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Imagining a right to health: HIV/AIDS, subjectivities and notions of entitlement

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Imagining a Right to Health

HIV/AIDS, Subjectivities and Notions of Entitlement

Rebecca Wanja Maina

A thesis submitted in partial fulfilment of the requirements of the University of Westminster for the degree of Doctor of Philosophy.

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Abstract

This research is an investigation into how the subjectivities of people living with HIV/AIDS (PLWHAs) are shaped by their illness and how this ultimately influences their conceptualization of entitlements and rights. It achieves this by analyzing the broader historical and modern contexts in which the Kenyan PLWHA's sense of self is constructed, including the norms on which attitudes about AIDS and those who suffer from it are grounded. As part of this analysis, the research also probes the intricate power dynamics and systems of privileges and obligations that bind individuals to their wider social network, including the family, community, and the State. It then looks at the responses of PLWHAs interviewed for this research in order to examine awareness about human rights, which health entitlements they claim (and which they do not), from whom and why. What emerges is an insight into how members of this sizeable population locate themselves within their wider socio-economic matrices; how HIV infection often then *dislocates* them; how they imagine their resultant entitlements; the competing moral frameworks of reference on which they base such claims, and last, but not least, the language they use to articulate them. As this research contends, the human rights paradigm is not the sole, or even the dominant, framework of reference by which Kenyan PLWHAs or laypeople more generally imagine and articulate their grievances and entitlements. Further, how the PLWHAs at the heart of this research incorporate human rights norms and how they attempt to reconcile the tensions and contradictions in these competing frames of reference illuminates the way in which the HIV epidemic has shaped the human rights discourse. Moreover, it highlights the often-ignored role of laypeople as agents in the advancement- or not- of the broader human rights project. As the research concludes, proponents of human rights have much to do to promote its norms and cultivate support for it in the grassroots. They would do well to understand the complex processes by which laypeople's notions of entitlement are constructed, and the pivotal role their varied subjectivities play.

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Author's Declaration:

I declare that all the material contained in this thesis is my own work.

List of Abbreviations

AIDS- Acquired Immuno-deficiency Syndrome
ART- Antiretroviral Therapy
ARV- Antiretroviral
CADRE- Centre for AIDS Development Research and Evaluation
CBO- Community-based organization
CHAI- Clinton HIV/AIDS Initiative
ESC- Economic, social and cultural
CSO- civil society organization
FBO- Faith-based organization
HIV- Human Immuno-deficiency Virus
ICESCR- International Covenant on Economic, Social and Cultural Rights
ICTSD-International Centre for Trade and Sustainable Development
IDS- Institute of Development Studies
IRIN- Integrated Regional Information Networks
IRRRAG – International Reproductive Rights Research Action Group
KAIS- The Kenya AIDS Indicator Survey
KANCO- Kenya AIDS NGOs Consortium
KAPC- Kenya Association of Professional Counsellors
KDHS – Kenya Demographic and Health Surveys
KENWA- Kenya Network of Women with AIDS
KHRC – Kenya Human Rights Commission
KNBS- Kenya National Bureau of Statistics
KNCHR- Kenya National Commission on Human Rights
KNDR- Kenya National Dialogue and Reconciliation Committee
KNH- Kenyatta National Hospital
LAO- Local administrative officials
MSF- Médecins Sans Frontières
NACC- National AIDS Control Council
NASCOP- Kenya National AIDS and STI Control Program
NEP- North-Eastern Province
NEPHAK- Network of People Living with HIV/AIDS in Kenya
NGO – Non-Governmental Organization
NHIF- National Hospital Insurance Fund
OHCHR- Office of the United Nations High Commissioner for Human Rights
PA- Provincial Administration
PEPFAR- (The United States) President’s Emergency Fund for AIDS Relief
PLWHA- People Living with HIV and AIDS
RBA – Rights Based Approach
SAP- Structural Adjustment Programme
STI- Sexually Transmitted Illness
TAC – Treatment Action Campaign
TAPWAK- The Association of People with AIDS in Kenya
TB – Tuberculosis
TRIPs- Trade-Related Aspects of Intellectual Property Rights

UDHR – Universal Declaration of Human Rights
UN – United Nations
UNDP- United Nations Development Programme
UNTC- United Nations Treaty Collection
VCT- Voluntary counselling and testing
WHO – World Health Organization
WOFAK – Women Fighting AIDS in Kenya
WTO- World Trade Organization

Chapter 1: Introduction and Literature Review

I. Introduction

a) The Human Element

When the idea for this research began to form, nearly a decade before its presentation, Kenya was just waking up to the magnitude of its HIV/AIDS problem. Questions were beginning to be asked about how a culturally and religiously conservative country had ended up with a significant portion of its population living with a largely sexually-transmitted illness¹; how its people living with HIV/AIDS (PLWHAs), most of whom were women, should be treated by society; what duty, if any, the State had to take care of them; what rights, if any, PLWHAs were due; and how the State should address the wider public health emergency. It was, to say the least, an interesting time to be asking these questions, for parallel dialogues were taking place on the political plane about the nature and role of the postcolonial State in the multi-party era; its duty to its citizens; the nature and scope of their human rights; the citizens' complex dual-membership to both a national as well as an ethnic public; the place of the rule of law in this changing political landscape; and the role of overseas governments and civil society organizations (CSOs) which were increasingly mediating the State-citizen relationship.

¹ In 2012, there were an estimated 1.6 million PLWHAs in Kenya. About 1.4 million are adults aged 15 years and over; an estimated 200,000 are children aged 0 to 14 years. The HIV prevalence rate among 15-49 year-olds was between 6.1%. The corresponding prevalence rate in 2001 was 8.4%. Kenya's national HIV prevalence in 2006 was 5%, down from around 14% in the mid-1990s. (2012 stats from UNAIDS Kenya webpage, 2013, at <http://www.unaids.org/en/regionscountries/countries/kenya/>, accessed 12/12/13. Comparative 2001 statistics from UNAIDS, *Global Report: UNAIDS Report on the Global AIDS Epidemic, 2010*, 2010, at http://www.unaids.org/documents/20101123_GlobalReport_em.pdf, accessed 12/03/12, at 28). Women account for 59.1% of adults with HIV, and among 15-49 year-olds HIV prevalence among women is 8% and nearly half that (4.3%) among men. (National AIDS Control Council (NACC) and National AIDS and STI Control Programme (NASCO), *The Kenya AIDS Epidemic Update 2011*, (Nairobi, Kenya: 2012) at http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce/KE_Narrative_Report.pdf, accessed 12/12/13; at 6). In 2011, nearly estimated 104,000 people became newly infected with HIV; 91,000 were adults. (NACC and NASCO, at 8). In 2012, 57,000 people are estimated to have died from AIDS-related causes, less than half the 120,000 estimated deaths in 2001. But the number of AIDS orphans (children aged between 0 and 17 years who have lost one or both parents to AIDS) had increased in 2012 to an estimated 1 million, up from an estimated 820,000 in 2001. (UNAIDS Kenya webpage).

For a law student whose graduate and post-graduate studies already had a strong human rights flavour and whose extra-curricular activities and personal experiences had brought her into contact with PLWHAs, the issues that this research deals with were ripe for investigation.

In the time it has taken to write this research, a number of key events, outlined later, have taken place. One of the most important is the adoption in August 2010 of a new constitution in Kenya. Among its innovations is an enforceable Bill of Rights that explicitly provides for individual health-related rights; or, more precisely, the right to “the highest attainable standard of health, which includes the right to health care services, including reproductive health care.”² This provision is buttressed by various legal assurances from the State such as equality and non-discrimination³ and the adoption of measures, within the boundaries of resource availability, to ensure the progressive realization of this right.⁴ This introduces the prospect for the first time in Kenya of legal challenges against the State by individuals alleging that it has failed to meet its healthcare obligations. This is precisely the charge made by many of the PLWHAs interviewed for this research.

Whether the new constitution can fulfil their expectations and those of other Kenyans remains to be seen, but in order to appreciate the hopes and expectations bound up with this legal instrument, one must first understand how rights have been employed as part of the legal and public political discourse in Kenya. That is, how rights relate to law, morality, community and the State and specifically, how they do this within the Kenyan context. Such an analysis should provide insights into how

² Art. 43(1)(a). Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010*, 2010, Kenya Law Reports (www.kenyalaw.org), accessed 10/12/13, at 31. (Published by the National Council for Law Reporting, with the Authority of the Attorney General).

³ The first four subsections of Art. 27 state that: “(1) Every person is equal before the law and has the right to equal protection and equal benefit of the law; (2) Equality includes the full and equal enjoyment of all rights and fundamental freedoms; (3) Women and men have the right to equal treatment, including the right to equal opportunities in political, economic, cultural and social spheres; and (4) The State shall not discriminate directly or indirectly against any person on any ground, including race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, disability, religion, conscience, belief, culture, dress, language or birth...” (ibid, at 24).

⁴ Specifically, the new constitution requires the State to “take legislative, policy and other measures, including the setting of standards, to achieve the progressive realisation of the [socio-economic] rights guaranteed under Article 43.” (Art. 21(2). Ibid, at 20).

rights operate as individual claims and responsibilities, but also interrogate their role as a cohesive moral force which holds the human community together.

Thus, investigating the issues at the core of this research necessarily covers a broad and varied landscape, which takes in law but also other fields, too, such as public health, medicine, sociology, anthropology and political science. This, therefore, is the interdisciplinary approach that this research adopts, and its rationale is three-fold: firstly, a central objective of this research is to explore how the complex experiences of PLWHAs have shaped their internalization- or not- of the language and norms of human rights, and how the human rights discourse manifests their individual and collective aspirations as well as their anxieties. This approach is thus the best, indeed, perhaps the only, way to capture the myriad and overlapping factors which converge to construct PLWHAs' subjectivities and their notions of entitlement. Secondly, an interdisciplinary approach reflects the present-day reality that human rights are not the exclusive domain of law, with other fields now claiming a stake in the wider rights debate and offering human rights-based perspectives from their particular vantage points. Last but not least, an interdisciplinary approach also reflects the author's varied experiences- as an academic in law as well as a campaigner on behalf of PLWHAs- experiences which not only inform her research interests but have also shaped the particular questions that this research pursues. It is vital, then, to find the most appropriate theoretical framework that accommodates the analysis of these myriad issues.

b) The Theoretical Framework

This research deals with a range of concepts, among them entitlements, rights, law, the State, citizenship, illness, sexuality, gender, stigmatisation, discrimination, dignity, duty, domination, community, and civil society.

Postcolonial theory provides the overarching theoretical framework which connects them. The postcolonial framework "represents a response to a genuine need: the need to overcome a crisis in understanding produced by the inability of old categories

to account for the world.”⁵ Its appeal as a framework for analysing the issues that this research is concerned with is clear: for what will become clear as this thesis unfolds is that these issues are manifestations of a postcolonial world.⁶

It is an ideal framework for drawing out the complexities and nuances which go into the construction of Kenyan PLWHAs’ subjectivities. It helps us understand how in their comments about their health entitlements and their attribution of duty, wider notions are at play: notions about their conceptualization of the relationship between the individual and the State, and their affiliations to both an ethnic and a national public. Because the nature of these relationships is central to the issues this research deals with, the work of Mahmood Mamdani and his theory of the bifurcated State provides the predominant framework within which the relationship of the individual and the postcolonial State is analysed. Mamdani’s theory fits perfectly within the broader postcolonial framework: his discussions explore the formation of the colonial state and its creation of citizens and subjects. He analyzes the creation of a ‘universal’ African legal subject whose cultural differences were purposely muted in order that customary law may be applied uniformly to all Africans. And yet, as he compellingly posits, the colonial state’s propagation and perpetuation of a race-based citizen-subject divide is sustained in the postcolony, albeit in a deracialized form. It is from this fundamental basis that this research builds so much of its analysis of PLWHA’s notions of identity and affiliation, entitlement and obligation. It provides a platform for the discussion of conceptualizations of the human rights project and its norms.

The postcolonial framework also facilitates the examination of the gender and cultural norms which define the PLWHA experience. These norms have shaped the pattern of the largely sexually-transmitted HIV infection in Kenya, as well as the development and ramifications of the AIDS epidemic. In modern Kenya, practices and beliefs which put groups such as women and young girls especially at risk of HIV infection are being primarily challenged from the normative perspective of human rights. This creates a flashpoint between African moral frames of reference (although they are today infused with imported, though now indigenized, religious norms) and a

⁵ Dirlik, Arif, *The Postcolonial Aura: Third World Criticism in the Age of Global Capitalism* (Boulder, Colorado; Oxford, UK: Westview Press, 1997), at 73.

⁶ *ibid*, at 76.

European/Western one. This sets the stage for an analysis of illness, sexuality, stigmatisation, discrimination, concepts of dignity, duty, domination and the location of the individual in the community. Postcolonial feminist theories are a particularly potent branch in the facilitation of this analysis. As Ratna Kapur asserts, they “provide a critical and necessary challenge to explanations of women’s subordination that have been furnished from liberal and Western positions, especially those that have come to occupy the international human rights arena in their understanding and articulation of concerns of third world women.”⁷

The fact that this articulation is being done by or through the auspices of CSOs, provides yet another potent issue on which a postcolonial framework can provide crucial insights. For the interpolation of civil society actors into the citizen-State dialogue not only alters the terms in which it is conducted but also the dynamics between the parties. The CSO phenomenon, and the favoured framework of rights within which many of its members seek to mediate individual-State relations, are a feature of globalization. And yet their role requires closer scrutiny in order to gain a better appreciation of their agenda in creating the dominant narratives of development today. The appeal of a postcolonial analytical framework is clear here: it facilitates the examination of key ideas like globalization and global capitalism; the Eurocentricity of capitalism (both now and historically) as well as that of human rights; the role of the nation in development; and how the local connects with the global.⁸ As Sankaran Krishna puts it, “postcolonialism articulates a politics of resistance to the inequalities, exploitation of humans and the environment, and the diminution of political and ethical choices that come in the wake of globalization.”⁹

A postcolonial analytical framework thus provides a more than adequate umbrella under which can shelter all the issues that this research deals with. But this research is also conscious of the criticisms that have been levelled against postcolonial analyses, and so strives to mitigate the risk of reducing all analyses to simplistic binary oppositions of dominion and subjection, of the European/Western/settler oppressors

⁷ Kapur, Ratna, *Erotic Justice: Law and the New Politics of Postcolonialism* (London: GlassHouse, 2005), at 4.

⁸ Dirlik (n 5), at 76.

⁹ Krishna, Sankaran, *Globalization and Postcolonialism: Hegemony and Resistance in the Twenty-First Century* (Lanham, Maryland: Rowman & Littlefield, 2009), at 2.

and the African/Sub-Saharan/indigenous oppressed. This research draws out the nuances that such narratives might conceal: for instance, the appeal to many PLWHAs of re-imagined identities, the possibility of which a human rights framework holds; their self-determined oscillating allegiances to both a national (modern) and ethnic (traditional) public; their agency in claiming dignity and rejecting stigma for themselves, even as they deny the dignity of, and stigmatize others within the PLWHA community; and last but not least, the multiple moral frameworks of reference within which PLWHAs articulate their health entitlement claims. By spotlighting findings such as these, this research is able to apply the most appropriate analytical framework for its investigation while avoiding some of its shortcomings. With this in mind, we must now turn to the conceptualization of one of the key terms of reference in this research: rights.

c) Conceptualizing Rights

The Bill of Rights in Kenya's new constitution can be seen as a symbol of the triumph of law as the source of rights in the modern age, and a triumph, too, of the text not only as the favoured receptacle that carries rights to the individual but grounds them in reality. The Kenyan government has crafted a much more robust Bill of Rights than the one of the independence-era- for it contains a detailed list of civil and political as well as cultural, social and economic rights (categories which are discussed later in this chapter as part of the literature review)- and presented it in its refurbished constitution. In so doing, Kenya has taken its place alongside nearly all the other countries of the world in "[constitutionalizing] the ideology of human rights."¹⁰

The definition of human rights used in this research is of "those claims which every human being is entitled to have and enjoy, as of right, by virtue of his or her humanity, without distinction on such grounds as sex, race, colour, religion, language, national origin, or social group."¹¹ It is a working definition, however, which does not specify the nature and content of such rights, as this research elucidates later in the

¹⁰ Henkin, Loius, 'Human Rights: Ideology and Aspiration, Reality and Prospect,' in Power, Samantha, and Allison, Graham (eds.), *Realizing Human Rights: Moving from Inspiration to Impact* (New York: St. Martin's Press, 2000), at 25.

¹¹ An-Na'im, Abdullahi Ahmed, 'Introduction: Expanding Legal Protection of Human Rights in African Contexts,' in An-Na'im, Abdullahi Ahmed (ed.), *Human Rights Under African Constitutions: Realizing the Promise for Ourselves* (Philadelphia: University of Pennsylvania Press, 2003), at 3.

literature review when it explores the debate around the content of a right to health. The term 'rights', meanwhile, is specifically ascribed in this research to formally recognized, often legally-enforceable claims, and is especially to be distinguished from the term 'entitlement', particularly when referring to claims made by the respondents interviewed for this research. This latter word is used in this respect to describe a claim to a privilege the basis for which may be varied (cultural, moral, legal or other norms) and/or unarticulated.

The preliminary definition of 'human rights' provided above locates the individual in the international human rights legal system as the rights-holder, and the State is confirmed as the duty-bearer, obliged to provide for and protect the individual's rights through the appropriate mechanisms and institutions at national level.¹² So in the new Bill of Rights the Kenyan State not only finds a symbol of modernity, it also has a shortcut to bolstering its legitimacy before, as will be seen throughout this thesis, an increasingly sceptical local and global audience. This drama is being played out in a world where rights, and human rights in particular, have acquired incredible currency. As Douzinas asserts, "[h]uman rights have become the *raison d'être* of the state system as its main constituents are challenged by economic, social and cultural trends. It is no coincidence that human rights 'triumphed' at the point of maximum angst about life chances and malaise about the collapse of moral certitudes and political blueprints."¹³ The international human rights regime, in the sense of the global movement for the protection, promotion and assertion of international responsibility for human rights at the national level¹⁴, thus underwrites the role of the State despite its diminution in the face of globalization. Further, the international law of human rights, in largely allocating no legal role for CSOs despite their growth in influence, a reality which this research confirms in this and subsequent chapters¹⁵, arguably suppresses their status. The State remains the pivotal framework for political, social and economic interaction.¹⁶

¹² *ibid*, at 2.

¹³ Douzinas, Costas, *The End of Human Rights: Critical Thought at the Turn of the Century* (Oxford: Hart, 2000), at 374.

¹⁴ Henkin (n 10), at 8.

¹⁵ An-Na'im (n 11), at 4-5.

¹⁶ *ibid*, at 4.

And the instruments by which the system of human rights law cements the State-individual dynamic are important to our understanding of rights today: Douzinas writes of the decline of the concept of nature as the source of rights; unless they are recognized in domestic and international law, rights cannot be called upon for the protection of individuals.¹⁷ In other words, the Bill of Rights in Kenya's constitution is a triumph of legal positivism and its proponents¹⁸, locating Kenya in the modern, rational age of law. As Ronald Dworkin asserted, "If the Government does not take rights seriously, then it doesn't take law seriously either."¹⁹ For the many who increasingly turn to the law when articulating their claims to entitlements, the law is confirmation of a political commitment to the moral principles on which those claimants base their demands.²⁰

Yet one of law's ingrained conceits is its presupposition of subjects "who can identify and use it."²¹ Stephen Hicks persuasively identifies a problem of perspective: the tendency in legal theory to accentuate the aspect of law that is external to the human being- law as a system of rules and norms- and de-emphasize its subjective aspect, thus dehumanizing it.²² He contends that law, like religion and morality, embodies the human being's attempt to organize the conceptual space she shares with others and is a manifestation of how she negotiates and regulates her relationship with them.²³ And it is in this internalized sense that we first experience law, "before we experience law as citizens, in law suits or otherwise as conventionally understood."²⁴

It is this interface between the internal aspect of the law and the external elements that this research finds more interesting, for here we might glimpse the real subject of law, one who, as Jacques Lacan argues in his theory of psychoanalysis and the law, has no 'inside' and 'outside' but who is constituted of all elements, from her psyche

¹⁷ Douzinas (n 13), 10-11.

