

<sup>93</sup> As above

The Abuja Declaration on HIV/AIDS, Tuberclosis and Other Related Infectious Diseases http://wwww.info/popups/articleswindow.php?id=38 (accessed 17 November 2009) para 26.

<sup>95</sup> Uganda AIDS Commission (n 91 above).

<sup>&</sup>lt;sup>96</sup> As above.

<sup>97</sup> As above.

<sup>98</sup> BK Twinomugisha 'Taking human rights seriously: Protection of the right of access to malaria treatment in Uganda' (2009) 2 Journal of African and International Law 161-200 170.

It is also important to point out that macro-economic institutions, such as the World Bank and the International Monetary Fund (IMF), which shape the socio-economic agenda in developing countries, argue that increasing public health spending undermines macroeconomic stability. 99 The macro-economic model designed by these institutions sets rigid budget ceilings for each ministry, including the Ministry of Health. It is argued that spending on treatment measures such as anti-retroviral treatment is costly and may have inflationary tendencies. 100 In our view, economic policies that result in the underfunding of health care services are antithetical to the protection of human rights because they make access to health care dependent on the individual's capacity to pay. Health care provision is not looked at from a human rights perspective, but from the desire to increase economic growth and the maintenance of macro-economic stability. 101 But if we may ask: If growth is not for health, what is it for and who is expected to enjoy it? Thus, although the policy framework aims at universal access to anti-retroviral treatment for all who are clinically eligible for it, this may not be possible unless the funding constraints are concretely addressed. The policy framework does not concretely address issues of equity, especially the fact that, because of their poverty, some persons living with HIV/AIDS may not afford expensive CD4 count tests, which are a prerequisite for starting antiretroviral treatment. Because of the absence of machines to carry out CD4 counts<sup>102</sup> in some rural areas, persons living with HIV/AIDS have to incur transport costs to travel to urban centres. It should also be noted that some of the machines are sophisticated and consequently there is a limited number of personnel able to perform the relevant tests. Even laboratories to carry out simple HIV tests may not be readily available in hard-to-reach areas. 103

To its credit, the policy framework recognises the gender dimensions of the epidemic. It notes that women (60 per cent) are infected more than men (40 per cent) across the age spectrum from birth to 45 to 49

Z Gariyo Participatory poverty reduction strategy papers: The PRSP process in Uganda (2002).
100 . . .

As above.

See L Trillo Diaz 'Protection of access to essential treatment for people living with HIV/AIDS in Uganda from a human rights perspective' unpublished LLM dissertation, University of Pretoria, 2005 33. On this argument, also see BK Twinomugisha 'Barriers to the protection of rural women's rights to maternal health care in Uganda' (2005) 11 East African Journal of Peace and Human Rights 1 67-92.

A CD4 count is a diagnostic system used primarily to test for HIV. It analyses blood by counting residual white blood cells and testing immunity. The CD4 count enables health workers to know those in need of ARVs by determining exact immunity levels.

BK Twinomugisha 'Protection of the right to health care of women living with HIV/ AIDS (WLA) in Uganda: The case of Mbarara Hospital' HURIPEC Working Paper 5 (2007).

years and the gender impact of the disease is significant. 104 However, the policy framework does not seriously analyse why vulnerable individuals and groups, such as women, may not adhere to the treatment regime. Women living with HIV/AIDS may not adhere to anti-retroviral treatment because of inequitable gender relations exacerbated by negative cultural practices. A gender analysis of the socio-economic and cultural causes of why women living with HIV/AIDS may not access and effectively utilise anti-retroviral treatment is necessary in order to achieve a more comprehensive picture of the magnitude of the problem. In a study of access to anti-retroviral treatment by women living with HIV/AIDS, one of us found that, because of their multiple gender roles, rural women hardly get enough time to effectively utilise anti-retroviral treatment in accordance with doctors' prescriptions. 105 Women seek care discreetly. Because of the associated stigma of HIV/ AIDS and the fear of violence from their husbands, women do not want their husbands, in-laws and the wider community to know that they are receiving care. 106

It is also important to note that most women are socialised to believe that the health of their children and families takes precedence over their own health. A pregnant woman readily accepts anti-retroviral treatment for reduction of MTCT even if she has not received care. The HIV/AIDS Strategic Plan correctly highlights this paradox: Most mothers who are eligible for anti-retroviral treatment only receive drugs to prevent infections in their infants and do not get treatment for their own infection. HIV-positive mothers need to access anti-retroviral treatment in order to enhance their health and be able to ensure quality survival for their children.

Before concluding this section, it may be important to briefly comment on the extent to which the policy framework takes into account the interconnectedness and indivisibility of human rights. The right to food, for example, which is closely linked with the right of access to anti-retroviral treatment, is not considered seriously by the policy framework. Like most patients on care, persons living with HIV/ AIDS need adequate food in order to adhere to the treatment regime. Adherence throughout the entire course of anti-retroviral treatment is an essential part of any successful treatment programme. Patients have

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n 85 above, 7. See also UAC The Uganda HIV/AIDS Status Report (2006).

<sup>&</sup>lt;sup>105</sup> Twinomugisha (n 98 above).

<sup>106</sup> As above.

<sup>&</sup>lt;sup>107</sup> n 91 above, 23.

The right to food is guaranteed under art 25 of the Universal Declaration, which couches the right within the broader context of an adequate standard of living that includes health, food, medical care, social services and economic security. See also art 11 of ICESCR; General Comment 12, The Right to Adequate Food, UN Doc E/C 12/199/5 (1999). For a discussion of the right to food, see BK Twinomugisha 'Challenges to the progressive realisation of the right to food in Uganda' (2005) 11 East African Journal of Peace and Human Rights 2 241-264.

to take at least 95 per cent of their pills in order to respond well. <sup>109</sup> When persons living with HIV/AIDS are not well fed, they may abandon the treatment for fear of serious adverse effects. Hunger reduces the efficacy of medication among persons living with HIV/AIDS and often affects drug adherence, especially to anti-retrovirals, hence a poor response to treatment.

# 4.2 Role of courts and civil society

While the judiciary in South Africa has been fairly innovative in the area of the right of access to health care by persons living with HIV/ AIDS, courts in Uganda have not yet pronounced themselves on this issue. This could be due to the fact that, unlike their counterparts in South Africa, CSOs in Uganda have not yet struggled for enhanced access to medicines through the courts. However, CSOs which are focused on HIV/AIDS have played a fundamental role in providing care and support for those who are ill, the infected and affected through information, education and communication strategies. CSOs are most effective at reaching marginalised populations due to their flexibility and location in remote areas. 110 CSOs, including faith-based organisations (FBOs), have provided critical support to the national response to HIV/AIDS in Uganda. CSOs such as the AIDS Support Organisation (TASO) have greatly contributed to the well-being of persons living with HIV/AIDS through the provision of integrated services for care and prevention. Their efforts have contributed to the reduction of stigmatisation of and discrimination against persons living with HIV/ AIDS. 111

As is the case in South Africa, CSOs have engaged in advocacy work to improve access to medicines in Uganda. For example, the Action Group for Health Rights in Uganda (AGHA) has, alongside other organisations, been involved in advocacy against proposed legislation that would have limited access to generic medicines. AGHA has also been engaged in efforts to increase the budget for health generally and the provision of HIV/AIDS-related goods and services. <sup>112</sup>

<sup>&</sup>lt;sup>109</sup> National ART Guidelines.

On the role of civil society in HIV/AIDS interventions, see, eg, AJ Horvoka & EE Kiley 'Civil society organisations and the national HIV/AIDS response in Botswana' (2006) 5 African Journal of AIDS Research 2 167-178.

P Mutabwire 'Participatory health service delivery: The fight against HIV/AIDS in Uganda' http://unpan1.un.org/intradoc/groups/public/documents/un/unpan023 881.pdf (accessed 18 November 2009).

AGHA Strategic Plan 2009/10.