¹⁸ See Edmundson, William A., *An Introduction to Rights* (Cambridge: Cambridge University Press, 2004), at 62-3.

¹⁹ Dworkin, Ronald, *Taking Rights Seriously* (London: Duckworth, 1977), at 205

²⁰ Harvey, Colin, 'Talking About human Rights,' *European Human Rights Law Review*, No. 5 (2004), pp. 500-516, at 500.

²¹ Hicks, Stephen, 'Law and Being in Law as Way of Being,' in Panou, S.; Bozonis, G.; Georgas, D.; and Trappe, P. (eds.), *Human Being and the Cultural Values: 12th World Congress, Athens, 1985* (Stuttgart: F. Steiner Verlag Weisbaden, 1988), at 41

²² *ibid.*, at 43

²³ *ibid.*, at 41-2

²⁴ *ibid.*, at 42

to her identity, language, society, law.²⁵ How do they aggregate in a PLWHA to mould her understanding about her health entitlements and how does she articulate this in the interviews? How, if at all, does she *imagine* a right to health? This discussion surely precedes or occurs contemporaneously with that about the structural framework within a society which facilitates and/or hinders an individual's realization of her right to health.

To that end, this research pursues its investigation by eschewing the typical top-down analysis of human rights: though it refers to relevant domestic and international legal instruments, it avoids a textual examination of the right to health, a task that has been better undertaken on many occasions by others.²⁶ This approach would be further limiting here because of the obvious gulf between the rhetoric of rights and the reality of their implementation in countries like Kenya, which is the focus of this research. Factors such as the (variable) acculturation of State institutions to human rights norms contribute to this.²⁷ Moreover, even while this research examines various established concepts and theories in human rights, this exercise is driven by a desire to interrogate how, if at all, laypeople interact with its norms and concepts in reality; how, if at all, they incorporate them with their lived experiences; and how, if at all, they attempt to reconcile them with their pre-existing value systems. This bottom-up perspective, often missing in the existing literature, promises new avenues for exploring these ideas in practice. It is inspired in part by the approach of Rosalind Petchesky and Karen Judd and the International Reproductive Rights Research Action Group (IRRRAG) in their study of the strategies and processes by which ordinary women around the world seek to assert and realize their reproductive and sexual rights.²⁸

²⁵ Caudill, David S., *Lacan and the Subject of Law: Toward a Psychoanalytic Critical Legal Theory* (Atlantic Highlands, N.J.: Humanities Press, 1997)

²⁶ See, for instance, Leary, Virginia, 'The Right to Health in International Human Rights Law,' *Health and Human Rights: An International Journal*, Vol.1, No. 1 (1994), pp.24-56; Toebe, Brigit, 'The Right to Health,' in Eide, Asbjørn; Krause, Catarina; and Rosas, Allan (eds.), *Economic, Social, and Cultural Rights: A Textbook* (2nd Revised Ed., Dordrecht; Boston : Martinus Nijhoff Publishers, 2001); Jayawickrama, Nihal, *The Judicial Application of Human Rights Law: National, Regional and International Jurisprudence* (Cambridge: Cambridge University Press, 2002)

²⁷ Ghai, Yash, in William Twining (ed.), *Human Rights, Southern Voices: Francis Deng, Abdullahi An-Na'im, Yash Ghai and Upendra Baxi* (Cambridge, UK ; New York : Cambridge University Press, 2009), at 131

²⁸ Petchesky, Rosalind and Judd, Karen (eds.), *Negotiating Reproductive Rights: Women's Perspectives Across Countries and Cultures* (London: Zed Books, 1998)

Unlike several of the women in Petchesky and Judd's study, however, many PLWHAs interviewed for this research did not make claims in relation to their health needs on the basis of the normative framework of human rights. Instead, the claims they made appealed to moral values housed within alternative normative frameworks. Such invocation of morality may appear unfashionable in the modern human rights legal system. Indeed, in the triumph of positive law Douzinas sees the "moral poverty of [liberal] jurisprudence" which subordinates the imaginary realm to positive law and its rules.²⁹ Yet the evidence from the interviewees in this research suggests that away from jurisprudential matters and the legal experts for whom it retains currency, among laypeople, that is- people who are non-experts in human rights- Douzinas' "imaginary domain" thrives. For when many of the respondents in this research made health claims it was not on the basis of formal legal obligations (of which few appeared aware) but moral obligations they ascribed to their spouses, families, relatives, CSOs or the State.

And this disjoint between claims made on legal as opposed to moral grounds is one which many legal positivists seek to emphasize, even suggesting that it privileges the former over the latter.³⁰ Although the notion of law as morally neutral is not a universal one³¹, the proponents of positivism are nevertheless driven in their views partly by a suspicion that moral judgements originating from customs, be they cultural or religious, are not always reliable foundations for "practical judgment."³² This argument exemplifies a broader, fundamental disconnect between ideas around rights as they are conceptualized by legal experts and practitioners- among whom my academic and professional background must cast me, with ramifications for the kind of research I undertake here (more of which in Chapter 2)- and as they are conceptualized by laypeople.

²⁹ Douzinas (n 13), at 373-4.

³⁰ See Perreau-Saussine, Amanda, 'Bentham and the Boot-strappers of Jurisprudence: The Moral Commitments of a Rationalist Legal Positivist.' *Cambridge Law Journal*, Vol. 63, No. 2 (2004), pp. 346-383, at 346 and 348.

³¹ See, for instance, Perreau-Saussine, *ibid.*

³² *ibid.*, at 348.

As will be seen shortly in the literature review (and discussed in more detail in subsequent chapters) the moral frameworks within which many PLWHAs conceptualized their health claims and whose vocabulary they often employed to state those claims, were based on cultural norms. Additionally, in an environment less in thrall to secularism than the West, they drew on religion, particularly perhaps Christianity, which has strong historical links to theories of natural law.³³ It is precisely from these ties that the age of the positivization of law, in its quest for rationality, sought to distance itself.³⁴ But for such PLWHAs, the end of this process which heralded positivism and delinked nature and the divine has yet to be realized; God is not [yet] in “retreat... [removed] from earthly matters.”³⁵

Yet it may be the case that morality has not been removed from the conceptualization of rights at all, merely reborn in a different form, and perhaps one, as Michael J. Perry has argued, which is so successful that it has become *the* definition of rights, not merely a dimension of it. He asserts that “the morality of human rights has become the dominant morality of our time; indeed, unlike any morality before it... a truly global morality.”³⁶ This argument embraces that of Douzinas, of the predominance- the morality, then- of positive law and its structures and mechanisms.

But in aligning itself to secularity, it has been posited that this new morality has left a hole in its philosophical narrative, for when it asserts the inalienable rights and dignities of individuals, *who*, precisely, makes this assertion? Quoting Art Leff’s reiteration of Nietzsche, Perry writes:

Napalming babies is bad.
Starving the poor is wicked. Buying and selling each other is depraved.
Those who stood up to and died resisting Hitler, Stalin, Amin, and Pol Pot- and General Custer too- have earned salvation. Those who acquiesced deserve to be damned.
There is in the world such a thing as evil.
[All together now:] Sez who?
God help us.³⁷

³³ Douzinas (n 13), at 53.

³⁴ *ibid*, at 63.

³⁵ *ibid*.

³⁶ Perry, Michael, J., ‘Morality and Normativity,’ *Legal Theory*, Vol. 13, No.3-4 (2007), pp 211-255, at 214. See also Henkin (n 10), at 3.

³⁷ Leff, Arthur Allen, ‘Unspeakable Ethics, Unnatural Law,’ *Duke Law Journal* (1979), pp. 1229, at 1249, quoted in Perry (n 36), at 236.

The PLWHAs' stance, therefore, arguably represents a lay-level rebuff to the "radical project of human rights [which accepts] modernity's rejection of religious transcendence."³⁸ Their moral-based claims are an affirmation of Perry's argument that in the real world fundamental moral questions and religious or metaphysical ones remain profoundly interlinked.³⁹ To ignore this fact is to negate the views and considerations of this grassroots base, the very people in whose name a notion has been popularized, justifiably or otherwise, of the human rights enterprise as the preeminent moral framework.

In the PLWHAs' stance, too, is perhaps a notion that is inherently threatening to the high priests- the experts and practitioners- of the human rights project: if the moral character of rights can be said to precede their legal character⁴⁰, if moral claims can be said to transcend legislation or adjudication, which is arguably what Dworkin suggests although he speaks specifically in relation to rights against governments⁴¹, then the systems and structures, be they cultural or religious, which authenticate and prop up these moral claims can rightly challenge the claim of pre-eminence currently asserted by the human rights project and its practitioners. As this research argues, this forms an aspect of the contest playing out in Kenya today as the national and ethnic spheres negotiate their fluid boundaries. At stake is the allegiance of, and claim of authority over, the citizen-subject.

But even the subject of the ethnic domain must in the modern human rights age stake a claim as a citizen of the national domain in order to enjoy the breadth of entitlements available to a citizen of Kenya. Thus the process of creating and recognizing a legal subject, law's "sovereign plaything and its potential critic, the autonomous centre of the world as well as the dissident and rebel"⁴² is a deeply political and contentious exercise, with both symbolic and real ramifications, as this research explains shortly in the literature review and expounds upon in Chapter 4. There is vital currency in being identified as a- indeed, as *the*- subject of law. Douzinas makes the argument, repeated in Chapter 8, that "it is not so much that humans have

³⁸ Douzinas (n 13), at 107.

³⁹ Perry (n 36), at 242.

⁴⁰ Henkin (n 10), at 5.

⁴¹ Dworkin (n 19), at 197.

⁴² Douzinas (n 13), at 373.

rights but that rights make human”⁴³, and the legal subject is hewn out of positive law and its rules.⁴⁴

It will therefore be interesting to consider, as is done shortly in the literature review and in greater detail in the last chapter, some of the vocabulary and concepts which are commonly associated with the human rights project that arose within the context of the interviews for this research, and on the basis of which, therefore, one might begin to speculate about the ideas or conceptualizations of rights at play among the laypeople interviewed for this research. These include ideas about ‘dignity’, ‘humanness’, ‘citizenship’, which appear to resonate with the wider lay public as it attempts to grasp something that is increasingly familiar yet still elusive and intangible. This is true not only among the relatively small number of PLWHAs interviewed for this research, but also the two-thousand-plus respondents who contributed to the Haki Index, a countrywide human rights perception survey published in 2006, whose findings are discussed in more detail in Chapter 8.⁴⁵

Does an increased familiarity with human rights-related concepts and vocabulary, however, mark it out as a cohesive moral force which binds together a community- a human rights community- across a range of levels from local to global? If one thinks of rights as an articulation of political interests, then community seems the natural condition in which to strive for and enjoy the fruits of such interests. As Perry argues, “few would deny that the social nature of human beings is such that a person is better off in virtue of being part of a network of loving family and friends and also in virtue of being a member of a safe, secure political community.”⁴⁶

⁴³ *ibid*, at 372.

⁴⁴ *ibid*, at 373.

⁴⁵ The Haki Index involved a general sample of 2,299 adult Kenyans, all but 300 of whom were randomly selected based on probability in proportion to the population size; the 300 extra respondents were made as an allowance to “human rights situation” faced by the population in the north and north-east of the country (particularly along the Kenya/Somalia border), although this allowance was then accounted for during analysis. (Kenya Human Rights Commission (KHRC), *The 2006 Haki Index: Measuring Public Perceptions on the State of Human Rights in Kenya and the Case of the Devolved Public Funds* (2006), at <http://www.khrc.or.ke/documents/2006%20Haki%20Index.pdf> (accessed 20/05/09), at VII). The survey was conducted under the auspices of the Kenya Human Rights Commission (KHRC); *Haki* is the Kiswahili word for ‘rights’. The Haki Index 2006 often refers in its analyses to a 2005 index, the first survey commissioned by KHRC, of which the Haki Index 2006 was follow-up, by way of comparison. This thesis relies on any such comparisons as given; as such, references to ‘the Haki Index’ here apply only to the 2006 index.

⁴⁶ Perry (n 36), at 241.

At the latter end of the local-through-global spectrum, the widely accepted notion of international responsibility for the protection of individual rights at the national level has already been mentioned.⁴⁷ Henkin, for instance, points out the cross-national policies and actions of States, CSOs and the media, which together drive “[t]he various influences that induce compliance with human rights norms [which] are cumulative, and some of them add up to an underappreciated means of enforcing human rights, which has been characterized as ‘mobilizing shame’.”⁴⁸ The power of this ‘mobilizing shame’ is exemplified, as the literature review assesses in more detail, by the global campaign for HIV/AIDS treatment and the recognition of PWLHAs’ rights, which influenced the re-conceptualization HIV/AIDS as a human rights issue at international, national and local levels. Such mobilization does reinforce the notion of shared community bound by the customs of human rights. Indeed, Douzinas points out that despite the human rights regime’s fetishization of the individual as the focus of human rights, “[i]ndividuals only have rights in community”, a privilege they enjoy among other individuals: fellow citizens.⁴⁹

But this idea begs a fundamental question: what are the parameters of this community? For notice the slippage in international human rights law from universal human rights, inalienable and adhering to all human beings, “not by grace, or love, or charity, or compassion,” as Henkin puts it⁵⁰, to a set of privileges to be enjoyed only by the very exclusive club of human beings designated as citizens.⁵¹ The first extends the embrace of community to us all; the other’s reach is narrower, depending on legal jurisdiction. Citizens enjoy political rights that others do not, and may make claims on the State on this basis. It marks the epitome of the modern subject’s humanity according to Douzinas⁵²; “[w]e become human through citizenship and subjectivity is based on the gap, the difference between universal man and state citizen.”⁵³ The international law of human rights, then, anticipates, even facilitates, this fractionalization of the ‘global human rights community’, for in reality the rights

⁴⁷ Henkin (n 10), at 8.

⁴⁸ *ibid*, at 24.

⁴⁹ Douzinas (n 13), at 106.

⁵⁰ Henkin (n 10), at 5.

⁵¹ Douzinas (n 13), at 106.

⁵² *ibid*, at 105.

⁵³ *ibid*, at 106.

of individual human beings can only be claimed against, and paradoxically protected by, the State in which they claim citizenship.⁵⁴ The individual without a State is excluded from the 'human' family as defined by the system of international human rights law. And if this community of human rights were not narrow enough, even within the national legal jurisdiction it is often further divided, with various sub-groups- PLWHAs are a good example- claiming specific rights that pertain to their particular lived experiences and concerns. Another layer is added in the postcolonial context of countries like Kenya: the State, the duty-holder in the human rights dynamic, forms only one locus of power in these settings, and not always the most influential at that. As explored shortly in Mamdani's bifurcated State theory, which as seen earlier is a key pillar in this research's framework of analysis, the citizen of the national public draws her rights, with their emphasis on the individual, from the State; meanwhile the subject of the ethnic realm draws hers, with their accent on community, from the exclusive tribe. And although this research argues and points to evidence from its own findings that there is much fluidity between these communities, there is nevertheless proof of "the culture of human rights [meeting] resistance from an older societal culture, a culture of gender inequalities and mistreatment of 'others'."⁵⁵ Arguably, then while the human rights project may act as a glue which binds part/s of the human community together, it also has the potential to expose and even foster social and political conflict and disharmony where the norms it proposes apply selectively or conflict with pre-existing or more established ones.

Despite all this, however, this research argues that the emergence of the HIV/AIDS epidemic has introduced and accelerated awareness of certain human rights concepts to a wider public, playing a role in opening up the discourse to a normally excluded constituency: laypeople. Moreover, the findings appear to challenge any notion that laypeople, when they are not part of a broader organized, grassroots human rights movement, an underdeveloped phenomenon in Africa anyway, are merely passive subjects of human rights laws and norms without a role to play as active agents in the rights dynamic. For in those instances when they are aware of them, they are able

⁵⁴ An-Na'im (n 11), at 1. See also Henkin (n 10), at 7-8.

⁵⁵ Henkin, *ibid*, at 26.

and willing to accept or reject these norms as part of the personal moral vocabulary by which they articulate their conditions or grievances, actively interpreting or reinterpreting them in accordance with their subjectivities and wider social, cultural and economic contexts. Indeed, the findings show clear instances of interviewees attempting to reconcile the received language and values of human rights with the more established and predominant moral frames of reference to which they are accountable, frameworks which are founded on cultural and/or religious norms.

By spotlighting and analyzing the basis of the resulting accommodations and paradoxes, this research casts laypeople in an atypical role from those they commonly occupy in academic narratives and examinations of human rights. In such narratives, they are often at one extreme passive victims of rights violations, at the other vocal, politicized, rights-aware agitants for the recognition and protection of rights. Thus, this research sheds light on other more subtle, often undocumented ways in which laypeople might influence the direction and emphasis of the rights discourse. Furthermore, it uncovers both challenges to, and opportunities for, the promulgation and sustainability of the seemingly unstoppable global human rights enterprise.

This research concludes that a greater understanding of how notions of entitlement and rights are constructed and human rights norms internalized, such as is attempted on a small scale here, contributes not only to the existing wealth of theoretical knowledge about rights but has practical implications for human rights advocates and promoters. Understanding the processes that the research highlights illuminates how one of their key target audience, laypeople, engages with the language and idea of rights when they articulate their needs and entitlement claims. This would aid the development of more effective strategies to shape what are, after all, mutable perceptions, and could contribute to a more successful propagation of these norms at the grassroots and the realization and protection of rights such as health in the long term. The research therefore strongly urges greater engagement by human rights organizations and practitioners with this constituency and a deeper commitment to an inquiry into the way in which the language, concepts and norms of rights are interpreted, internalized and articulated by laypeople in practice.

Having set out the overarching theoretical framework within which the discussions in this research take place, as well as its conceptualization of rights, the rest of this chapter will now proceed to provide a clearer outline of the scope of principal terms of reference that frame the research. This is done by integrating the discussion into a review of the significant literature which informs the research's main arguments. The scope of the two concepts which straddle this research, health and human rights, come up first for analysis, with a look into how the literature delineates them and comparing and contrasting this with the meanings attached to them by the interviewees for this research. This exercise highlights a number of similar perspectives, such as that between some laypeople's and public health theorists' conceptions of health as broadly encompassing physical, mental and social aspects. It also addresses the contribution of dominant health paradigms to our understanding of the modern subject. Meanwhile, the terminology and fundamental concepts relating to human rights, touched upon at the beginning of this chapter, prove just as contentious. The chapter delves further into the disputed notions, dealt with in even more detail in later chapters, like dignity, citizenship and what it means to be human. A showcasing of interviewees' responses here differentiate this part of the discussion of rights with the one at the beginning of this chapter; for the interviews again serve to illustrate that the debate about their meaning is not confined to theorists and academics. Last but not least, the chapter charts the conceptual and practical development of linkages between health and rights, and in particular the emergence of the so-called rights-based approaches (RBAs) in the development arena. The chapter then concludes with an outline of the thesis structure.