# 5 Accountability for the implementation of the right to health care

# 5.1 Accountability in the human rights context

Accountability has various meanings. 113 Black's law dictionary defines accountability as the 'state of being responsible or answerable'. 114 Cook<sup>115</sup> cautions that accountability is a wider concept than responsibility, which simply denotes liability for a breach of the law. She argues that accountability 'requires a state to explain an apparent violation and to offer an exculpatory explanation if it can'. 116 In the context of this paper, accountability involves states being answerable for their acts or omissions regarding their right to health obligations. If accountability mechanisms are lacking, the right to health care will be meaningless or ineffective for rights holders. As Yamin<sup>117</sup> has observed, accountability is a central concept of any rights-based approach to health because it converts passive beneficiaries into claims holders, and identifies the state and other actors as duty bearers, who may be held to account for their policies, programmes and strategies to provide universal access to health care. Yamin has also noted that accountability from a human rights perspective requires<sup>118</sup>

monitoring and oversight by both government officials and those who are affected; such accountability demands transparency, access to information and active popular participation. It is not enough to have access to reliable information and indicators; true accountability requires processes that empower and mobilise ordinary people to become engaged in political and social action ... accountability in a human rights framework also requires effective and accessible mechanisms for redress in the event of violations.

Viewed through a human rights lens, the concept of accountability is thus important in determining which health policies and institutions are working and which are not and why. In any case, as Langford has pointed out, the *raison d'être* of the rights-based approach is accountability.<sup>119</sup> It assists in identifying who should take credit for what has

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On the many meanings of accountability, see eg H Potts *Accountability and the highest attainable standard of health* (2008). Meanings include social accountability, professional accountability, political accountability and legal accountability. See also A Schedler *et al The self-restraining state: Power and accountability in new democracies* (1999).

HC Black Black's law dictionary (1990) 19.

RJ Cook 'State accountability under the Convention on the Elimination of All Forms of Discrimination Against Women' in RJ Cook (ed) Human rights of women: National and international perspectives (1994) 222 228.

<sup>116</sup> As above

AE Yamin 'Beyond compassion: The central role of accountability in applying a human rights framework to health' (2008) 10 Health and Human Rights 1-20.

<sup>&</sup>lt;sup>110</sup> n 117 above, 1-2

M Langford Claiming the Millennium Development Goals: A human rights approach (2008) 15.

been performed well, and who has the responsibility to carry out certain tasks in the context of health care. Accountability helps in determining the extent to which the state has fulfilled its obligations and, if not, why not, and explores whether any redress needs to be made. Although non-state actors also have obligations in respect of the right to health, space constraints do not permit us to delve into how they can be held accountable for failure to fulfill their obligations in the field of health care.

# 5.2 How to hold the state accountable

Egregious and pervasive violations of the rights of persons living with HIV/AIDS, including the right to health care, often go unrecognised and, when they are recognised, they may not attract any punishment or remedy. Although states make promises for meeting the right to health care of persons living with HIV/AIDS in the policy framework, they may renege on such promises. The question therefore is how the states in question can be held accountable for violations of the right to health generally and the right to health care of persons living with HIV/AIDS in particular. It has been argued that, in determining whether the state is complying with its obligations in the field of health care, it may be necessary to focus more on violations than only on progressive realisation. For example, in respect of women's right to health care, Chapman<sup>120</sup> argues that there are three types of violations, namely, violations resulting from government actions and policies; violations related to patterns of discrimination; and violations related to a failure to fulfil the minimum core obligations. According to the ECSR Committee, violations may occur through acts of commission (through the direct actions of states or other entities insufficiently regulated by states)<sup>121</sup> and of omission (such as failure to take steps). 122 Violations may also occur when the state does not prevent, regulate or control infringements of the right to health by third parties. 123 In the next section we explore mechanisms of accountability for violations of the right to health care.

#### 5.2.1 Legislative mechanisms

It may be argued that Uganda has a fairly more elaborate policy framework than South Africa in the specific context of HIV/AIDS. However, policies are not legally binding: They simply contain political obligations. Consequently, Uganda should, like South Africa, explicitly recognise the right to health care in the Constitution, which would

AR Chapman 'A violations approach to monitoring economic, social and cultural rights' (1996) 18 *Human Rights Quarterly* 23-66.

General Comment 14 (n 15 above) para 48.

<sup>&</sup>lt;sup>122</sup> Para 49.