II. Literature Review

The literature for this research is drawn from a range of cross-cutting disciplines including law, public health, political science, anthropology and sociology. It includes several sources that provide useful critiques on some of the underlying events, systems and processes that the research identifies as pivotal in the formation of PLWHAs' subjectivities and notions of entitlement. The main ones include literature which problematizes the global human rights enterprise and some central norms, primarily the State-citizen relationship; postcolonial critiques, which spotlight the

dubious and enduring legacy of colonialism, especially its imprint on the post-independence African State; feminist critiques, and their sub-species of African feminist critique, crucial to the examination of the specific social, cultural and economic context which has shaped the demographics of Kenya's AIDS epidemic. The latter provide an especially vital perspective given that women constitute the greater portion of PLWHAs in Kenya and interviewees for this research. This literature also provides crucial insights into law's attempts to address the concerns of marginalized constituencies, which mirror and inform the PLWHA struggle. Finally, the research draws from literature which critiques the values latently or overtly articulated by public health policies. These have significantly influenced how modern medical service users such as the PLWHA interviewees acquire prescribed knowledge and ideas that mould and transfigure their conceptions of themselves as patients and human beings, despite living in a society where traditional medicine and its supporting institutions and norms predominate. What the literature in its totality helps to underscore is a research topic whose essential terms and concepts are far from settled.

a) (Elusive) Terms of Reference: Health and Human Rights

The totemic 1946 World Health Organization (WHO) Constitution defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity,” and was the first to assert that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”⁵⁶ The right has been recognized in numerous international instruments since, including Art. 12 of the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR)⁵⁷, and the phrase the ‘right to health’ or its variations is to be found in

⁵⁶ WHO, *WHO Constitution, Forty-fifth Edition*, October 2006, at http://www.who.int/governance/eb/who_constitution_en.pdf, accessed 20/11/09. See also Ely Yamin, Alicia, ‘Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care,’ *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 45-63, at 47.

⁵⁷ Office of the United Nations High Commissioner for Human Rights (OHCHR), International Covenant on Economic, Social and Cultural Rights (ICESCR), 1966, at <http://www2.ohchr.org/english/law/cescr.htm>, accessed 12/03/10, Art. 12. See, for instance, UN, *Universal Declaration of Human Rights (UDHR)*, 1948, at <http://www.un.org/en/documents/udhr/>, accessed 22/06/09), Art.25, and the landmark Declaration of Alma-Ata , 1978: WHO, *Declaration of*

various regional conventions and replicated or modified in the Bills of Rights of national constitutions such as Kenya's, as noted earlier. The country itself acceded to the ICESCR on 1st May 1972.⁵⁸

This acknowledgement of the duality of mental and social aspects was reflected in the PLWHA interviewees' responses about their health needs.⁵⁹ Indeed, as human rights and public health literature acknowledge, health is an ideal lens through which to analyze not only the cross-cutting factors that determine vulnerability to HIV infection but also those that influence capacity to realize rights.⁶⁰ Schweitzer, *et al*⁶¹ and Peter DeRoche and Kenneth Citron⁶² point out the transformative effect that HIV/AIDS has on a PLWHA's psychological make-up and stress that addressing her psychosocial needs improves her health outcomes. Yet this element of their health needs, especially for those in poor countries, is, as Kelly, *et al*⁶³ and Collins, *et al*⁶⁴ underline, little investigated and scarcely provided for. Meanwhile, in its overt reference to 'social well-being', the WHO's definition of health recognizes that power relations

Alma-Ata, 1978, at http://www.who.int/hpr/NPH/docs/declaration_almaata.pdf, accessed 22/06/09.

For a list of more of these see Leary, *op. cit.*, at 33

⁵⁸ The ICESCR entered into force on 3rd January 1976. However, Kenya entered a reservation on Art. 10(2) which says: "Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits." The reservation declared, "While the Kenya Government recognizes and endorses the principles laid down in paragraph 2 of article 10 of the Covenant, the present circumstances obtaining in Kenya do not render necessary or expedient the imposition of those principles by legislation." (See the text at UN, *ICESCR*, 1966, UN Treaty Series at <http://treaties.un.org/doc/Publication/UNTS/Volume%20993/volume-993-I-14531-English.pdf>, at 89)

⁵⁹ For instance, interviewee 48 listed her needs as, "food, medicine and treatment, and I also have to have moral support, and the acceptance plays a big role; there's also spiritual nourishment and shelter."

⁶⁰ As Turiano and Smith rightly argue, health particularly lends itself to an analysis of the full implications of human rights because of the overlapping factors it encompasses and because "health indicators are the same for every person and population, whereas other human rights may be more particular to local contexts." (Turiano, Laura and Smith, Lanny, 'The Catalytic Synergy of Health and Human Rights: The People's Health Movement and the Rights to Health and Health Care Campaign,' *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 137-147, at 142)

⁶¹ Schweitzer, Ana-Maria; Mizwa, Michael B.; and Ross, Michael W., 'Psychosocial Aspects of HIV/AIDS: Adults,' *HIV Curriculum*, Baylor International Pediatric AIDS Initiative (updated 28/01/10), at <http://bayloraids.org/curriculum/files/25.pdf>, accessed 01/03/10.

⁶² DeRoche, Peter and Citron, Kenneth, 'Psychotherapy,' in Citron, Kenneth; Brouillette, Marie-Josée; and Beckett, Alexandra (eds.), *HIV and Psychiatry: A Training and Resource Manual* (Cambridge: Cambridge University Press, 2005).

⁶³ Kelly, Kevin; Freeman, Melvyn; Nkomo, Nkululeko; and Ntlabati, Pumla, *The Vicious Circularity of Mental Health Effects of HIV/AIDS: Symptom and Cause of Poor Responses to the Epidemic*, Centre for AIDS Development Research and Evaluation (CADRE), 11th July 2007, <http://www.cadre.org.za/files/Mental%20Health%20Kelly%20et%20al.pdf> (accessed 02/03/10).

⁶⁴ Collins, Pamela Y.; Holman, Alea R.; Freeman, Melvyn C.; and Patel, Vikram, 'Relevance of Mental Health to HIV/AIDS Care: What are the Mental Health Consequences of HIV?' *AIDS*, Vol. 20, No. 12 (2006): pp. 1571-1582.

determine health outcomes⁶⁵; that health, in the words of Lynn Freedman, “is socially produced.”⁶⁶ However, this aspect has been de-emphasized and the “biological individualism” at the heart of the predominant biomedical paradigm has become embedded.⁶⁷ As will be seen, some of the human rights literature critiques this model, which is nevertheless a core aspect of training for health experts and professionals, with Alicia Ely Yamin⁶⁸, Mark Finn and Srikant Sarangi⁶⁹ and others condemning it for delinking ill-health from the social, cultural, economic and political environment in which it is created.⁷⁰ The tendency in public health to downplay how these structural factors, as they are sometimes referred to⁷¹, predispose one to ill-health, and to accentuate the impact of personal behaviour on individual health outcomes⁷² is often mirrored by HIV prevention policies. It may also help explain some interviewees’ notions about individual choice and free will being fundamental to ensuring health.⁷³ Interviewee 16, for example, saw the requirements of health as entailing, “[d]rinking boiled water, stay away from people who are coughing, and from mosquitoes! Eating fruits and vegetables, which I get from the supermarkets and not just on the street, and I wash them very carefully, and I cook my food well and I don’t eat food that is too old.” Interviewee 11, who later said she had not heard about a right to healthcare, defined ‘healthcare’ as “keeping yourself healthy, so that even though you don’t get cured you get the right treatment at the right time, getting a balanced diet, keeping yourself smart.” Similarly, interviewee 41 explained that healthcare meant, “Being conscious of my general health. I have to monitor my own body, what to do if there’s anything wrong. Taking care myself, nutritionally, my

⁶⁵ Ely Yamin (n 56), at 47.

⁶⁶ Freedman, Lynn P., ‘Reflection on Emerging Frameworks of Health and Human Rights,’ *Health and Human Rights: An International Journal*, Vol.1, No.4 (1995), pp. 315-348, at 323. See also de Negri Filho, Armando, ‘A Human Rights Approach to Quality of Life and Health: Applications to Public Health Programming,’ *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 93-101

⁶⁷ Ely Yamin (n 56), at 47. See also Ruger, Jennifer Prah, ‘Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements,’ *Yale Journal of Law and the Humanities*, Vol. 18, No. 2 (2006), pp. 273-326, at 287.

⁶⁸ Ely Yamin (n 56).

⁶⁹ Finn, Mark and Sarangi, Srikant, ‘Articulations of Knowing: NGOs and HIV-Positive Health in India,’ in Higgins, Christina and Norton, Bonny (eds.), *Language and HIV/AIDS* (Multilingual Matters: Bristol; Buffalo; Toronto, 2010).

⁷⁰ Ely Yamin (n 56), at 47. See also Ruger (n 67), at 314.

⁷¹ See, for instance, Gupta, Geeta Rao; Parkhurst, Justin O.; Ogden; Jessica A., Aggleton, Peter; Mahal, Ajay, ‘Structural Approaches to HIV Prevention,’ *The Lancet* (2008) 372, pp. 764-775.

⁷² Ely Yamin (n 56), at 48.

⁷³ See also conversations with NGO officials in India, explaining the role of the ‘behaviour change’ paradigm, which stresses individual choice as the key ingredient, in their work among local communities. (Finn and Sarangi (n 69)).

social life- I have to know what to do because that's an important factor. So in totality, you have to take care of you body health." Along the same lines, interviewee 10 defined health as, "[T]aking care of yourself. Especially this business of associating with men anyhow, this is not supposed to be there."

The broad conception of health adopted by several PLWHAs also transcended access to curative healthcare goods and services and included the conditions that support and sustain health, such as proper nutrition, sanitation, drinking water.⁷⁴ For instance, interviewee 7 listed her health needs as "food, that is, a balanced diet, shelter, proper sanitation, ventilation, urgent medical care." Interviewee 5's list consisted of "food, shelter, clothing, medication and counselling." For interviewee 38, part of whose response is revisited in Chapter 5, her health needs comprised, "Food first! You need shelter, a place to sleep; money, because I am not working now but I have a child who needs food and school fees and clothing. I am not on ARVs but I need medicine because of the infections. I am trying to talk to these people to see if they can put me on ARVs." Yet, as the latter chapters reveal, despite articulating the myriad socio-economic barriers they encountered in their attempts to meet these needs, and their insistence that overcoming them was often beyond their means, many interviewees nevertheless felt that they themselves bore the sole or primary responsibility for guaranteeing their health.

The public health literature also reveals the role of health practitioners in the construction of a self-aware, self-monitoring patient, familiar with the language and values of biomedicine; yet critics have highlighted the failure to acknowledge that the "power to choose and access to choice are unevenly distributed in a given societal context."⁷⁵ Finn and Sarangi view this approach as part of an overall agenda to downsize the role of State in accordance with neoliberal ideology.⁷⁶ And yet there is perhaps an interesting paradox that a health model which envisions an 'empowered', self-governing patient, stridently independent from a minimalist State, should share the same neoliberal parentage as the human rights paradigm. This lineage, while it also conceives the subject as unfettered by the State, outlines a raft of civil, political,

⁷⁴ Turiano and Smith (n 60), at 141.

⁷⁵ Finn and Sarangi (n 69), at 235.

⁷⁶ *ibid*, at 237

and crucially, social, economic and cultural obligations it owes to the individual. In other words, the subject of the human rights model is inextricably yoked to a duty-laden State.

It is perhaps unsurprising, then, that the concept of human rights is as hard to pin down as that of health, if not more so, as the lengthy discussion of a concept of rights earlier in this chapter illustrated. Upendra Baxi espouses the views of Henkin and Douzinas quoted there that the latter part of the twentieth century will be remembered as the 'Age of Human Rights,' with its global profusion of human rights-related activity.⁷⁷ He rejects the kind of narratives which would seek to "reduce the forbiddingly diverse range of human rights enunciations or totality of sentiments that give rise to them to some uniform narrative that seeks family resemblance in such ideas as 'dignity,' 'well-being,' or human 'flourishing.'" He continues:

The expression 'human rights' shelters an incredibly diverse range of *desire-in-dominance politics* and *desire-in-insurrection politics*. These forms of politics resist encapsulation in any formula. The best one may hope for is to let the contexts of domination and resistance articulate themselves as separate but equal perspectives on the meaning of 'human rights.'⁷⁸

Indeed, this research highlights a number of flashpoints where these tensions are exposed and where rights are invoked by one or all protagonists, in recognition of their modern currency. And yet while Baxi is right that a definition of human rights cannot be contained within the popular notions associated with it, it is interesting to note how, as noted earlier in this chapter concepts associated with human rights, like 'dignity,' 'humanness' and 'citizenship' were detectable in PLWHAs' responses. The first of these concepts, dignity, though now established as a mainstay of human rights, as Oscar Schachter underlines, remains undefined by the many instruments which entrench its status.⁷⁹ Whether all societies have an inherent appreciation of the notion of dignity, as Makau Mutua⁸⁰ argues, and thus arguably a human rights

⁷⁷ Baxi, Upendra, in Twining (n 27), at 163.

⁷⁸ Baxi, Upendra, 'Voices of Suffering and the Future of Human Rights', *Transnational Law and Contemporary Problems*, Vol.8, No. 2 (1998), pp.125-169, at 128-9.

⁷⁹ Schachter, Oscar, 'Human Dignity as a Normative Concept,' *The American Journal of International Law*, Vol.77, No.4 (1983), pp. 848-854.

⁸⁰ Mutua, Makau, *Human Rights: A Political and Cultural Critique*, (Philadelphia: University of Pennsylvania, 2002).

culture, a contention Howard and Donnelly⁸¹ reject, compounds the difficulty in locating the role of this concept in human rights discourse. Howard and Donnelly argue that dignity is objective in nature, bestowed upon those deemed to conform with and uphold societal norms. Jonathan Mann⁸² and Mariana Chilton⁸³ propose a more compelling theory of dignity as possessing a dual aspect: objective, and subjective. For them, the concept also embraces a notion of how one sees oneself. This theory seems to have been borne out by a number of female PLWHAs who expressed distress at the thought that their HIV infection would be (wrongly) interpreted by others as having resulted from the violation of society's strict sexual codes. Their responses sometimes hinted at self-stigmatization and a belief that those PLWHAs, particularly women, who may become infected through counter-normative sexual behaviour did indeed deserve to be ostracized. This further highlights the complex effects of HIV/AIDS on a PLWHA's subjectivity.

Similarly, the seemingly straight-forward task of defining a human being, the subject of law, proves complicated, for the subject has meant many things to many cultures over the ages, as Douzinas⁸⁴ illustrates. Delineating the character of the ideal human, who is the candidate for legal personhood, is highly political. It has, and continues to variously exclude, among others, non-whites, women, homosexuals, the poor and arguably- and crucially for PLWHAs- the infirm. Winfried Brugger explores and attempts to bridge the paradoxes of this process in his 'image of the person' concept.⁸⁵ Beyond theory, however, as the illuminating research of Petchesky and Judd and the IRRRAG team proves, many traditionally-marginalized groups- in their case women- often approach the struggle for greater social and/or legal recognition in a subtler manner than is normally appreciated by human rights advocates, balancing their resistance to exclusion with an accommodation of it in order to retain

⁸¹ Howard, Rhoda E. and Donnelly, Jack, 'Human Dignity, Human Rights and Political Regimes,' *American Political Science Review*, Vol. 80, No. 3 (1986), pp. 801-817. See also Howard, Rhoda E., 'Dignity, Community, and Human Rights,' in An-Na'im, Abdullahi Ahmed, *Human Rights in Cross-Cultural Perspectives: A Quest for Consensus* (Philadelphia : University of Pennsylvania Press, 1992).

⁸² Mann, Jonathan, 'Dignity and Health: The UDHR's Revolutionary First Article,' *Health and Human Rights: An International Journal*, Vol.3, No.2 (1998), pp. 31-38.

⁸³ Chilton, Mariana, 'Developing a Measure of Dignity for Stress-related Health Outcomes,' *Health and Human Rights: An International Journal*, Vol.9, No.2 (2006), pp. 208-233.

⁸⁴ Douzinas (n 13).

⁸⁵ Brugger, Winfried, 'Image of the Person in the Human Rights Concept,' *Human Rights Quarterly*, Vol.18, No.3 (1996) pp. 594-611.

their valued place within the social matrix.⁸⁶ Indeed, critical feminist analysis of the politics of establishing the legal subjecthood of women provides a useful parallel for the challenges faced by PLWHAs in their attempts to have their rights recognized, with the work of Arvonne Fraser⁸⁷ and Alice Miller⁸⁸ particularly insightful.

Feminist critiques again provide useful avenues for exploring the crucial issue of citizenship: for establishing the individual as a subject of law is one thing; it is the possession of rights that transforms her into a citizen. Kenyan human rights advocate L. Muthoni Wanyeki, who argues that this is precisely what the new Constitution offers women, makes an analogy between membership to the State and membership to the family. Citizenship, which has been a gendered privilege thus far, carries “a right not just to be present, but to engage with that State- and engage in a manner akin to that with one’s own functional family. One can demand, expect- and contribute. Visitors to a home obviously also can engage- but rather more politely, without the same demands or expectations. And certainly without the obligation to contribute.”⁸⁹ They have a right to decide how the accrued benefits of membership are utilized and apportioned, and the State should not be a “mafia or a protection racket,” for the profit a privileged few.⁹⁰

In Kenya, this discussion inevitably occurs against the backdrop of colonialism, whose racially-bifurcated State divided subject Africans from citizen white settlers. A handful of accounts of Europeans attempting to articulate the myriad, sometimes conflicting objectives of the British colonial enterprise are highlighted in Chapter 4. These literatures provide fascinating insights into efforts to classify, explain, and perhaps excuse their supposed racial inferiors. The words of William Howitt⁹¹, Charles William

⁸⁶ Petchesky and Judd (n 28).

⁸⁷ Fraser, Arvonne S., ‘Becoming Human: The Origins and Developments of Women’s Human Rights,’ *Human Rights Quarterly*, Vol. 21, No. 4 (1999) pp. 853-906

⁸⁸ Miller, Alice M., ‘Sexuality, Violence Against Women, and Human Rights: Women Make Demands and Ladies Get Protection,’ *Health and Human Rights: An International Journal*, Vol.7 No. 2 (2004), pp. 16-47

⁸⁹ Wanyeki, L. Muthoni, ‘Now Women Can Enjoy True Citizenship,’ *The Daily Nation*, 26th August 2010.

⁹⁰ *ibid.*

⁹¹ Howitt, William, *Colonization and Christianity: a Popular History of the Treatment of the Natives by the Europeans in all their Colonies* (London: 1838)

Hobley⁹², Charles Roden Buxton⁹³ and others are windows into the prevailing notions of the age, on whose basis the denial of Africans' rights was justified. As subjects, the indigenes were granted sufficient recognition in law to enable its (often violent) application to them; but they could not draw from the emerging colonial State the rights that would check its incursive powers and designate them as fully-fledged citizens. The machinery of the State was structured to facilitate this citizen-subject divide with, as Bruce Berman⁹⁴ Mamdani⁹⁵ Stephen Ndegwa⁹⁶ and Peter Ekeh⁹⁷ (mentioned earlier in this chapter) clearly demonstrate, the artifice of the customary conceived entirely to serve the exigencies of the colonial enterprise.

The discussions at the beginning of this chapter on a concept of rights underlined the varied notions attached to human rights. This research is particularly interested in the ideas interviewees' appeared to link to or attach to this phrase, the processes by which such ideas were constructed and the role their subjectivities played in determining how they internalize these ideas. The State, civil society and others, including, as I have already acknowledged, I, the interviewer, are revealed as actively or passively engaging in the contest to mould these notions and PLWHAs' responses may be seen, therefore, as manifestations of the successful inculcation- or not- of certain political ideas and the triumph of specific agenda.