<sup>&</sup>lt;sup>123</sup> Para 51.

clear any misgivings about the justiciability of the right. 124 It should be noted, however, that it is not sufficient to merely recognise the right in the Constitution. The ESCR Committee enjoins states to consider adopting a national framework law to give effect to the right. 125 To this end, there is an urgent need for health legislation that unequivocally obliges the state to provide adequate, affordable and accessible health care, including anti-retroviral treatment to its people with special attention to the poor and vulnerable. The legislation should contain provisions that permit the Minister of Health to formulate regulations relevant to the health sector. Such regulations would contain measurable benchmarks and targets against which performance may be measured. 126 The regulations should also include provisions on periodic review, monitoring and evaluation of performance of relevant health sectors. They should also prescribe offences and penalties against officers who may misappropriate essential drugs, or negligently fail to address stock-outs of anti-retroviral drugs and other medicines for opportunistic infections in hospitals or health centres, or negligently fail to distribute the drugs on time. 127 The regulations should also address access to medicines provided by private providers, by including fees structures or guidelines in order to minimise the exploitation of patients. As is the case in South Africa, the Ugandan legislation should promote the use of generic medicines. Both countries should take legislative steps to ensure that they benefit from the international trade regime, which permits public health exceptions to intellectual property rights and allows the manufacture, exportation and importation of cheaper generic versions of anti-retroviral drugs. 128

There is a need for South Africa to ratify ICESCR. It may also be necessary for both countries to domesticate ICECR, since domestic legal systems may guarantee more protection and promotion of human rights than international law, which may experience enforcement problems. On the need for domestication of international treaties, see C Heyns & F Viljoen 'The impact of the United Nations treaties on the domestic level' (2001) 23 Human Rights Quarterly 483; MA Torres 'The human right to health, national courts and access to HIV/AIDS treatment: A case study from Venezuela' (2002) 3 Chicago Journal of International Law 107-108.

General Comment 14 (n 15 above) para 53.

<sup>126</sup> This method has been successfully utilised by the National Environment Act, a framework legislation which lays down major principles and concepts on the protection of the environment, but leaves details to lead agencies and the sector ministry.

<sup>127</sup> Trillo Diaz (n 101 above).

There have been calls for Uganda to domesticate the Trade Related Aspects of Intellectual Property Rights (TRIPS) Agreement flexibilities, such as parallel importation and compulsory licensing, which may enhance access to generic medicines in the country. On the problems and prospects of utilising such flexibilities, see BK Twinomugisha 'Implications of the TRIPS Agreement for the protection of the right of access to medicines in Uganda' (2008) 2 Malawi Law Journal 253-278.

# 5.2.2 Accountability through national courts

It is true that international accountability mechanisms through, for example, the reporting system, or even communications by the African Commission may be helpful in ensuring that states meet their obligations under international human rights law. However, in order for the right to health care to be meaningful for vulnerable persons such as persons living with HIV/AIDS, there must be adequate legal and other remedies provided at the domestic level. These remedies should be open to any right holder who claims that his or her right has been violated.

National courts can play a crucial role in addressing issues of social justice such as health care. Judges can be creative in their interpretation of relevant constitutional provisions to compel the state to meet its obligations under international human rights law. Even where there is no explicit recognition of the right to health care (as in Uganda), court action may succeed, either by inferring this right from other rights, such as the right to life, or by relying on human rights instruments which the state has ratified. Ugandan courts may also boldly apply the Directive Principles of State Policy to hold the state accountable. In many jurisdictions, litigation has been used as a mechanism to advance the right to health by holding states accountable to human rights norms in the specific context of HIV/AIDS. Litigation may serve to hold states accountable to their laws and policies and also to empower individuals and groups to enforce the laws more directly.

Unlike Uganda, there has been increased litigation and activism in the area of socio-economic rights in South Africa. For example, in the

<sup>129</sup> Courts in Uganda have increasingly referred to the jurisprudence of treaty bodies and case law from other jurisdictions. See eg *Charles Onyango Obbo & Another v Attorney-General* (Constitutional Appeal 2/2002); *Col (Rtd) Dr Besigye Kiiza v Museveni Yoweri Kaguta and the Electoral Commission* (Electoral Petititon 1/2001).