All interviewees were asked about their knowledge and understanding of the term human rights. None gave what might be regarded a 'text book' definition of it, which may be unsurprising and perhaps even inevitable. No specific parameters were set for this research regarding a meaning, and respondents' definitions sometimes even exceeded the anticipation of the interviewer. The Haki Index, however, while noting correctly that there is no hard and fast definition, nor that there were any right or

⁹² Hobley, Charles William, *Kenya: From Chartered Company to Crown Colony: 30 years of Exploration and Administration in British East Africa* (London: 1929)

⁹³ Buxton, Charles Roden, 'Kenya and Its Natives: Some Impressions,' Reprinted from *The Manchester Guardian*, 27th October 1932 (Manchester: 1932)

⁹⁴ Berman, Bruce, *Control and Crisis in Kenya: The Dialectic of Domination* (London: James Currey, 1990)

⁹⁵ Mamdani, Mahmood, *Citizen and Subject: Contemporary Africa and the Legacy of Late Colonialism*, Princeton, NJ: Princeton University Press, 1996)

⁹⁶ Ndegwa, Stephen N., 'Citizenship and Ethnicity: An Examination of Two Transition Moments in Kenyan Politics,' *American Political Science Review*, Vol. 91, No.3 (1997), pp. 599-617.

⁹⁷ Ekeh, Peter P., 'Colonialism and the Two Publics in Africa: A Theoretical Statement,' *Comparative Studies in Society and History*, Vol. 17, No.1 (1975), pp. 91-112

wrong answers⁹⁸ provided for its survey a working one, noting those responses which could be considered to fall outside it. This characterized human rights as “entitlements which are due to every human being by virtue simply of their being human and are founded on the notion of respect for the inherent dignity of the human person.”⁹⁹

The Haki Index observed a generally substantial awareness of human rights among Kenyans, with only 4% of responses falling outside the survey’s operational definition; yet nearly a quarter of the survey respondents failed to provide any definition of the term.¹⁰⁰ Among the PLWHAs interviewed for this research, many indicated familiarity with the phrase even without quite being able to define it: Interviewee 30 said he had heard of the phrase “but I have never understood what it means.” Interviewee 18 said she had heard “about [human rights] but I don’t know what it means.” Interviewee 22 had also heard of it but as to its meaning, he had not “taken much notice.” Interviewee 45 said: “It is difficult to explain although I feel I know the meaning.”; and interviewee 35 noted: “I think it means... I don’t think I can explain very well...it’s like... I can’t explain!” For some, as will be seen in the next chapter, the problem was one of the language and vocabulary of rights. But even some vague responses, such as the one by interviewee 15 who defined rights as “talking about my rights,” may nevertheless point to useful ideas: this one, for instance, might suggest that the respondent associated rights with debate or public discussion, may perhaps even be articulating a claim to that space, dominated by professionals, where the exercise of “rights-talk” or “discursivity” takes place.¹⁰¹ In so doing, she seemed to anticipate Marie-Bénédicte Dembour’s assertion that “human rights exist only because they are talked about.”¹⁰² This may reflect the idea that acknowledging an

⁹⁸ KHRC (n 45), at 124.

⁹⁹ *ibid.*, at 19.

¹⁰⁰ *ibid.*, at 10.

¹⁰¹ Baxi’s concept of “discursivity” encompasses “both erudite and ordinary practices or ‘rights-talk.’” He continues: “Rights-talk (or discursive practice) occurs within traditions (discursive formations). Traditions, themselves codes for power and hierarchy, allocate competences (who may speak), construct forms (how one may speak, what forms of discourse are proper), determine boundaries (what may not be named or conversed about), and structure exclusion (denial of voice). What I call ‘modern’ human rights offers powerful examples of the power of the rights-talk tradition.” (Baxi (n 78), at 129)

¹⁰² Dembour, Marie-Bénédicte, ‘Human Rights Talk and Anthropological Ambivalence: The Particular Contexts of Universal Claims,’ in Harris, Olivia (ed.), *Inside and Outside the Law* (London: Routledge, 1996), at 18

individual's rights admits her onto the public arena, an analysis undertaken in more detail in Chapter 8. This has sometimes been a challenging proposition for PLWHAs, as some interviews revealed, often denied a voice because they may not be deemed exemplars of society's highest ideals or the ideal subjects of human rights.

Interestingly, those interviewees unable to offer a definition of rights that they considered correct or acceptable were often noticeably uneasy or embarrassed. Interviewee 2, for example, unable to name some examples of the human rights she had heard of or knew of said falteringly, "Maybe you'll help me there..." Interviewee 16, who admitted to political ambitions, said when she could not offer a definition of rights, "That's a major question- and I'm aspiring to be an MP and I don't know that one!" Such discomfort is perhaps inherent in the interviewing process, which, as the next chapter notes, arguably instils in a respondent the belief that her selection carries an expectation of knowledge. But there was an additional dimension arguably peculiar to the subject itself: as the final chapter explores, several respondents regarded human rights as pertinent to them as human beings and perhaps particularly as PLWHAs, such as interviewee 17, who though could not offer any examples of rights, highlighted this view saying, "My own definition is that, as a human, I need to know my rights." Interviewee 32, although he defined rights tautologically as "the rights someone is supposed to know" echoes this view. He added, importantly, "[T]hey are his rights, he doesn't have to beg for them." The notion of rights as an issue of great contemporary importance arguably has a generational aspect. This may be illustrated by the process of interview 33, more of which in Chapter 2. In what may be called vicarious embarrassment at a perceived lack of human rights awareness, the respondent's daughter, who voluntarily acted as her interpreter, was forced to concede that, despite much coaxing, her mother did not know any examples of human rights.¹⁰³

¹⁰³ Apparently incredulous and rather impatient at her mother's lack of knowledge of what she seemed to regard a crucial issue, she added at the end of the question, "It's hard for her to give examples but for instance children's rights, I am sure she must have heard of those."

In the last decade, there has been a rise in the public's interest in- and arguably knowledge of¹⁰⁴- human rights issues in Kenya, with concerted efforts to draw it into the wider debate. A huge nationwide civic education drive on the eve of the December 2002 national elections- about 18 months prior to the interviews for this research- helped raise grassroots political awareness and assertiveness about rights.¹⁰⁵ Similarly, there were public consultations and debates in the run-up to the constitutional referendums in November 2005 and August 2010, which will have drawn renewed attention to issues of rights and the entitlements of citizens from their government. These referendums sandwiched the post-election violence of 2007/8, which provided a fresh impetus for the latter referendum and spotlighted concerns about State abuse of power, persistent socio-economic inequalities and the unresolved multiple allegiances of the Kenyan citizen-subject.

These political changes have compelled CSOs, so crucial in animating human rights issues in Kenya, to address concerns about lack of inclusion and local participation and ownership of output, as Celestine Nyamu-Musembi and Samuel Musyoki illustrated in a 2004 study, which also provides a critique of civil society practice and human rights in action.¹⁰⁶ They highlighted positive changes in approach by human rights groups like the Kenya Human Rights Organization (KHRC), aimed at grounding rights in the community. These included a shift in emphasis from fixed-term to more long-term, responsive programming, greater willingness to traverse both its usual urban (Nairobi) base and civil and political rights agenda.¹⁰⁷ KHRC's co-founder and former head, Maina Kiai, accepted that human rights organizations like his had neglected socio-economic rights to a degree but pointed to projects the KHRC had

¹⁰⁴ Although it does not offer a baseline for its survey, the Haki Index reveals an impressive level of spontaneous awareness of human rights, as Chapter 8 explains.

¹⁰⁵ Nyamu-Musembi, Celestine and Musyoki, Samuel, 'Kenyan Civil Society Perspectives on Rights, Rights-Based Approaches to Development, and Participation,' *IDS Working Paper 236* (Institute of Development Studies (IDS): Brighton, Sussex, December, 2004), at 1.

¹⁰⁶ *ibid.*

¹⁰⁷ *ibid.*, at 17-18. Other organizations involved in human rights education, which Nyamu-Musembi and Musyoki looked at included the Centre for Law and Research International, CLARION, a research and advocacy organization involved in civic education and anti-corruption work, and Centre for Governance Development (CGD), which were both using methods such as theatre, featuring community residents, to communicate key messages. Such was the emphasis on local grounding that CLARION, for instance, as part of its selection criteria for trainees included, "residency, local language, knowledge of local geography and history, a certain aptitude level and political awareness. These criteria eliminate the transient category of recent school leavers who would only be looking for something temporary to do and who are unlikely to remain in the community." (at 18).

undertaken with overlapping civil and political and socio-economic elements, and cited general capacity problems in dealing with the latter concerns.¹⁰⁸

Baxi stresses that grassroots movements must be nurtured if human rights are to be institutionalized around the world, and denounces attempts to locate the source of human rights exclusively in the West as “sensible only within a meta-narrative tradition that in the past served the domineering ends of colonial/imperial power formations and that now serve these ends for the Euro-Atlantic community or the ‘triadic states’ (the USA, the EC, and Japan).”¹⁰⁹ And yet human rights activists and organizations have been accused of failing to provide the direction that could help harness a more aware, perhaps more receptive, public into a mass movement to advance the adoption and protection of rights at local level. Nigerian human rights lawyer, Chidi Odinkalu, writing in 1999, was scathing in his criticism, arguing that their failure to embrace the grassroots in Africa was responsible for the poor permeation of rights language and norms here. “In the absence of a membership base,” he noted, “there is no constituency-driven obligation or framework for popularizing the language or objectives of the group beyond the community of inward-looking professionals or careerists who run it.”¹¹⁰ They had failed to maximize on the power of the language of rights and the ideas it brings to life.¹¹¹ As this thesis argues, such ideas not only play a crucial role in shaping subjectivities but are also an effective organizing tool.¹¹² Nyamu-Musembi and Musyoki’s findings in Kenya five years later seem to support aspects of Odinkalu’s criticisms: their interviews with officials from key development agencies about the impact of rights-based approaches (RBAs, more of which shortly) on their policies and operations highlighted concerns about the exclusionary “working methods that have characterised the professionalised elitist practice of rights advocacy,” with one official owning that the human rights debate

¹⁰⁸ Interview with Maina Kiai, 26th May 2004.

¹⁰⁹ Baxi (n 78), at 148.

¹¹⁰ Odinkalu, Chidi Anselm, ‘Why More Africans Don’t Use Human Rights Language,’ *Human Rights Dialogue*, Series 2, No. 1 (1999), Carnegie Council on Ethics and International Affairs, at http://www.cceia.org/resources/publications/dialogue/2_01/articles/602.html (accessed 20/05/09).

¹¹¹ See Kirby, Michael, ‘The Rights to Health Fifty Years On: Still Sceptical?’, *Health and Human Rights: An International Journal*, Vol.4, No. 1 (1999), pp.6-25. He writes about the power of the UDHR and its ideals, which have spawned a multitude of NGOs and CSOs dedicated to actualizing these ideals around the world. (at 15).

¹¹² Roth, Kenneth, ‘Defending Economic Social and Cultural Rights: Practical Issues Faced by an International Human Rights Organization,’ *Human Rights Quarterly*, Vol. 26, No.1 (2004), pp. 63-73, at 65.

had not yet become “a people’s debate.”¹¹³ This observation recalls a comment by an official at the Kenyan AIDS non-governmental organization (NGO) Women Fighting AIDS in Kenya (WOFAK), where the first interviews for this research were conducted. Asked by this author to characterize the knowledge of rights among his clients he commented that human rights “are not like the Bible; [they are] not something you’re brought up on from a very early age.”¹¹⁴ Moreover, Nyamu-Musembi and Musyoki noted perceptions of official aloofness, dismissiveness of locals and their concerns and mistrust of locals in the management of finances, which were cited by some grassroots communities and which further hampered the former’s capacity to cultivate mass movements and make rights advocacy and practice more participatory.¹¹⁵

And yet the intervening decade since Odinkalu’s observations has also seen increased steps to propagate such movements. This is evinced by the periodic emphasis on mass civic education described earlier by Musyoki, *et al*, but can also be detected at the beginning of the decade in the efforts of human rights organizations to transform themselves into membership organizations.¹¹⁶ The other compelling reason for qualifying Odinkalu’s thesis today, of course, is the documented success of grassroots movements dealing with specific human rights issues, particularly those on the health entitlements of PLWHAs, as Ely Yamin¹¹⁷ and London¹¹⁸ highlight.

b) What Have Rights Got to do With It?: Health, HIV/AIDS and Rights-Based Approaches

For well over a decade now, advocates and practitioners have been attempting to enunciate the linkages between health and human rights, and health, human rights and HIV/AIDS. Commentators and practitioners, such as the contributors to the *Health and Human Rights: An International Journal*, a vital resource for this research,

¹¹³ Nyamu-Musembi and Musyoki (n 105), at 6.

¹¹⁴ Informal exploratory discussion with WOFAK Program Officer, 22nd March 2004.

¹¹⁵ Nyamu-Musembi and Musyoki (n 105), at 15-16.

¹¹⁶ Musyoki, Sammy; Nyamu-Musembi, Celestine; Mwasaru, Mwambi; and Mtsami, Patrick, *Linking Rights and Participation: Kenya Country Study* (Just Associates: Washington, DC; Institute of Development Studies (I.D.S.):Brighton, Sussex, November 2004), <http://www.afrimap.org/english/images/documents/file438edb948d7ed.pdf>, at 26-7

¹¹⁷ Ely Yamin (n 56), at 50

¹¹⁸ London, Leslie, ‘What is a Human Rights-Based Approach to Health and Does it Matter?’, *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 65-80, at 70-73

building on the pioneering work of Jonathan Mann and others, have sought to highlight and reaffirm these connections in theory and practice. The AIDS epidemic has unsurprisingly impacted on the discourse about the individual's right to health for, unlike other diseases "it most starkly locates the body at the crossroads of gender, race, class, sexuality and geography,"¹¹⁹ amplifying the differences in health already wrought by these factors.¹²⁰ The role of Mann¹²¹ and other campaigners in shaping and internationalizing the debate on access to treatment, which represented a new paradigm shift in late 1990s, will be outlined in Chapters 6 and 7.¹²² As noted by Helen Epstein¹²³, Tony Barnett and Alan Whiteside¹²⁴ and other chroniclers and analysts of the African epidemic, the start was characterized by government inaction and public ignorance, fear and suspicion of HIV/AIDS and PLWHAs. These problems persist in varying degrees but governments like Kenya's have been forced to become more responsive to issues such as stigma and discrimination and scarcity of antiretrovirals (ARVs) for PLWHAs, and have, indeed, made strides in each of these areas.

As Tarantola¹²⁵ and Heywood and Altman¹²⁶ explain, a consensus about the interconnectedness of human rights and HIV/AIDS largely appears to have been

¹¹⁹ Petchesky, Rosalind, *Global Prescriptions: Gendering Health and Human Rights* (London; New York: Zed Books, 2003), 116.

¹²⁰ Booker, Salih and Minter, William, 'Global Apartheid,' *The Nation*, 21st June 2001 (<http://www.thenation.com/doc/20010709/booker/single>, accessed 15/07/09). See also Veil, Simone, 'A Personal Perspective on Human Rights and Health,' *Health and Human Rights: An International Journal*, Vol. 2, No. 3 (1997), pp. 91-94, at 92.

¹²¹ See, for instance, Mann, Jonathan; Gostin, Lawrence; Gruskin, Sofia; Brennan, Troyen; Lazzarini, Zita and Fineberg, Harvey V., 'Health and Human Rights,' *Health and Human Rights: An International Journal*, Vol.1, No.1 (1994), pp. 6-23.

¹²² For a comprehensive list of rights-related issues that affect risk, vulnerability and impact of HIV/AIDS, see the seminal UN General Assembly Special Session (UNGASS) on HIV/AIDS *Declaration of Commitment on HIV/AIDS* (UNAIDS, *Declaration of Commitment on HIV/AIDS*, UNGASS on HIV/AIDS (25th -27th June 2001), at http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf, accessed 17/07/09). See also Heywood, Mark and Altman, Dennis, 'Confronting AIDS: Human Rights, Law, and Social Transformation,' *Health and Human Rights: An International Journal*, Vol.5, No.1, 149-179.

¹²³ Epstein, Helen, *The Invisible Cure: Africa, The West and the Fight Against AIDS* (New York, NY: Farrar, Straus and Giroux, 2007).

¹²⁴ Barnett, Tony and Whiteside, Alan, *AIDS in the Twenty-First Century: Disease and Globalization* (Basingstoke; New York: Palgrave Macmillan, 2006).

¹²⁵ Tarantola, Daniel, 'The Shifting HIV/AIDS Paradigm: Twenty Years and Counting,' *Health and Human Rights: An International Journal*, Vol.5, No. 1, pp.1-6, at 1-2.

¹²⁶ Heywood and Altman, *op. cit.*, at 156, on the wide adoption of *HIV/AIDS and Human Rights: International Guidelines* as an advocacy tool (the 2006 consolidated version can be found at OHCHR/UNAIDS, *International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version*,

reached over a decade ago. In many ways, this achievement exemplifies the triumph of the age of globalization, the forces of which must be read into all discussions throughout this research on the popularization of the international human rights project generally, and especially into the movement to recognize and secure the rights of PWLHAs. The ideas encompassed by the term 'globalization' in this thesis correspond to those Sankaran Krishna describes as "the combined economic and socio-political cultural changes of the contemporary epoch..."¹²⁷ Hakan Seckinelgin states that "the appearance of HIV/AIDS has been one of the most important determinants of the changing nature of globalization in which people's need began to take precedence over the institutionalized politics of health.... AIDS activism constructed as a social movement for people has inspired approaches to many other diseases and changed the way people think about their relationship to health policies."¹²⁸ Many CSOs, and HIV/AIDS and human rights ones are especially good examples of these as will be seen in Chapters 6, 7 and 8, have also acquired dimensions that are manifestations of the globalization phenomenon; that is, the internationalization of their activities.¹²⁹ Seckinelgin identifies the globalization of the AIDS debate, firstly in manner in which it became a fixture in the agendas of intergovernmental groups, and secondly in the multinational response to it.¹³⁰

The argument was popularized that in order to tackle the epidemic effectively the rights of sufferers had to be accounted for, contrary to the old strategies in which the individual right to health was often subordinated to public health requirements. HIV/AIDS, it was argued, absolutely illustrated the intersection of human rights and public health goals.¹³¹ The "risk-vulnerability" concept of the early 1990s highlighted

2006, at http://www2.ohchr.org/english/issues/hiv/docs/consolidated_guidelines.pdf, accessed 27/04/09)).

¹²⁷ Krishna (n 9), at 3.

¹²⁸ Seckinelgin, Hakan, 'Time to Stop and Think: HIV/AIDS, Global Civil Society, and People's Politics,' in Glasius, Marlies; Kaldor, Mary; and Anheier, Helmut (eds.). *Global Civil Society 2002*, (Oxford: Oxford University Press, 2002) at 119-20.

¹²⁹ Anheier, Helmut, and Themudo, Nuno, 'Organisational Forms of Global Civil Society: Implications of Going Global,' in Glasius, Marlies; Kaldor, Mary; and Anheier, Helmut (eds.). *Global Civil Society 2002*, (Oxford: Oxford University Press, 2002) at 207.

¹³⁰ Seckinelgin (n 128), at 120.

¹³¹ Kirby (n 111), at 17

the underlying factors- social, economic, cultural- that influenced the patterns of infection and forced a rethink in strategy.¹³²

With health outcomes correlating with patterns of wealth both domestically and globally, issues of access to, and distribution of, resources were becoming a central- and divisive- part of the health and rights discourse. The challenges presented by HIV/AIDS, as Heywood and Altman underline, were increasingly framed in language that was a combination of rights, law and ethics.¹³³ But the main platform that has been sought to promote and enforce human rights in the context of HIV/AIDS, the UN system, continues to present structural difficulties for campaigners: among other issues, there is still an aversion to addressing the socio-economic asymmetries that define the epidemic; a persistent imbalance of power among States; and a continued absence of enforcement mechanisms to promote adherence to human rights obligations, all of which will be revisited in the latter chapters of this research.¹³⁴ The discrepancy between the promises of human rights rhetoric and the still limited possibility of their realization has a profound effect on an increasingly rights-aware audience: it helps create expectations which, when unmet by the appointed duty-bearer, the State, feeds the perception not only of an ineffective entity but an illegitimate one. But crucially for the advancement of the human rights enterprise, this gulf feeds disillusionment about human rights as an effective alternative moral language and framework of reference by which to imagine and articulate grievances. This adds yet another layer of complexity to the constitution of individual notions of entitlement and obligation.

Despite the increased application of rights to health policy and public health issues like HIV/AIDS, it has been contended that a coherent philosophical basis for the right to health remains elusive.¹³⁵ Indeed, the scope of the right is so contentious that even the terminology used to express it is disputed. As Leary and others point out, the phrasing the 'right to health' "[s]uperficially... seems to presume that government or international organizations must guarantee a person's right to good health- an absurd

¹³² Tarantola (n 125), at 3.

¹³³ Heywood and Altman (n 126), at 155

¹³⁴ *ibid*, at 159.

¹³⁵ Ruger (n 67).

interpretation and not the one assumed in the context of human rights law.”¹³⁶ The practical difficulties of this shorthand, revisited in the next chapter, meant that in order to invite PLWHAs to engage with questions about issues around the right to health without resorting to defining the right for them in advance (and so cancelling out an important element of this research), it was easier to refer to the more specific phraseology, the ‘right to healthcare’. This narrower terminology commonly defines “only the provision of medical services”¹³⁷; its downsides will be addressed in Chapter 2 but in the context of interview questions aimed at laypeople, it provided a more convenient entry into the subject than its more nebulous species.

To be sure, there are references in this research to both a ‘right to healthcare’ and a ‘right to health’, a fact which does not hinder the central task defined by the research. Indeed, the issue of terminology adds an extra dimension to the discussion which problematizes, as other commentators have done, the ability of the language of rights to adequately give expression to multiple and complex concepts.¹³⁸ For regardless of the expression applied, the underlying elements that contribute to perceptions about entitlements- however they may be expressed- remain the same. A right to healthcare is applied here particularly in the exploration of interviewees’ responses about the problems of accessing medical care. A right to health connotes wider health factors such as nutrition, sanitation and water.¹³⁹ In fact, this latter phrase is retained in the title of this research, in part as a convenient shorthand but significantly, too, because the interviews revealed that most PLWHAs viewed the issue of health more holistically, embracing a range of concepts and issues more akin to those associated with the broader-ranging ‘right to health’.

¹³⁶ Leary (n 26), at 28. See also Ruger (n 67), at 275.

¹³⁷ Leary (n 26), at 31. Nevertheless, this apparently narrower phrase has also at times been given an unprecedentedly broad interpretation. Leary notes that “Professor Ruth Roemer, writing in [the Pan-American Health Organization] PAHO’s *Right to Health in the Americas*, entitles her contribution ‘The Right to Health *Care*,’ endorsing the opinion that the phrase ‘right to health’ conveys an absurdity: the guarantee of perfect health. However, she goes on to give an extensive definition to the right to health care, considering it to encompass ‘protective environmental services, prevention and health promotion and therapeutic services as well as related actions in sanitation, environmental engineering, housing and social welfare.’ Such an extensive definition seems contrary to common understanding of the phrase ‘right to health care’...” (at 31)

¹³⁸ See, for instance, *ibid*, at 30.

¹³⁹ See Turiano and Smith (n 60), at 141.

The preference of the phrase ‘right to health’ is also additionally important in the Kenyan context: it is the chosen wording in the new constitution, which, as mentioned earlier in this chapter, secures in the relevant Art. 43(1)(a) a right to “the highest attainable standard of *health*”, not healthcare, going on to explicitly include within its concept of ‘a right to health’ “the right to health care services, including reproductive health care.”¹⁴⁰ Interestingly, however, it provides for rights to adequate housing, sanitation, food and water in separate subsequent sub-sections (Art. 43(1)(b) to (d)), the very same content that a right to health on its own is often conceived as automatically encompassing. It could then be argued that the drafters of the new constitution did not take for granted that the concept of a ‘right to health’ inclusively covered the content often accorded to it, and instead viewed it narrowly (although the wording in Art. 43(1)(a) might suggest an non-exhaustive list of services, so that while their concept of ‘health’ expressly includes healthcare services, including reproductive healthcare, it may comprise other services, too). Alternatively, their explicit allocation of separate rights to the further socio-economic goods often associated with health may have been good sense, a practical and sensible insurance which might in future give claimants an alternative basis on which to claim these goods should their arguments that their provision is automatically implied in a right to health be rejected.

Conceptual and ideological arguments notwithstanding, the last decade-and-a-half or so has seen widespread promotion by NGOs and international agencies of ‘rights-based approaches’ to development and health.¹⁴¹ The role and impact of civil society organizations (CSOs) forms a key strand of the debate in this research because they have also been critical players in the HIV/AIDS narrative in Kenya and across the globe. Charles Taylor provides a neat analysis of the evolution of civil society in the West from the 17th through the 20th centuries, and this research adopts his definition of civil society as an entity that “stands in contrast to ‘the state’... a web of autonomous associations, independent of the state, which bound citizens together in matters of common concern, and by their mere existence or action could have an

¹⁴⁰ Republic of Kenya (n 2), at 31.

¹⁴¹ Ely Yamin (n 56), at 45. See also Nyamu-Musembi and Musyoki (n 105); Turiano and Smith (n 60).

effect on public policy.”¹⁴² But he warns against the over-simplification of the idea of civil society, underlining its multi-faceted nature and highlighting the fact that the perimeters separating State and non-State actors are not always clearly defined.¹⁴³ This complex view of civil society is reiterated by John L. and Jean Comaroff and other commentators in *Civil Society and the Political Imagination in Africa: Critical Perspectives*, who in their attempt to locate civil society in the African cultural, social and economic context find promise in the very intangibility of the concept.¹⁴⁴

Non-governmental organizations (NGOs), about which the interviewees for this research were asked to comment, are a species of CSOs. The kind of NGOs which are involved in HIV/AIDS-related work are easily embraced in Sarah Michael’s definition of NGOs as “independent development actors existing apart from governments and corporations, operating on a non-profit or not-for-profit basis with an emphasis on voluntarism, and pursuing a mandate of providing development services, undertaking communal development work or advocating on development issues.”¹⁴⁵

Marlies Glasius and Mary Kaldor observe that the term NGO has “in common parlance at least, taken on the much more specific meaning of a rather institutionalized organization, with fixed headquarters and paid staff, working in advocacy and service-delivery mainly in the fields of developments, the environment, human rights, and humanitarian relief.”¹⁴⁶ Though this may well describe the kinds of organizations that the interviewees may have had in mind when they responded to questions in the interview, as Glasius and Kaldor compellingly assert, the term NGO fails to capture the “richness and variety of organizations found in 45 civil society, including, in terms of structure, one-woman bedsit organizations and all-volunteer groups, or, in terms of activities, trade unions, churches and cultural organization.”¹⁴⁷

¹⁴² Taylor, Charles, *Philosophical Arguments* (Cambridge, Massachusetts; London, England: Harvard University Press, 1995), at 204.

¹⁴³ *ibid.*, at 206.

¹⁴⁴ Comaroff, John L. and Comaroff, Jean (eds.), *Civil Society and the Political Imagination in Africa: Critical Perspectives* (London: University of Chicago Press, Ltd, 1999).

¹⁴⁵ Michael, Sarah, *Undermining Development: The Absence of Power Among Local NGOs in Africa* (Oxford: James Currey; Bloomington: Indiana University Press, 2004) at 3.

¹⁴⁶ Glasius, Marlies and Kaldor, Mary, ‘The State of Global Civil Society: Before and After September 11,’ in Glasius, Marlies; Kaldor, Mary; and Anheier, Helmut (eds.). *Global Civil Society 2002*, (Oxford: Oxford University Press, 2002) at 5.

¹⁴⁷ *ibid.*

Therefore, though this thesis often makes reference to NGOs here and elsewhere as the most visible representation of CSOs, the analysis it provides especially in Chapter 7 is an interrogation of the phenomenon of CSOs more generally.

A combination of factors fed the resurgence of CSOs, including: the end of the Cold War; their increased focus on socio-economic rights in the 1990s; changes in the delivery of aid which, amid the rhetoric of 'partnership', encouraged the application of rights to interrogate and enhance the accountability of recipient States; the emphasis on participation in development, and on raising public awareness about rights and boosting capacity to claim them; and the evisceration of the ideological baggage of the controversial, non-binding UN Declaration on the Right to Development (1986), with its references to underlying global economic inequalities and clearly defined obligations for donor States, which sanitized the application of rights language in the modern development context and made its use more acceptable to them.¹⁴⁸

This oft-applied term or the similar-sounding 'human rights approach' is, again, imprecise and means a variety of things to its avowed adherents. As Nyamu-Musembi and Andrea Cornwall have pointed out in their critique, agencies or organizations' political and other sensitivities may indeed be served by this vagueness and malleability.¹⁴⁹ Their 2004 analysis of a number of key multilateral, bilateral and international organizations working in Kenya identified a general recognition of the benefits of applying a human rights framework to improve the efficacy of development practice. They critiqued the terms applied by various organizations in the rights and development dialogue, noting, for instance, the nuanced but crucial difference between a 'rights-based approach' and 'human rights approach': the latter places more explicit emphasis on human rights as universal and underwritten by international law; the former espouses looser notions about legal guarantees and more general human rights-inspired notions such as entitlement, fairness, justice,

¹⁴⁸ Nyamu-Musembi, Celestine and Cornwall, Andrea, 'What is the 'Rights-Based Approach' All About? Perspectives from International Development Agencies,' *IDS Working Paper 234* (Institute of Development Studies (IDS): Brighton, Sussex, November, 2004), at 10-12. See also Baxi (n 78), at 167.

¹⁴⁹ Nyamu-Musembi and Cornwall (n 148), at 12-13.

equity and participation.¹⁵⁰ There is, indeed, concern that the popularity of RBAs has and will be applied by organizations keen on “rights-washing”, which, like its environmental equivalent, ‘green-washing’, “gives political cover to groups whose overall impact on human rights is negative.”¹⁵¹

Yet this may be inevitable in the current environment in which ever-increasing numbers of NGOs compete for finite funds, a reality which particularly characterizes the health sector, as Chapter 7 illustrates. A report from the NGO ActionAid noted:

With the growing demands and complexities of advocacy and donor needs for accountability, [advocacy and rights] work has become more professionalised and, in some cases, taken on the language of business and government. As this has happened, important concepts have been toned down or co-opted, making them less challenging of the status quo and current relations of power. At times, terms become so loosely defined that people can easily use the same language while actually talking about fundamentally different notions.¹⁵²

To be sure, a rights framework provides new avenues for examining and altering “the way people perceive themselves vis-à-vis the government and other actors. [It] provides a mechanism for reanalyzing and renaming ‘problems’ as ‘violations,’ and, as such, something that need not and should not be tolerated.”¹⁵³ Applied to health, it locates rights as both a site and a tool of struggle, and offers some instruction (though, as Ruger argues, not in a conceptually clear or coherent manner) on how the human rights paradigm conceives health and human beings: the latter are perceived as more than “mere containers of desires to be maximized in a utilitarian calculus.”¹⁵⁴ Meanwhile, the former is underlined as a special social good as opposed to a market commodity. As Ely Yamin and Ruger assert, a health system is not just a vehicle for the distribution of goods and services but a vital institution that offers integrated care on a par with other central social institutions.¹⁵⁵ How a government fundamentally conceives health dictates the public health policies it adopts: London, writing with reference to South Africa’s transition from a political struggle against apartheid to a

¹⁵⁰ *ibid.*, at 13-14. See also Ely Yamin (n 56), at 46.

¹⁵¹ Turiano and Smith (n 60), at 143.

¹⁵² ActionAid, *Critical Webs of Power and Change- An Introduction*, ActionAid, at <http://www.actionaid.org/assets/pdf/intro.pdf> (accessed 10/08/10), at 1. (Also quoted in Turiano and Smith (n 60), at note 101).

¹⁵³ Jochnick, Chris, ‘Confronting the Impunity of Non-State Actors: New Fields for the Promotion of Human Rights,’ *Human Rights Quarterly*, Vol. 21, No.1 (1999), pp. 56-79, at 59.

¹⁵⁴ Ely Yamin (n 56), at 46-7.

¹⁵⁵ *ibid.*, and *ibid.*, at 49; see also Ruger (n 67).

broader struggle for human rights-based policies, raises a point about policy-level conceptions of public health as intrinsic rather than external to human rights, which has resonance beyond that particular context:

The consequence for health is that, rather than acknowledging health as a right, policy-makers frame health policy decisions as service delivery issues, requiring technical inputs to reach the best 'evidence-based' decisions, a public health phenomenon gaining increasing popularity worldwide. In doing so, the state is relieved of its burden of having to answer to its constitutional obligations for progressive realization of socio-economic rights, and its public servants are able to retain their own identities as servants of a social good, keeping up the tradition of being part of a movement for social justice. Such reframing of health away from its nature as a socio-economic right strips health policy-making of its inherent elements of power and the contestation that goes with the recognition of power. For that reason, it absolutely does matter what is understood by a human rights framework.¹⁵⁶

She affirms the importance of evidence to a rights-based framework for health but stresses that health must be respected as a right rather than merely a service, a charitable act by the State or merely an enabling factor towards the wider goal of economic development.¹⁵⁷ But RBAs have not always fitted seamlessly into the health discourse: there have been tensions, for instance, between some of their articulated goals, such as valuing and respecting the rights of individuals, and public health policies in which the wider population's interests take precedence. An example is the debate about mandatory HIV testing (for which Elizabeth Pisani argues there is empirical evidence of effectiveness¹⁵⁸) or quarantining those who may be infected with drug-resistant TB. Given the stigma and inflamed passions that often attend the AIDS debate, London argues, it will be important for proponents of RBAs to reaffirm the links between rights and health and prove the former a necessary precondition for the realization of the latter.¹⁵⁹ To do so, Paul Farmer insists they must overcome two "orthodoxies": firstly, the preoccupation in public health policy with cost-effectiveness and sustainability (although he argues a right-based approach can actually enhance these objectives¹⁶⁰), rather than with meeting the needs of those on the ground and addressing underlying issues such as poverty. Secondly, they must

¹⁵⁶ London (n 118), at 71.

¹⁵⁷ *ibid.*, at 71-2. See also Turiano and Smith (n 60), at 144.

¹⁵⁸ Pisani, Elizabeth, *The Wisdom of Whores: Bureaucrats, Brothels and the Business of AIDS* (London: Granta Publications, 2008), at 169-172.

¹⁵⁹ See London (n 118), at 66.

¹⁶⁰ Farmer, Paul, 'Challenging Orthodoxies: The Road Ahead for Health and Human Rights,' *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp.5-19, at 12.

challenge the emphasis, inspired by neo-liberal ideology, on civil and political rather than socio-economic rights¹⁶¹, and grapple with an unpalatable notion: that only large scale “redistributive transfers” of resources, ideally by public authorities, will effectively tackle fundamental health problems.¹⁶² Human rights organizations, he argues, must traverse the as-yet “unchartered territory” of framing specific health problems in explicit human rights terms to realize the desired outcomes.¹⁶³ He asserts that, “if we believe in health and human rights, we will need to broaden, very considerably, our efforts to promote social and economic rights for the poor. This, I would argue, is the leading human rights issue now facing public health.”¹⁶⁴

If the discourse on the linkages between health and rights is to engage and carry those at the grassroots, then a crucial test will be the extent to which the language of rights has gained traction among laypeople like the PLWHAs interviewed for this research and the extent to which they use it to articulate their health (and other) entitlements. As will be reviewed in later chapters, while many interviewees were familiar with issues around stigmatization and discrimination which do indeed impact on their health outcomes, on the whole the responses suggested that many people still viewed their healthcare needs as needs rather than rights which may be legally enforceable. Most had not heard or thought of a link between health and human rights; fewer yet claimed to have heard specifically of a right to healthcare and the quality of responses in this part of the interviews varied widely, with only fewer still providing answers that can be regarded as coming within the conventional content associated with a right to health or healthcare. Only a couple of interviewees, for instance, spontaneously mentioned a right to healthcare (or treatment, as would be the Kiswahili translation (more of which in Chapter 2)) although one or two others did mention rights to medicine or to health determinants such as food or shelter.

¹⁶¹ *ibid.*, at 6.

¹⁶² *ibid.*, at 10.

¹⁶³ *ibid.* He provides anecdotal evidence of an experience in Malawi in which one of the obstetricians working in an under-resourced in the maternity hospital explicitly spoke of the patients’ needs in rights terms: ... The day I first visited, Tarek showed me a hospital that was fairly clean but sorely lacked ‘This is an abuse of human rights,’ he said, lifting up one of the rags. ‘It would never happen if people considered the women we serve as human beings.’... Should there be a right to sutures? To sterile drapes? To anesthesia?....” (at 9-10).

¹⁶⁴ *ibid.*, at 8.

Interviewee 42, for example, recalled the moment it occurred to her that rights might apply to the sick:

“I haven’t thought about [the link between health and rights] but there was a time I had been lying in the ward and a lady was brought in. The nurses asked those who had brought her what their relationship was to her. That’s when I found out that human rights can also help an ill person... I didn’t find out where those people came from. So I see the connection because they speak out for us.”

Another suggested a nexus based on a notion of corporate responsibility for care of the infirm, arguing that the two issues were connected because anyone could fall sick and “you’re supposed to be taken care of well if you’re sick.”¹⁶⁵ Another respondent admitted he had not heard of a right to healthcare but reasoned that it might be linked to human rights because a multilateral organization which he associated with human rights had addressed an issue that was pertinent to health.¹⁶⁶

One of the principal features of the few responses on a right to healthcare was the futility of having, or being aware of, what might be merely a nominal right: arguably, part of the reason for the gap between respondents’ thorough articulation of their health needs and what appeared to be a generally limited sense of entitlement to the legal rights that might derive from them may be their low expectations that these rights would be realized. Tarek Meguid notes that “believing in human rights does not make them real in our communities.”¹⁶⁷ As one interviewee opined, despite her conviction that everyone, regardless of their situation, should be provided with appropriate healthcare, finding out she had a right to it was useless to her unless it could be actualized.¹⁶⁸ It was a view echoed by others, some of whom thought the government nevertheless capable of turning the right into a reality: These include interviewee 39, for whom the right meant that “basic needs like food should be affordable.” For him, the government could provide these needs “if they wanted to.” Interviewee 42, too, was similarly convinced. For her, a right to healthcare meant free medication for those who could not afford it and that the government could provide

¹⁶⁵ Interviewee 1.

¹⁶⁶ He said he had heard of “the organization called UN who look after people who are starving.” (Interviewee 24).

¹⁶⁷ Meguid, Tarek, ‘Notes on the Rights of A Poor Woman in a Poor Country,’ *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp.105-108, at 106.

¹⁶⁸ According to interviewee 41, “[W]hat is happening in Kenya is that people know they have a right to healthcare but they cannot access it. So what you would be telling me would be meaningless if you cannot assist me in accessing that healthcare!”.

it if they did not “misuse and steal funds.” Interviewee 45 also thought the government could afford to provide healthcare and the lifesaving drugs it entailed “if they are honest to the people.” Indeed, others proposed strategies for achieving this.¹⁶⁹ In any event, thought one respondent, Interviewee 29, the enormity of the task of public healthcare provision could not be left up to the charity of other actors and required government action and legal guarantees: “Because who else can? Do you think you can? It is a big task and it should be done by the government because it runs the country. .. The way I see it, [families do not always assist.] There are others who will leave a person to die without offering any help. So it should be part of the law, not just voluntary, otherwise some people will not want to get involved.”