On this view, see eg BO Okere 'Fundamental Objectives and Directive Principles of State Policy under the Nigerian Constitution' (1983) 32 International and Comparative Law Quarterly 214-215. Experiences from other jurisdictions, especially India, also show that a creative court can effectively apply Directive Principles to issues of human rights. Eg, in Keshanavanda Bharati v State of Kerala (1963) 4 SCC 225, the Supreme Court stated that, although the Indian Constitution expressly provides that the Directive Principles are not enforceable by any court, they should enjoy the same status as traditional fundamental rights.

On cases concerning human rights of people living with HIV/AIDS, see eg UNAIDS Courting rights: Case studies in litigating the human rights of people living with HIV (2006).

On litigation as a mechanism to enhance protection of the right to health, see S Gloppen 'Litigation as a strategy to hold governments accountable for implementing the right to health' (2008) 10 Health and Human Rights 23 24; S Gloppen 'Social rights litigation as transformation: South African perspectives' in P Jones & K Stokke (eds) Democratising development: The politics of socio-economic rights in South Africa (2005) 153-180; HV Hogerzeil et al 'Is access to essential medicines as part of the fulfilment of the right to health enforceable through the courts?' (2006) 368 Lancet 305-311.

Treatment Action Campaign case, <sup>133</sup> the Constitutional Court relied on General Comments of the ESCR Committee to determine that the health policy must be reasonable in development and implementation. The Court noted that for a policy to be 'reasonable', it had to be comprehensive, co-ordinated between the various levels of government and focused on those in greatest need. However, courts may be reluctant to interfere with policy decisions except where the court finds that there is no other lawful alternative but for it to adjudicate. <sup>134</sup> Courts may also be cautious about decisions involving the allocation of money, for example, in Soobramoney v Minister of Health (KwaZulu-Natal), <sup>135</sup> where the court stated: <sup>136</sup>

[Health funding] choices involve difficult decisions to be taken at the political level in fixing the health budget and at the functional level in deciding the priorities to be met. A court will be slow to interfere with rational decisions taken in good faith by the political organs and medical authorities whose responsibility is to deal with such matters.

Litigation, of course, cannot function as a mechanism to hold states accountable for the right to health care unless cases are brought to court by public-spirited individuals or civil society. Civil society organisations in Uganda should, like their counterparts in South Africa, engage in public interest litigation on behalf of the indigent and other disadvantaged members of society such as persons living with HIV/ AIDS. Public interest litigation is particularly important given the poverty levels where potential litigants may not be aware of their rights, let alone being able to meet litigation costs. Civil society organisations can challenge the state in court to demonstrate that it has employed the available resources maximally towards the realisation of the right in question. <sup>137</sup> Given that legislative or juridical action may not necessarily change social behaviour unless supported by other plans or strategies, we now explore other accountability mechanisms.

On how courts in Uganda can use the approach taken by the Constitutional Court in South Africa to protect socio-economic human rights, see BK Twinomugisha 'Exploring judicial strategies to protect the right of access to emergency obstetric care in Uganda' (2007) 7 African Human Rights Law Journal 283 300-301.

See eg Grootboom & Others v Government of the Republic of South Africa & Others (2000) ICHRL 72.

<sup>135 1998 1</sup> SA 765.

<sup>&</sup>lt;sup>136</sup> Para 29

Trillo Diaz (n 101 above) 45. Art 50(2) of the Constitution permits PIL, which has been utilised by public-spirited individuals and organisations to challenge violations of human rights or the constitutionality of certain laws or other acts or omissions by government officials or agencies. Eg, in *Environmental Action Network (TEAN) v Attorney-General and the National Environment Management Authority* (Misc Appl 39/2001), the court relaxed the rules of standing and permitted the applicants, who did not have a direct interest in the infringing act, to bring an action on behalf of the non-smoking public. For a discussion of this and other cases, see BK Twinomugisha 'Some reflections on judicial protection of the right to a clean and healthy environment in Uganda' (2007) 3 *Law, Environment and Development Journal* 3.