The breadth of perceived duty-bearers cited by the PLWHAs, as Chapter 8 illustrates, and the vocabulary which they use to articulate their health entitlements exemplifies one of the principal contentions in this research that rights will have to compete with traditional custom and religion as the primary moral language, to use Baxi’s expression¹⁷⁰, in which claims to entitlements are framed and expressed. The varied foundations of PLWHAs’ claims also illuminate, again, how individuals situate themselves in the wider social, economic and political grid and the role played by agency. As London observes, agency, which relates to issues of power and the lack of power, is a crucial determinant in the actualization of health rights.¹⁷¹ Individual perceptions about how power is configured, one’s capacity to manipulate its apparatus and operate within its structures come across strongly in the interviews. The last chapter shows that many respondents made healthcare claims on the government, often founded on the privileges of membership to a national public-citizenship. Further claims on the government were based on financial contributions made to the national coffers by taxpayers: interviewee 31 appeared concerned with the entitlements of taxpayers, when she argued that some of the revenues collected should be go towards health provisions as it would remove the strain from her and free her to meet her other responsibilities comfortably. She felt that one could not

¹⁶⁹ Interviewee 3, for instance, thought a right to healthcare could only be of benefit if it led to him actually getting healthcare as he could not afford treatment. He proposed a health fund, like the National Health Insurance Fund, that the government and donors should contribute to, for everyone’s benefit, whether or not they could pay for their healthcare.

¹⁷⁰ See Baxi (n 78), at 131.

¹⁷¹ London (n 118), at 68.

have an adequate standard of healthcare in Kenya today without money and yet, “[A human right to healthcare] means that whether you have money or not you should be treated as a human being. But that’s not happening because when you’re told to cost-share and you don’t have, does that mean you remain sick?” However, this may exclude claims by the majority of the population which does not pay income tax either due to unemployment or employment in the informal sector.¹⁷² Interviewee 14’s apparently strong sense of entitlement to healthcare, for instance, stemmed from her belief that if one had paid for it, one deserved it: “I think as a taxpayer I already provide. So from there, the central government, of course, has to organize so that healthcare is provided.” By this reasoning, healthcare is no longer a right but a commodity, access to which is predicated upon one’s ability to purchase it; by extension she is less a rights-holder than a consumer. However grim this may sound, it is the experience of many Kenyans today. To her, the government’s responsibility seemed limited to that of supplier, and it is a role she felt it could fulfil with better fiscal management.¹⁷³ For another respondent, taxes could guarantee the provision of health needs but, as with several others, the government’s role was not obligatory, a view probably inspired by his wider pessimism about whether it could be legally compelled to act:

The duty of the government would be to volunteer to help people get treatment and then, if it does that, to fulfil its promise. If they don’t volunteer, they cannot be compelled because they will not budget for it, and they have the power to do so. But the President’s motto has been that we should unite to fight this illness, so it seems they have committed themselves. So they should fulfil their promise. (Interviewee 44)

¹⁷² This may be particularly the case for contributors into the National Health Insurance Fund (NHIF). The NHIF, a department in the Kenya Ministry of Health at its inception in 1966 and now a parastatal in the middle of a contentious structural overhaul, currently provides health cover for its 2.3 million members and their approximately 9 million dependants, altogether less than a third of the entire population. (The 2009 official population census, whose results were released in August 2010 gives the figure as 38,610,097. (*The Daily Nation*, ‘Census: Kenya has 38.6m People’, 31st August 2010)). However, there are proposals (currently stalled by a lawsuit lodged by trade unions) to introduce contribution rates that it is hoped would see comprehensive universal outpatient services for all Kenyans. For a brief background on the NHIF and its work, see the NHIF website at <http://www.nhif.or.ke> (accessed 29th August 2010). On the controversy about proposed changes in service provision and contribution rates, see, for instance: Kang’aru, Wachira, ‘The Poor Will Finance the Rich in New Medical Plan,’ *The Daily Nation*, 16th August 2010 and Kerich, Richard, ‘How New NHIF Package Will Benefit Members,’ *The Daily Nation*, 29th August 2010. The NHIF claims to base its reforms for “on the social principle... that ‘the rich should support the poor, the healthy should support the sick and the young should support the old’.” (Ngirachu, John, ‘Wanted: Brothers’ Keepers for NHIF,’ *The Daily Nation*, 9th August 2010).

¹⁷³ “With proper budgeting it should be able to. We have seen billions of shillings siphoned off in very dubious ways so those billions, if put to proper use, can assist.” (Interviewee 14).

As will be seen in Chapter 4, perceptions of the State as venal, avaricious, unresponsive to the electorate's needs and somewhat external to, and beyond the control of, citizens have roots in the colonial era. As Berman¹⁷⁴ and Ghai and McAuslan¹⁷⁵ explain, colonial administrators were prepared to allow coercive, corrupt or unjust institutions and practices to evolve if they furthered- or at least did not impede- the paramount objectives of the colonial enterprise. Additionally, the PLWHAs are also witnesses to its well-advertised ineffectiveness in dealing with the AIDS epidemic. The cumulative effect of these largely negative views about the colonial and postcolonial State is captured by many of the responses: in querying the State's inefficiency in addressing their health needs some interviewees appeared to question its legitimacy. Others, alluding to a culture of impunity, cited a State obligation to assist in meeting health needs but appeared to be suggesting that such entitlements impossible to secure through (enforceable) laws. Instead they resorted to appealing to the unpredictable, unguaranteed generosity of the State in the hope that it would act morally to alleviate their needs.

Making the State accountable for its health rights obligations based on the more substantial grounds of domestic or international law, then, remains one of the key challenges facing advocates. As Ely Yamin notes, "To assert that health is an issue of rights is to assert that the state and other actors bear some responsibility in ensuring fair distributions of the social determinants of health as well as availability and access to care."¹⁷⁶ One of the strategies currently attracting much commentary, and which the new Kenyan Constitution is intended to enable, is judicial activism by individual or group claimants, which Gloppen¹⁷⁷, Abramovich and Pautassi¹⁷⁸ and Ely Yamin¹⁷⁹ explore. The juridical model is fast gaining popularity in South America and has been tested, too, in South Africa. And while London highlights the successes in the latter of

¹⁷⁴ Berman (n 94), at 215.

¹⁷⁵ Ghai, Y.P., and McAuslan, J.P.W.B., *Public Law and Political Change in Kenya: A Study of the Legal Framework of Government from Colonial Times to the Present*, (Nairobi; New York: Oxford University Press, 1970), at 173.

¹⁷⁶ Ely Yamin (n 56), at 45.

¹⁷⁷ Gloppen, Siri, 'Litigation as a Strategy to Hold Governments Accountable for Implementing the Right to Health,' *Health and Human Rights: An International Journal*, Vol.10. No. 2 (2008), pp.21-36.

¹⁷⁸ Abramovich, Victor and Pautassi, Laura, 'Judicial Activism in the Argentine Health System: Recent Trends,' *Health and Human Rights: An International Journal*, Vol.10, No. 2 (2008), pp. 53-65.

¹⁷⁹ Ely Yamin, Alicia, 'Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health,' *Health and Human Rights: An International Journal*, Vol. 10, No. 2 (2008), pp.1-20.

the Treatment Action Campaign (TAC) and stresses the possibilities of court actions allied to social mobilization¹⁸⁰, others like Karin Lehmann¹⁸¹, Octavio Luiz Motta Ferraz¹⁸² and Charles Ngwena¹⁸³ are less convinced. They critique its jurisprudential and procedural problems and the historical exclusion of marginalized groups from judicial processes, and raise doubts about the capacity of legal action to bring real and long-term benefits for litigants and the public at large, as will be seen in Chapter 8.

Proponents of judicial action in countries like Argentina have also sought to use it to highlight the role and obligations of non-State actors in healthcare provision. NGOs may be hugely influential in this capacity in Kenya, as Chapter 7 demonstrates, but despite this many respondents resisted the idea that such actors were (legally) obliged to assist in meeting PLWHAs' healthcare needs, arguing instead that their endeavours were more rightly based on charity. Indeed, though there were questions about the practices of some local groups, the work of NGOs drew broadly favourable comments from interviewees, a reflection of their often commendable involvement in highlighting and alleviating the health concerns of PLWHAs. But the relationship between civil-society groups and those they ostensibly serve is much more nuanced and more problematic than many interviewees appeared to regard it. Nyamu-Musembi and Cornwall, Sarah Michael¹⁸⁴, Neera Chandhoke¹⁸⁵ and Elizabeth Garland¹⁸⁶ all question the capacity of locals to set the agenda and participate meaningfully in the policy-making and programming activities carried out by such groups, raising concerns that they often replicate and entrench existing power imbalances at national and global level. As Ely Yamin underlines, participation is itself

¹⁸⁰ London (n 118), at 67-8.

¹⁸¹ Lehmann, Karin, 'In Defense of the Constitutional Court: Litigating Socio-Economic Rights and the Myth of the Minimum Core,' *American University International Law Review*, Vol. 22, No.1 (2006-2007), pp. 163-198.

¹⁸² Motta Ferraz, Octavio Luiz, 'The Right to Health in the Courts of Brazil: Worsening Health Inequities?' *Health and Human Rights: An International Journal*, Vol. 11, No 2 (2010).

¹⁸³ Ngwena, Charles, 'The Recognition of Access to Health Care as a Human Right in South Africa: Is It Enough?' *Health and Human Rights: An International Journals*, Vol.5, No.1 (2008), pp. 26-44.

¹⁸⁴ Michael (n 145).

¹⁸⁵ Chandhoke, Neera, 'The Limits of Global Civil Society,' in Glasius, Marlies; Kaldor, Mary; and Anheier, Helmut (eds.), *Global Civil Society 2002* (Oxford: Oxford University Press, 2002).

¹⁸⁶ Garland, Elizabeth, 'Developing Bushmen: Building Civil(ized) Society in the Kalahari and Beyond,' in Comaroff, John L. and Comaroff, Jean (eds.), *Civil Society and the Political Imagination in Africa: Critical Perspectives* (London: University of Chicago Press, Ltd, 1999).

reliant upon transparency and accessibility of information¹⁸⁷, yet the workings and structures of accountability of many extra-State actors remain hidden or inaccessible to locals.

Moreover, the significant role played by powerful overseas donor agencies in setting national health priorities is particularly worth critiquing, as Jeremy Shiffman¹⁸⁸, Ilona Kickbusch and Evelyne de Leeuw¹⁸⁹ and Laurie Garrett¹⁹⁰ assert: Shelley Jones and Bonny Norton's account of former US President George W. Bush's Presidential Emergency Plan for AIDS Relief (PEPFAR's) involvement in Uganda's HIV prevention programming offers a reminder of the real and sometimes disastrous consequences of the unequal, highly dependent power relations between donor States and their recipient 'partners'.¹⁹¹

The perceived lack of agency vis-à-vis a range of State and non-State actors perhaps inevitably meant that many PLWHAs may be basing their health entitlement claims on relationships which they were better able to influence and whose levers of power were less remote: their kinship and close social links. For despite the rise of individuality, the dilution of kinship structures and the diminution of their cohesive functions and obligations during the colonial era¹⁹², they survive still in contemporary Kenyan society, animated by such ideas as '*Harambee*' or voluntary pooling of collective resources.¹⁹³ This notion was echoed by a number of respondents, some of whom appeared to presume a moral obligation for relatives, friends, and wider society to help those unable to meet their health needs. Interviewee 44, considering the nexus between health and human rights, asserted:

¹⁸⁷ Ely Yamin, 'Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care' (n 56), at 49.

¹⁸⁸ Shiffman, Jeremy, 'Donor Funding Priorities for Communicable Disease Control in the Developing World,' *Health Policy and Planning*, Vol. 21, No. 6 (2006), pp. 411-420.

¹⁸⁹ Kickbusch, I. and de Leeuw, E., 'Global Public Health: Revisiting Health Public Policy at the Global Level,' *Health Promotion International*, Vol. 14, No.4 (1999), pp. 285-288.

¹⁹⁰ Garrett, Laurie, 'The Challenge of Global Health,' *Foreign Affairs* (Jan/Feb 2007), at <http://www.foreignaffairs.org/20070101faessay86103/laurie-garrett/the-challenge-of-global-health.html>, accessed 05/05/08.

¹⁹¹ Jones, Shelley and Norton, Bonny, 'Uganda's ABC Program on HIV/AIDS Prevention: A Discursive Site of Struggle,' in Higgins, Christina and Norton, Bonny (eds.), *Language and HIV/AIDS* (Multilingual Matters: Bristol; Buffalo; Toronto, 2010).

¹⁹² Mamdani (n 95), at 119.

¹⁹³ See Ngau, Peter M., 'Tensions in Empowerment: The Experience of the "Harambee" (Self-Help) Movement in Kenya,' *Economic Development and Cultural Change*, Vol. 35, No. 3 (1987), pp.523-538, at 524.

[People], whether they can afford treatment or not, still need it. If you have been asked to pay Ksh. 5,000 and you don't have it, are you supposed to just sit and die without treatment? Of what benefit is that to the government? Isn't it better you get treatment, then owe the hospital the money, get well and then go and organize a *Harambee* and pay off the debt? So there is a right for people there to be treated, even though they haven't the money, when they get sick.

For interviewee 24, even the government's now-defunct cost-sharing system for ARV provisioning was "not a bad idea because given the money they have put aside for people, even if a poor person had a *Harambee* done for them they could [at least] afford to look after themselves." There was often a sense of an unarticulated system of duties and privileges binding individuals within society which substitutes or co-exists alongside the duties and rights that may bind individuals to the State. It is not surprising then that successive governments should attempt to co-opt and exploit the concept of *Harambee*. Ngau laments that *Harambee* "used to provide local mutual assistance and foster cultural values; today, those roles have been abandoned while only [its] material ends are appropriated. Furthermore, local people have taken less and less part in decision making, management, and control of projects. This perversion of *Harambee*¹⁹⁴ [I term] departicipation and reflects disempowerment at the grass-roots level."¹⁹⁵

c) Imagining Human Rights

What, then, may the interviews be saying about the place of rights in the imagination of ordinary Kenyans? To be sure, the PLWHAs were eloquent about their multifaceted health needs- primarily nutrition and lack of financial resources, and psychosocial and medical needs- as Chapters 5 and 6, respectively, illustrate. To be sure, a few PLWHAs mentioned other health-related concerns relating to sanitation, shelter and water, all of which, as earlier noted, are now individually provided for in the Bill of Rights of Kenya's new constitution alongside health, but the four requirements explored in detail in research are those which were most commonly identified by respondents. Moreover, these four particular health concerns tie together the cross-cutting social, economic, cultural and political themes of Kenya's pre-colonial past, addressed in Chapter 3, and its more recent colonial and postcolonial history (Chapter 4). For it is

¹⁹⁴ Italics added by author for consistency.

¹⁹⁵ Ngau (n 193), at 523.

against such an expansive background that contemporary notions of entitlement and the relationship between the individual, her wider community and the State have developed. Three pivotal aspects of social organization in traditional Kenya in particular emerge, which continue to dictate the configuration of power today and shape individual identity, subjectivity and conception of rights and privileges: the systems of land ownership, kinship and patriarchy. The multilayered rights and duties entailed by African systems of land tenure were, and remain, skewed in favour of male progeny, as Akinyi Nzioki¹⁹⁶, Perpetua Karanja¹⁹⁷, Ikdahl, *et al*¹⁹⁸, and others point out.¹⁹⁹ Yet they also often guaranteed female members certain rights within the kinship group (which, paradoxically, as Chapter 6 explores through the work of Karanja and Patricia Kameri-Mbote²⁰⁰, modern land tenure reforms have threatened). Meanwhile, the function and lasting importance of the obligations and privileges of kinship delineated in the anthropological texts of Jomo Kenyatta²⁰¹, Thomas Spear²⁰² and A.R. Radcliff-Brown²⁰³ is underscored by the several PLWHAs who appeared to make claims to health entitlements from husbands, families or relatives. But patriarchy is the thread that runs through these first two socio-historical factors: the gender disparity it effects shapes ideas about women's rights, their roles in society, so

¹⁹⁶ Nzioki, Akinyi, 'The Effects of Land Tenure on Women's Access and Control of Land in Kenya,' in An-Na'im, Abdullahi A. (ed.), *Cultural Transformation and Human Rights in Africa*, (London: Zed Books Ltd, 2002).

¹⁹⁷ Karanja, Perpetua W. , 'Women's Land Ownership Rights in Kenya,' *Third World Legal Studies* (1991), pp. 109-136.

¹⁹⁸ Ikdahl I.; Hellum A.; Kaarhus R.; Benjaminsen T.A. and Kameri-Mbote P., 'Human Rights, Formalisation and Women's Land Rights in Southern and Eastern Africa', *Studies in Women's Law*, No. 57 (July 2005).

¹⁹⁹ For instance, Pinckney, Thomas C. and Kimuyu, Peter K., 'Land Tenure Reform in East Africa: Good, Bad or Unimportant?' *Journal of African Economies*, Vol. 3, No. 1 (1994), pp. 1-28; Haugerud, Angelique, 'Land Tenure and Agrarian Change in Kenya,' *Africa: Journal of the International African Institute*, Vol. 59, No. 1 (1989), pp. 61-90. In Chapter 5, see also Place, Frank and Migot-Adholla, S. E., 'The Economic Effects of Land Registration on Smallholder Farms in Kenya: Evidence from Nyeri and Kakamega Districts,' *Land Economics*, Vol. 74, No. 3 (1998), pp. 360-373 and Gray, Leslie and Kevane, Michael, 'Diminished Access, Diverted Exclusion: Women and Land Tenure in Sub-Saharan Africa', *African Studies Review*, Vol. 42, No. 2. (1999), pp. 15-39.

²⁰⁰ Kameri-Mbote, Patricia, 'Gender Dimension of Law, Colonialism and Inheritance in East Africa: Kenyan Women's Experiences', *IELRC Working Paper 2001-1*, International Environmental Law Research Centre (IELRC), at <http://www.ielrc.org/content/w0101.pdf>, accessed 12/10/05. Also Kameri-Mbote, Patricia, 'The Land Has Its Owners: Gender Issues in Land Tenure Under Customary Law in Kenya,' *IELRC Working Paper, 2005-9*, International Environmental Law Research Centre (IELRC), at <http://www.ielrc.org/content/w0509.pdf>, accessed 20/12/09.

²⁰¹ Kenyatta, Jomo, *Facing Mount Kenya: The Tribal Life of the Gikuyu* (London: Mercury Books, 1961).

²⁰² Spear, Thomas, *Kenya's Past: An Introduction to Historical Method in Africa* (London: Longman Group Ltd, 1981).

²⁰³ Radcliffe-Brown, A.R., 'Introduction,' in A.R. Radcliffe-Brown and Daryll Forde, (eds.), *African Systems of Kinship and Marriage* (London: OUP, 1960).

often centred on their sexual and reproductive functions, as Regina Smith Oboler²⁰⁴ and Kenyatta illustrate, and even impacts on historical research about women as Beth Maina Ahlberg²⁰⁵ and Ulrike von Mitzlaff²⁰⁶ explain. A picture emerges of a corporate ownership of female sexuality in particular and a restrictive social, cultural and economic space for women whose boundaries are rigidly patrolled in the name of their protection and that of society's integrity and stability as a whole.

As many responses indicated, all three elements and the norms they engender strongly influence how individuals- particularly women- in contemporary Kenyan society locate themselves within the wider social matrix, and their perceptions of themselves, their entitlements, rights and obligations. The convergence of issues around land, kinship and patriarchy are revealed again in Chapters 5 and 6: in the former, PLWHAs' challenges in accessing nutrition and resources affect their capacity to attain and maintain their health, exacerbated, as Alex de Waal and Alan Whiteside²⁰⁷ and Gabriel Rugalema²⁰⁸ show, by the HIV/AIDS factor. Meanwhile, the marginalization of women in resource control and ownership, the general economy and other areas of public life, which Karanja, Kameri-Mbote and Nzomo²⁰⁹ consider, significantly increases their vulnerability to HIV infection, as Bayliss, *et al*²¹⁰ show. The same issues and patterns crop up in Chapter 6's analysis of PLWHAs' psychosocial and medical needs; the latter, in particular, are severely curtailed by access to resources

²⁰⁴ Oboler, Regina Smith, *Women Power and Economic Change: The Nandi of Kenya* (Stanford, California: Stanford University Press, 1985).

²⁰⁵ Maina Ahlberg, Beth, *Women, Sexuality and the Changing Social Order: The Impact of Government Policies on the Reproductive Behaviour in Kenya* (Philadelphia: Gordon and Breach, 1991).

²⁰⁶ von Mitzlaff, Ulrike, *Maasai Women: Life in a Patriarchal Society: Field Research Among the Parakuyo Tanzania* (München : Trickster Verlag ; Dar es Salaam: Tanzania Publishing House, 1994).

²⁰⁷ de Waal, Alex and Whiteside, Alan, 'New variant famine: AIDS and food crisis in southern Africa,' *The Lancet*, Vol. 362, No. 9391 (2003), pp. 1234-1237. See also Tony Barnett and Alan Whiteside (n 124).

²⁰⁸ Rugalema, Gabriel, 'HIV/AIDS and Adult Mortality in Rural Tanzania,' *East African Geographical Review*, Vol. 20, No. 2 (1998), pp. 25-38.

²⁰⁹ Nzomo, Maria, 'The Political Economy of the African Crisis: Gender Impacts and Responses,' *International Journal*, Vol. 51, No.1 (1995-1996), pp. 78-102. See also Nzomo, Maria and Kameri-Mbote, Patricia, 'Gender Issues in the Draft Bill of the Constitution of Kenya: an Analysis (Contribution for the Constitution Review Commission of Kenya),' *IELRC Working Paper 2003-1*, International Environmental Law Research Centre (IELRC), at <http://www.ielrc.org/content/w0301.pdf>, accessed 21/11/09.

²¹⁰ Baylies, Carolyn; Chabala, Tashisho; and Mkandawire, Faustina, 'AIDS in Kanyama: Contested Sexual Practice and the Gendered Dynamics of Community Interventions,' in Baylies, Carolyn and Bujra, Janet, *AIDS, Sexuality and Gender in Africa: Collective Strategies and Struggles in Tanzania and Zambia* (London: Routledge, 2000).

although, as Mamdani asserts²¹¹ and the interviews revealed, the old systems and obligations of kinship, altered but not obliterated by the convulsions of colonization often aided PLWHAs in need. How gender and sexual norms, as revealed, for instance, in the Kenya Demographic and Health Surveys (KDHS), frame attitudes towards sex, HIV infection and PLWHAs, transfiguring PLWHAs' subjectivities and impinging on their claims to rights, becomes especially clear in the analysis of their psychosocial needs. In the absence of biomedically-sanctioned psychological care, it is the acceptance and support of members of familial, social, religious and other networks that patients mostly seek, even when the values championed by these communities conflict with human rights norms.

While this may have inspired certain inconsistencies, the PLWHAs' responses nevertheless indicated an internalization of various ideas often associated with human rights, such as the entitlements of citizenship, the innate dignity of the human being and the obligations of the State. They also appeared to reflect certain advocacy messages about rights and health entitlements, especially those targeted at their particular group, underscoring the importance of such strategies. After all, perceptions and attitudes are changeable and advocacy not only helps inculcate human rights norms within the general population but also provides an impetus for their adoption across State institutions. In turn, this may create or boost expectations of (future) fulfilment of the obligations that these human rights entitlements imply, which in turn would reinforce the citizenry's demands for action, and so on. The increasing expectation of provision of ARVs by the State, based on repeated campaign messages and the successful demands by fellow PLWHAs elsewhere, was cited by some respondents and is a good example.

Furthermore, Turiano and Smith point to efforts by a range of health experts and stakeholders in Uruguay to inform the public about the right to health and its various aspects, with the intention to create a sustainable social movement to agitate for the fulfilment of this right.²¹² They emphasize, too, that building the capacity of grassroots groups to conduct their own rights-based assessments of government's

²¹¹ Mamdani (n 95).

²¹² Turiano and Smith (n 60), at 139.

health policies and its adherence to health rights obligations has been proven to transcend the rarefied circles of intellectuals and professionals and transfer ownership of health rights initiatives to communities.²¹³ This, as Ruger might assert, is imperative if individuals are to “internalize the *public moral norm* that health is worthy of social recognition, investment and regulation to the point of successfully operationalizing such a right.”²¹⁴

In addition, the high numbers of people who seemed unaware of a right to health or healthcare should not be taken to suggest that PLWHAs, or indeed other laypeople, possess no notions of entitlements to these socio-economic goods or make no claims to them. As Nyamu-Musembi and Cornwall rightly point out in particular reference to proponents of rights-based approaches but a charge arguably relevant beyond this group, little regard is often paid to the “range of strategies, tactics and institutions through which people frame and make rights claims *outside* of formal legal instruments and institutions.” Unless practitioners and advocates recognize this, they may not fully understand the dynamics and relationships that these strategies are attempting to balance and how they may be harnessed towards strengthening human rights understanding.²¹⁵

Yet, as earlier noted, the interviews also revealed a number of fundamental contradictions: for instance, recognition of the role, authority and legitimacy of the other key party in the human rights dynamic, the State, often seemed to exist contemporaneously with a rejection of the same. Indeed, one likely effect of successfully inculcating a notion of State responsibility for actualizing socio-economic rights is that (the highly probable) non-delivery reinforces public perceptions of its ineffectiveness, which may only reaffirm lingering doubts about its legitimacy. Another paradox lay in some PLWHAs’ apparent claims of espousal or acceptance of fundamental human rights norms like the dignity of all human beings while asserting a fervent belief that this could be justifiably denied to those deemed to have violated societal norms, particularly on sex. And yet practitioners and advocates must prepare

²¹³ This, for instance, is the approach supported by global network the People’s Health Movement (PHM), which works in a range of crosscutting areas within health and human rights, in its Rights to Health and Health Care Campaign (RTHHCC). (ibid., at 140).

²¹⁴ Ruger (n 67), at 318.

²¹⁵ Nyamu-Musembi and Cornwall (n 148), at 4.

to engage with the agency of individuals and the indeterminate possibilities that emerge from opening up the human rights dialogue, as its values and notions about obligations and entitlements are evaluated, processed, assimilated or rejected and re-articulated by laypeople with varied moral frames of reference and subjectivities.

While the interviews appear to suggest fertile ground on which to cultivate human rights norms, however, some commentators are sceptical about the future of human rights in its current framework, and the debate on the relationship between morality and the modern human rights framework was seen earlier in this chapter. Where PLWHAs' claims to health entitlements appeared to be founded on the moral responsibility owed to individuals, especially those in need, because of their special status as human beings, Baxi, for instance, has questioned whether notions of morality that are intertwined with human rights can survive the modern age, noting that, "[t]he prospects of recycling the moral languages of human rights appear rather bleak in our globalizing human condition in ways that they did not to the forerunners and founders of human rights, from Grotius to Gandhi."²¹⁶ He does not reject the importance of the human rights project as whole, arguing, in fact, that it is even more vital to places like Asia and Africa which, bereft of the centuries-old practice of most European societies, do not often operate in accordance with human rights values.²¹⁷ But Baxi has posited a bleak theory of a global market-driven human rights paradigm. This new "trade-related, market-friendly" paradigm prioritizes the "promotion and protection of the collective rights of global capital in ways that 'justifies' corporate well-being and dignity over that of human persons", and threatens to supersede the paradigm laid out in the iconic UDHR.²¹⁸ It is contingent upon a State that eschews any redistribution of resources in the way that Farmer and others contend is necessary to realize a right to health. In this new paradigm, Baxi continues, the malleability of the State, which is soft and hard in turns, only serves to facilitate the flow of global capital (soft), and to remove and enforce the removal of obstacles to this flow (hard).²¹⁹ Over a decade after the publication of Baxi's work, and in the throes of global economic convulsions in which falls in public spending are being

²¹⁶ Baxi (n 78), at 131.

²¹⁷ Baxi (n 77), at 149.

²¹⁸ Baxi (n 78), at 163-4.

²¹⁹ *ibid.*, at 164.

registered alongside individual unemployment and loss of earnings, this a sobering thought. Indeed, one may argue that modern health paradigms which promote the idea of the 'empowered' individual without accounting for the lack of free will or choice often produced by asymmetrical domestic and global power relations are more closely linked to Baxi's gloomy model than they are to the UDHR.

Ely Yamin and Baxi both stress that taking rights seriously necessitates taking suffering seriously.²²⁰ Indeed, the normalization of suffering, implied, for instance, by the unrelenting gap between the rhetoric and reality of rights which a number of interviewees rightly pointed out, is one of the ways in which Baxi's market-driven paradigm of human rights arguably begins to take root.²²¹ Such discrepancies must surely make even the noblest human rights ideals sound hollow, breed disillusionment in prospective adapters of human rights norms and hamper the overall goal of internalization. And yet Nyamu-Musembi and Musyoki noted the comments of officials from the development organization CARE in Kenya, who opined that there was nevertheless an obligation to increase people's knowledge of their entitlements as an aspect of a rights-based approach to development, even when the organization could not itself assist in actualizing those rights.²²²

Whether human rights laws and norms are ultimately effective in helping PLWHAs articulate their health-related grievances and address them- or in alleviating suffering, as Baxi and Ely Yamin would have it- remains to be seen. Human rights theories and covenants appear to conceive the individual, her sense of entitlements and obligations and her relationship to the State, in particular, in a narrow, unrealistic manner drained of the complexities of her reality. Yet Lisa Forman maintains that while they often seem to address issues only abstractly, they may be the vehicle through which systemic shifts towards justice can be injected.²²³ Carol Smart

²²⁰ Ely Yamin, 'Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care' (n 56), at 50.

²²¹ Baxi (n 78), at 166.

²²² Nyamu-Musembi and Musyoki (n 105), at 14. They argue that such a duty entails, therefore, the "additional role of informing the people about other actors – such as the state and international organisations – whom they could approach to meet the shortfall."

²²³ Forman, Lisa, "'Rights' and Wrongs: What Utility for the Rights to Health in Reforming Trade Rules on Medicines,' *Health and Human Rights: An International Journal*, Vol.10, No.2 (2008), pp.37-52, at 41.

addressed similar questions about the law's efficacy in the feminist struggle, arguing that, "[i]f we reject the idea of law as a simple tool of liberation or of oppression, and look at how it constitutes a kind of institutionalized and formalized site of power struggles- one that can provide resources for women, children and men, albeit differentially- then it is possible to acknowledge that it remains an important strategic element in political confrontations."²²⁴ There are lessons here for the struggle for the health rights of PLWHAs and others: for allocation of resources for health and the entitlements of the infirm are nothing if not political struggles.

The leveraging of the right to health by South African HIV/AIDS activists in the fight for access to treatment provides a good example of the potent confluence of human rights law and knowledge of rights. And although Smart rejects a return to a previous age when women had no rights, as indeed we must surely reject as regressive the failure to recognize the health entitlements of human beings, she is also cautious, warning, as Ferraz and others do in relation to juridical action for health rights, that recourse to the law has often proved more beneficial to one class, race or sex than to others.²²⁵ Furthermore, and in common with the discrimination of women, the current problems with access to healthcare are propped up by a host of structural factors, many of which may be beyond the reach of legislation.²²⁶ The successful rooting of human rights will depend on how their advocates and proponents negotiate these hurdles, package and sell rights to the wider public and manage the often-unfulfilled expectations they create. But the real test of success is arguably whether the language of rights becomes the reflexive vocabulary of laypeople who wish to articulate their entitlements. If the right to health can traverse the divide from a generally accepted norm among experts to an internalized norm among laypeople, then advocates may rightfully claim that it has truly been established.

III. Thesis Structure

²²⁴ Smart, Carol, *Feminism and the Power of Law* (Routledge: London, 1989), at 138.

²²⁵ *ibid.* She notes: "In resorting to law, especially law structured on patriarchal precedents, women risk invoking a power that will work against them rather than for them. We know, for example, that Sex and Discrimination Act 1975 and Race Relations Act 1976 in the UK have been unsuccessful in changing the discrimination, against women and ethnic communities."

²²⁶ See *ibid.*, at 139.

Chapter 2 is an analysis of the research's methodology. But it has two further aims: to demonstrate, firstly, how HIV/AIDS dominates the interviewer- respondent interaction and thus determines the information collected; secondly, how this phase of the fieldwork illustrated and entrenched many of the overall issues that the research deals with. The chapter begins with a brief overview of the sources on which the research relies, before moving on to a detailed analysis of the process and challenges of conducting the 49 PLWHA interviews which form the core of this research. To facilitate this, the section splits the process into three separate phases: pre-interview, interview and post-interview. The first of these stages explores this researcher's decisions regarding the choice of interview structure and the personal interviewing style which would maximize the opportunity. It then addresses the in-built challenges of attempting to gain access to often unseen subjects whose illness not only attracts public accusations of normative violation but also leads to ostracization. Finally it details the challenges of designing interview questions in two languages which could capture as precisely as possible the nuances of human rights terms and concepts in both English and Kiswahili. The next stage examines issues around interviewer-respondent interaction which arose while conducting the actual interviews. The final stage comprises general reflections about the interview process, particularly regarding the search for objectivity in a research about a subject as sensitive and emotive as AIDS.

Chapter 3 then looks at the socio-historical context of the events and processes that the research covers. It starts by outlining common problems faced by the researcher who seeks to investigate pre- and early colonial African history, briefly examining how sources and channels of knowledge shape knowledge itself. The chapter then proceeds to analyze three mutually reinforcing features around which power and social relations were organized in pre-colonial Kenya: land, kinship and patriarchy. The chapter emphasizes the enduring importance of these customary features, whose supporting systems and structures persist, albeit in altered forms, despite the convulsions of colonialism and independence.

Chapter 4 focuses on the impact of the colonial experience on the principle issues addressed in this research. The broad subject of colonialism and its transformative

effects on Kenya and the general narrative of this period in the country's history, though interesting, is not the main focus of this research. Nor indeed is the decolonization discourse, the independence struggle or the minutiae of political upheaval post-independence. These issues are briefly mentioned in this chapter where relevant but it begins with a brief analysis of the often conflicting objectives of the colonial project and the centrality of the subject of race. The postcolonial analytical framework is especially underlined in the second part of the chapter, which explores the influence of colonialism on the AIDS discourse, as well as its possible impact on notions of entitlement, looking at how issues like race, culture and the State-individual relationship have shaped modern debates about power, health, sex, rights and obligations. As the third section of the chapter shows, these recurrent themes also influenced the colonial administration's somewhat contradictory construction of both the African legal subject and the customary sphere within which she was to be governed. This section also explores the construction of a new entity, the State, whose agents and their exercise of power was to leave an enduring impression on the African subjects of what the State was and what it was for. The chapter concludes with an examination of how post-independence this new entity created an alternative locus of power to the customary, the bifurcated State, and, in turn, the dual identity of the citizen-subject.

Chapter 5 is the first of four consecutive empirical chapters and it deconstructs the PLWHAs' responses about their nutritional and financial requirements. It also looks at their attribution of duty for the fulfilment of these needs to discover how they construct their notions of entitlement and obligation. The chapter starts by underlining the significance of food to a PLWHA's health, and then the importance of a steady and reliable income source, illustrating the vicious circle that binds HIV/AIDS, inadequate nutrition, low food production and poverty. The two requirements of food and income converge in the issue next addressed by the chapter: the impact of unequal rights to land use and ownership. This section considers how historical and contemporary systems of land tenure entrench the social, economic and political marginalization, in particular that of women, perhaps the most vital constituency in the HIV narrative. As the final section of the chapter emphasizes, this inequality

deprives women of much-needed access to resources and increases their vulnerability to HIV infection.

In **Chapter 6**, the empirical analysis is based on PLWHAs' responses about their psychosocial and medical needs. It begins by looking at the former requirement, especially the effects of the financial stresses detailed in the previous chapter and the shame and stigma, including self-stigma, associated with the illness. Next, it addresses PLWHAs' medical needs, highlighting gaps in both availability and accessibility of ARVs despite great strides in improving both aspects of treatment, and the crucial role played by private social networks and non-State actors in fulfilling these needs for PLWHAs. The chapter concludes by exploring the role of the more widely available and widely accessible, if sometimes controversial, traditional medicine in PLWHAs' healthcare. It outlines the dominance of biomedicine in the AIDS discourse, as evinced by several PLWHAs' perceptions of themselves as medical subjects and their overt rejection of traditional treatments. It concludes by illustrating how such statements can be interpreted as ciphers for the broader conflicts between the social, legal and moral frameworks to which these different medical paradigms belong.

With access to treatment a dominant- if not the predominant- strand of the AIDS discourse, **Chapter 7** uses interviewees' responses to provide a practical context for an analysis of the altered dynamics of the traditional individual-State relationship, as effected by the proponents of access to antiretroviral therapy. These include the range of actors who constitute 'civil society', particularly NGOs, as well as overseas donors. The chapter begins with a background to the debate around access to treatment in Kenya, from the government's slow and counterproductive initial response to the epidemic, to the mounting pressure exerted by campaigners for universal access to treatment and PLWHA rights in countries like Kenya, as well as rich, low-HIV prevalence ones. It then explores PLWHAs' attitudes about the intervention of NGOs and overseas donors, interrogating how and on what basis recipients of ART may attribute responsibility for their healthcare on these actors, and how this in turn reconfigures their apportionment of responsibility to other actors, such as the State, who are more traditionally associated with the provision of

healthcare. The last part of chapter rationalizes the broad definition of the term 'civil society' adopted by this research and analyzes how the intervention of civil society is reshaping the dialogue between the State and the individual and reconfiguring the balance of power between them.

Chapter 8, the last of the empirical chapters, provides a detailed analysis of PLWHAs' responses in relation to rights and locates the broader human rights theories and debates. It starts by looking at the respondents' general human rights awareness, comparing and contrasting it with a more widespread survey on similar issues conducted by the Kenya Human Rights Commission. The chapter then interrogates the three main themes which emerge from the PLWHAs' responses about rights: humanness, dignity and citizenship. As the chapter illustrates, many interviewees often defined these fundamental human rights concepts from their unique perspective as PLWHAs, one which draws parallels with the rights struggles of other marginalized groups like women. The chapter then briefly identifies the importance of subjectivity to legal research. To this end, it examines the apparent contradictions and peculiarities of the legal subject, in whom theorists like Lacan saw no separation between inner aspects like identity and desire and outer ones like society and law. The chapter concludes by analyzing how the multiple subjectivities of PWLHAs and the competing moral frames of reference by which they live produce varying notions about health entitlements, the rights of the individual and the obligations of the State and other actors. It underlines the fact that while the human rights enterprise has made some strides in promoting its values, major challenges persist, primarily in the grassroots which remains largely unconverted.

Finally, the **conclusion** draws together the key theses of the research, re-emphasizing the role of subjectivity, and the myriad elements of which it is constructed, appears to have on the formation of an individual's notions of entitlement to health and other socio-economic goods. Further, it underscores how subjectivity may influence one's sense of location in the broader socio-economic matrix, shaping individual assignment of obligations to fulfil such entitlements. But ultimately, as the research stresses, the nature, content and scope of these claims of entitlement, their moral basis and the language in which they seem to be articulated does not solely, or even

primarily, belong to human rights. Its normative system, as the conclusion points out, is only one moral framework, indeed, it appears, the least established, by which this research's interviewees imagined and formulated their entitlement claims. Its advocates must not assume that human rights are generally taken for granted by laypeople. The conclusion stresses that campaigners will have to engage more deeply with laypeople and recognise and contend with the alternative normative paradigms by which those whom they aim to assist experience their lives. They must compete to promote and establish human rights values if they are to become the automatic language for laypeople to conceive of and express their grievances. As the conclusion affirms, only then can they hope to root human rights values in a real and lasting way among this pivotal constituency whose role and contribution to the wider success of the human rights enterprise is so often overlooked.