#### 5.2.3 Democratic participation in the policy framework

One of the cardinal requirements of accountability is participation of all relevant stakeholders in the design, implementation, monitoring and evaluation of the policy framework. The concept of democratic participation is recognised in various legal and policy documents. For example, the Ugandan Constitution provides that 'the state shall be based on democratic principles which empower and encourage the active participation of all citizens at all levels in their own governance'. 138 The cornerstone of the health policy framework in both South Africa and Uganda is Primary Health Care, which calls for the provision of health care to individuals and families through their full participation. According to WHO and UNAIDS, the people have the right and duty to participate individually and collectively in the planning and implementation of strategies for their treatment and care. 139 However, the major problem is that some of the policies and programmes are top-down and undemocratic. They are envisaged, planned and implemented by bureaucrats, planners and other outsiders without any direct involvement of vulnerable groups, such as prisoners, women, children and the poor. Although the policy framework in both countries encourages participation of the poor, vulnerable groups and civil society in its formulation, such participation is simply cosmetic. For example, in Uganda, civil society organisations were invited to provide input into the development of the PEAP. However, no input was sought from these organisations on the nature of the policies necessary to tackle poverty issues such as health care. 140

Although civil society organisations may have their own interests and may not necessarily represent or be accountable to the poor, they can play a critical role in the promotion and protection of the right to health care of persons living with HIV/AIDS, by monitoring the delivery of anti-retroviral drugs and other HIV/AIDS-related goods and services. Civil society organisations may also conduct public hearings about various issues concerning access to health care by persons living with HIV/AIDS, such as the misappropriation of HIV/AIDS-related funds and expose such issues in the media. Civil society organisations can also actively follow up the national budgeting process to ensure that governments allocate adequate funds to the health sector generally and the provision of anti-retroviral drugs in particular. Civil society organisations may also form partnerships with Health Unit Management Committees (HUMCs) to ensure health protection generally and HIV/AIDS-related care in particular. These committees are mainly charged with mobilising communities

Objective XXVI (ii) of the 1995 Constitution.

WHO/UNAIDS Ensuring equitable access to anti-retroviral treatment for women (2004).

BK Twinomugisha 'A critique of Uganda's poverty eradication action plan' in K Matlosa et al (eds) The state, democracy and poverty eradication in Africa (2008) 298-312.

for health messages or resource support to the health unit. They are supposed to aid the state in promoting the active involvement of the communities in setting up and maintaining health infrastructure.

#### 6 Conclusion

Uganda and South Africa have adopted different approaches towards the protection of the right to health care generally and the right of access to HIV/AIDS medicines in particular. Although these approaches have resulted in varying and disparate consequences, both countries should be held accountable for the violation of those health care rights, albeit in varying degrees. More importantly, however, it is clear that Uganda and South Africa have a lot to learn from each other.

Like South Africa, Uganda needs to give greater recognition to the right to health care in its Constitution. Moreover, there is also a dire need for a legislative framework for the protection of health care rights (and specifically the right to HIV/AIDS medicines) as the existing policy framework alone is not enough. A higher level of constitutional protection and an elaborate legislative framework will enable Ugandan courts to play a more meaningful role in addressing issues of access to health care through interpretation and litigation.

Both countries need to make better use of civil society organisations in a collaborative rather than an antagonistic relationship. A broad-based partnership between the state and civil society formations should target vulnerable groups, including prisoners, women, children and the poor. Moreover, the public health care system should be pro-poor and accessible.

As mentioned earlier, the lack of political will and commitment is largely responsible for the current state of the HIV/AIDS epidemic in South Africa. There is no better lesson that South Africa can learn from Uganda than the need for high-level political intervention, commitment and resoluteness. The new political era and recent change of government in South Africa will hopefully usher in the necessary political will that will scale up the provision of, and access to, HIV/AIDS medicines. It is still too early to tell whether the new political leadership will live up to what it has promised. But what is clear is that such commitment should enable the government to ratify and/or domesticate relevant international and regional human rights instruments, all of which play an important role in the realisation of the right of access to health care and other rights. It is, for example, inexplicable that South Africa has so far failed (or refused) to ratify ICESCR. Such refusal will continue to cast doubt on South Africa's commitment to the protection of socioeconomic rights, in spite of its record.

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