Chapter 2: Methodology

While this chapter looks at the methodology used in this research, its analysis goes beyond this narrow if crucial remit and picks up on some critical themes introduced in the previous chapter, examining how they were reinforced during the process of conducting the research.

The primary focus of the discussions in the chapter is the process of interviewing the 49 PLWHAs whose responses are the foundation of this research. This aspect of the analysis separates the pre-interview, interview and post-interview phases. Thus organized, the chapter examines the challenges, limitations and opportunities, unexpected or otherwise, imposed by the subject matter. But the discussion of the interviewing process also illuminates a number of themes at the heart of the research. In particular, it enables a closer look at the role of HIV in the production of PLWHAs' subjectivities and how the interviewer and interviewees played out roles informed largely by their knowledge and/or presumptions about the illness and those it affects. Additionally, the challenges of choosing the correct terms of reference and capturing and communicating, in two languages no less, the intended nuances sought by this research revealed much about the pivotal issues that this research is concerned with.

Ultimately, by examining the interviewing process, this chapter is able to further the investigation of pivotal issues at the heart of this research: the construction of PLWHAs' subjectivities and the struggle of the human rights language, its norms and its paradigm to become a reflexive frame of reference.

I. General Sources

This research focuses on how individual and collective PLWHAs' notions of entitlement to healthcare and conceptualizations about rights are constructed, and the role of subjectivity in the internalization, or not, of the human rights norms which increasingly frame local and global discussions about the AIDS epidemic and treatment of PLWHAs. The 49 interviews conducted with Kenyan PLWHAs therefore

rightfully form the core of the research: they are pivotal to the analysis because they provide a window into the perceptions of Kenyan PLWHAs. Indeed, the very process of organizing and carrying out the interviews not only highlighted many of the fundamental issues that this research is substantively concerned with, but was itself arguably a live and protracted demonstration of how prevailing notions about AIDS intrude on the research in this area and sometimes mould or reaffirm PLWHAs' subjectivities. The process of conducting these interviews will thus be discussed in much detail shortly.

Firstly, however, other crucial aspects of the research must be acknowledged. These include a semi-structured interview with Maina Kiai, co-founder and former director of the pioneering civil society human rights organization in Kenya, the Kenya Human Rights Commission (KHRC). At the time of the interview, on 26th May 2004, Kiai was the chairman of the new, statutorily-constituted national human rights institution, the Kenya National Commission on Human Rights (KNCHR). His input provided a context for, and firsthand account of, the development of a key example of human activism in the country and enabled me to put direct questions to a key figure in this movement about the status of socio-economic rights in the government and civil society human rights agenda. Further, he was able to respond to follow-up questions on pertinent issues such as the role of the media and civic education in nurturing a public consciousness about rights, all of which came up organically in the course of the interview. Interviews were sought with persons at other key organizations, too, in particular the KHRC itself, as it remains a preeminent actor in human rights advocacy in the country. However, my contacts here were unable or unwilling to make the time to conduct an interview, referring me instead to the KHRC website, which I had access to anyway and which was unlikely to provide the personal insights which would have been more useful to this research. Indeed, this became the trend with other interviewees: while a number of NGOs and institutions were contacted in the hope of providing interviews or further contacts for interviewing, only those who responded and did so positively within the limited timeframe of the fieldwork were interviewed. As such, as will be seen later, in addition to Maina Kiai, the organization WOFAK, 7 of its clients, Mbagathi District Hospital (MDH) and 42 of its HIV patients were interviewed.

This primary research was supported by the wealth of secondary research, mainly desk-based and consisting of grey literature from a number of government agencies, NGOs and UN agencies active in the relevant fields.¹ Further, archival research of the print and electronic media in Kenya illuminated aspects of the local public debate on HIV and human rights-related issues and the social, cultural and political context of this research, and provided references for some events cited by respondents. There were, however, some gaps: for instance, it was not always possible to access complete, up-to-date and consistent data on employment numbers, wages and income, or consumer price indices for particular periods from the institution charged with collecting and distributing it, the Kenya National Bureau of Statistics (KNBS).² This was because that data was not consistently uploaded or updated on their website, which was the most convenient way for the researcher to access it remotely.

II. The PLWHA Interviews:

a) General Points

Before embarking on an analysis of the interview process itself, some general points must be made which have a bearing on the overall research.

i. Qualitative, not Quantitative

The qualitative nature of this research means that the interviews conducted for it were intended to inform and provide insights into discussions about PLWHAs' notions of health-related entitlements and rights. As such, although this research often links them with related studies or findings elsewhere, using them to support or challenge, compare or contrast ideas therein, the interviewees' comments stand on their own

¹ Some of these sources, however, particularly those that take the form of policy statements or documents, come with a health warning, as Nyamu-Musembi and Cornwall note in their analysis of rights-based approaches across the development industry. For though they can provide useful insights into an organization's approach on particular issues, "policy statements have different resonance in different parts of an organisation, and cannot in themselves be taken as evidence of a shift in approach or practice across the agency as a whole even when this is the declared intention of the policy.... [T]he presentational- even performative- uses of policies may exaggerate the gap between ideals and actual daily practice, especially when parallel agendas and processes co-exist within different parts of the organisation." (Nyamu-Musembi, Celestine and Cornwall, Andrea, 'What is the 'Rights-Based Approach' All About? Perspectives from International Development Agencies,' *IDS Working Paper 234* (Institute of Development Studies (IDS): Brighton, Sussex, November, 2004), at 14)

² Kenya National Bureau of Statistics (KNBS) website, at <http://www.knbs.or.ke/index.html>, accessed 10/02/09.

and in suggesting how interviews conceptualize and articulate health entitlements and rights they add a unique dimension to the analyses in this research as well as provide new avenues for thought. The research is always careful to qualify any conclusions it may draw based on interviewees' comments, and seeks to clarify that the views expressed by PLWHAs in these interviews are not aimed at making generalizations which can be extrapolated to other Kenyan PLWHAs, let alone the wider population. The respondents' comments can therefore only provide indications, albeit strong ones at times, about some of the ideas which exist on the issues they discuss.

ii. Accommodating the Lapse of Time

Because they were undertaken in 2004, it might be suggested that the interviews offer snapshots of (possibly prevailing) opinions from only a transitory period in Kenya's contemporary history. From this viewpoint, the time lapse may limit the interviews' value even as it suggests new, interesting avenues for investigation. A couple of points must be clarified in relation to this: firstly, there was a time lapse of about 9 years between the interviewing process and the presentation of the research, due to unprecedented delays caused by the researcher's other academic and teaching obligations. Secondly, however, the interviews were transcribed, processed and analyzed immediately after they were conducted (in April and May 2004) in order to create a full and accurate record of the information therein. Thirdly, further analysis during the write-up enabled the interviewees' responses to be located within the context of different phases in the country's recent history. For instance, the period before 2004, the year the interviews were conducted, provides the context for the fight for ARV treatment which the interviewees were referencing, in particular the government's efforts, or lack thereof, in relation to this. Meanwhile, the period in early 2004 during which the interviews took place provided a background to responses such as those relating to opinions about cost of ARV medication, and media reports about popular rights issues of the time. Further, the 5-year period between 2005 and 2010, bookends the well-publicized constitutional debates preceding the referenda of these two years. This period also encompasses the widespread ethnic violence that followed the December 2007 general elections and the promulgation of the new Kenyan constitution. And finally the research also

references additional data between this period and 2012, when the research was first presented, which particularly takes into account updates on HIV data and related findings, but also mentions the ongoing trials at the International Criminal Court (ICC) of key figures cited as perpetrators of the post-poll violence, two of whom are now the country's president and vice-president, for crimes against humanity³.

It is important to acknowledge these different phases in the cycle of the research, and how they have shaped the analysis in the years subsequent to the interviews. To be sure, there have been some significant developments, particularly around issues of HIV/AIDS and rights. For instance, the interviews were conducted only 5 years after the Kenyan government took the symbolic but important tentative first step of declaring HIV/AIDS a national disaster. And despite uneven and sub-optimal implementation, the State has since made significant headway in crucial areas such as greater access to ARVs, not least because of pressure from PLWHA advocacy groups. There has also been increased government and the general public awareness about the health and human rights issues affecting PLWHAs, as well as the structural factors which exacerbate vulnerability to HIV infection at national and global levels.

Further, the Constitutional referenda of 2005 and 2010 entailed public debate and countrywide civic education exercises, and similarly the violent elections and aftermath of 2007/8 brought human rights issues particularly to the fore. Indeed, the ICC trials are a live and hotly-debated issue.⁴ As such, there may be greater public awareness about human rights issues as well as shifts in opinions about the role of the State in a multiethnic society where people have alternative political, social and moral allegiances. I have utilized more recent quantitative and qualitative data on

³ See, for instance, *The Sunday Nation*, 'Road to The Hague: ICC Debate- Uhuru and Ruto Dispel Fears of Power Vacuum as ICC ate Beckons', 8th September 2013.

⁴ See, for instance, International Criminal Court (ICC), 'OTP Press Conference on Kenya, Prosecutor Moreno-Ocampo's Statement, 1 April 2010,' I.C.C. Press Release, 1st April 2010, at <http://www.icc-cpi.int/NR/exeres/6B518FB1-C68F-405A-887C-19CEACF91C05.htm>, accessed 12/08/10; Wa Ngugi, Kiriro, 'Let's Choose Peace Over Justice in ICC Case', *The Daily Nation*, 22nd February 2011; *The Daily Nation*, 'Distant Dutch City Looms Large in Our Political and Electoral Future,' 19th February 2011; *The Daily Nation*, 'Kenya Petitions UN Organ to Delay Trials', 10th February 2011; *The Daily Nation*, 'Uhuru Says Hague Case "Political"', 8th February 2011; *The Daily Nation*, 'Imanyara Pushes for Another Attempt at Kenya Tribunal', 5th February 2011; wa Ngugi, Wanjiku, 'This is Impunity, the Usual Kenyan style', *The Daily Nation*, 7th February 2011; Wanzala, Ouma, 'Film on Poll Chaos to be Screened', *The Daily Nation*, 7th February 2011.

human rights and health-related issues, such as the aforementioned Haki Index and the KDHS reports, in an attempt to account for these developments.

But this lag does not make the interviews themselves redundant or invalidate the opinions therein. Indeed, the subsequent developments allow speculation about the protean nature of notions about entitlements and rights and the effects of social, economic and political upheaval on the citizen-subject's relationship with the State.

Also, the interviews are inherently unique due to the special group of respondents they feature, that is, people living with HIV/AIDS, whose particular health concerns it is argued gives them a distinctive perspective on rights issues. Their contribution to the wider discourse on health and human rights is undiminished by (this) time.

Last but not least, the responses often reflect entrenched beliefs, values and concerns and it is unlikely that these have shifted significantly, if at all, since the interviews were conducted. Moreover, many of them are also still contemporary in the general discourse on rights.

iii. Whose Notions of Entitlements and Rights Are They Anyway?

As will be seen in more detail later in this chapter when the sequencing of the interview questions is addressed in detail, in the first part of their interviews the respondents for this research were asked to comment on their health requirements, to whom they attributed the duty to meet these needs, and why. In the second they were asked more precise questions about their knowledge of rights generally, and depending on how the interview progressed they were also asked to comment on a right to healthcare more specifically. As such, it is important to address the extent to which by explicitly raising the issue of rights I, as the interviewer, arguably ushered the respondents into a social context dominated by the rights discourse in which they were led to confirm their familiarity with, and knowledge of, rights. This issue is perhaps given added importance by the fact of my background, outlined at the start of Chapter 1 and again at the end of this chapter, as a rights academic and more specifically as a PLWHA rights activist, which suggests a vested interest. It rightly raises the question of how many interviewees would otherwise have described their

experience of living with HIV/AIDS in terms of rights had they not been briefed that the interview was on health and rights (if not a right to health(care) more specifically, as was the case for the handful with whom the questioning got this far, as will be explained later in the chapter).

The role of a researcher- any researcher- in defining the parameters of discussion within her research, its terms of reference, and so on, is indisputable. However, it is not the intention of this research to wrongly infer from interviewees' responses knowledge of, or an adherence to, the human rights normative framework. Indeed, as this research stresses in Chapter 1 and throughout the thesis, the evidence from the interviews largely suggests that interviewees used different normative frames of reference when describing their experiences as PLWHAs. Moreover, it can be argued that it would be too simplistic to view interviewees as mere objects, entirely lacking in agency, during the interviewing process, despite the unequal power dynamics that may be at play between interviewer and interviewee. Thus any analysis of their role in this exchange must appreciate their ability to independently introduce and reinterpret the ideas discussed, and in so doing shape the dialogue.

Indeed many interviewees did make voluntary, explicit references to terms or concepts commonly associated with human rights, and often did so unbidden by the interviewer. The most obvious ones were references to "stigma", "discrimination" and "equality", all of them now a familiar part of the HIV/AIDS lexicon, and all of them concepts in the human rights dialogue and popularized within this framework. They have become key components in the vocabulary which is commonly used to describe the experiences of PLWHAs, to the extent that it can be argued that a term like stigma, for instance, owes its popular usage in Kenya today solely because of its application in the HIV/AIDS discourse. These terms are often featured in media reports about these PLWHAs' issues and it is not surprising to hear PLWHAs use them in the interviews. Further, it should not be surprising that PLWHAs may demonstrate a familiarity with rights-related terms and concepts which predates their contact with this researcher, given the likelihood, as some attested, that many in their number had previous contact with other interviewers as well PLWHA rights campaigners. The level of attention given to HIV/AIDS in Kenya and around the world in the late 1990s and

2000s means that the PLWHA constituency was a particular target of human rights discussions and activism. Some interviewees for this research even spoke of interview fatigue among some in their number. As such, the interviews conducted by this researcher will not have been the first time that some respondents will have thought of, described or heard their experience of HIV/AIDS described in terms of often associated with the human rights discourse.

This explicit and voluntary usage of terms like 'stigma', 'discrimination' and 'equality' will be discussed particularly in Chapters 4, 5, 6, 7 and 8, where, as will be seen, many PLWHAs employed these terms to describe aspects of their treatment in the workplace, in health institutions, at home, and so on. Indeed, it is primarily on the basis of such data that this research suggests a link may be made between PLWHAs' experience of HIV/AIDS and their perceptions of and attitudes to their illness and their conceptualization of entitlements and rights. It argues that further inferences about how HIV/AIDS may affect PLWHAs' notions of entitlements may be drawn from other data where interviewees appeared to suggest that their own perceptions of HIV/AIDS, which sometimes hinted at self-stigmatization, as well as their sensitivity to their families' and friends' attitudes to it, may affect the demands they felt they could make on them in relation to meeting their health needs. These discussions may be seen in Chapters 3, 5, 6 and 8.

Thus this research cannot ignore in its analysis the argument that the familiarity with or voluntary invocation by a number of PLWHAs' of vocabulary and concepts often associated with the intersecting human rights and HIV/AIDS discourses suggests some pre-existing awareness of human rights among them. Explicitly connecting the use of these terms to the framework to which they belong in the analysis is by no means an argument that any interviewee who employs them conceptualizes her experience of HIV/AIDS solely- or even largely- in terms of rights, or that she exemplifies a coherent or consistent human rights analysis of her illness. Indeed, this research argues that it is other frameworks of reference which appear to dominate PLWHAs' narratives of their AIDS experience.

And it is in recognition of this that this research applies caution or restraint in any inferences it makes based on the data about interviewees' internalization of human rights terms and norms, or the links between their illness and their conceptualization of entitlements. It maintains this restraint even as it notes that Kenya, as with every corner of the globe today, has not been untouched by the human rights project. The fingerprints that attest to this contact may indeed be discerned in some comments by PLWHAs, but even then this research disputes throughout the notion of the pre-eminence of the human rights framework in the conceptualization and articulation of claims and entitlements by PLWHAs.

The issue of access to medicine or treatment as a right is illustrative of this, as this chapter will explain in more detail later. For while medicine or treatment was one of the requirements most commonly raised by interviews at the start of their interviews, few went on to suggest it was a right, and among these some appeared to have drawn such connections on the spot, which, while not invalidating the interviewees' beliefs, may raise concerns that such views were influenced by the process of the interview itself and the presence of the interviewer and the questions she was asking.

But there were few such occurrences. As such, while the researcher must acknowledge explicitly raising the topic of rights, there are overwhelming reasons to believe that this does not diminish or invalidate the unique and important findings of this research.

iv. Of Deviations and Dual Objectives

The validity of the interviews and their findings notwithstanding, this research must address an inherent tension in the methodological approach which stemmed from the scope of its ambitions. For in seeking to maximize the rare opportunity that conducting these interviews presented, the interviews attempted to combine two objectives: that of investigating PLWHAs' subjectivities generally, and that of seeking more specific information about respondents' knowledge relating to rights. In the pursuit of these twin objectives, the method of collecting information encounters a tension: to achieve the first objective, it must maximize the parameters and method of its inquiry in order to give respondents the widest possible space to expound on

issues like stigmatization, which are generated inter-subjectively through social interaction. In its contemporaneous pursuit of the second, however, it must impose some parameters in order to try and extract opinions about a very specific topic.

It is these tensions that are manifested in the interview questions and method, in the interviewer's concerns about deviations from the topic at hand, and in the selection of a semi-structured interviewing process. As will be seen shortly, the design of the interview questions attempts to encapsulate the two issues that the researcher is trying to learn by separating the questioning into two sections: the first deals with general questions about PLWHAs' self-identified health requirements and so on, while the second asks specific questions about rights. The first part allows the interviewees the freedom that the accomplishment of its objectives demands; having set this standard, the second then has to focus the respondents' attentions on more specific issues, employing techniques such as filters, and remaining alert to situations where the respondents might digress or evade the questions, concerns which by and large do not affect the first section of questions. This dual aim which the interviews seek to achieve, then, is the essence of the freedom-control dynamic displayed in the methodology.

In spite of these tensions, it must be reiterated, the interviewer's aim is always to learn from the interviewees, and the issues of vested interests noted earlier notwithstanding, this is precisely what this research achieves. Further, it is the argument here that the interviews not only produce valid results but that each section overwhelmingly succeeds in its task. Indeed, one of the main successes of this research, which comes from interpreting the combined findings of the two parts of the interviews, is the evidence that the while experts make automatic linkages between the health needs of PLWHAs and human rights obligations, many PLWHAs do not. This has important ramifications for the conceptualization of the rights as the preeminent framework for articulating and characterizing socio-economic deprivation. Moreover, there is much to credit in the idea that rare opportunities to conduct crucial fieldwork must be maximized, especially when the subjects in question are often driven into the shadows by the stigma of their illness, and when

the issues on which they are being asked to comment are those, like human rights, about which the opinions of laypeople are so rarely sought.

These important points aside, however, this researcher concedes that there is a lesson to be learnt in the methodological consequences of the enthusiasm she displayed here: for should another such interviewing opportunity present itself, it will be worth separating one's objectives so that one does not seek to achieve in one sitting worthy aims which nevertheless have methodological implications. This avid researcher must, and does, acknowledge this valuable lesson.

v. Interviewees' Demographic Information

Before analyzing the interviewing exercise, below is a table which provides a snapshot of the sociological profiles of the interviewees who eventually participated in the process. It contains information about their sex, age at the time of the interview, the year when the interviewee was diagnosed with HIV, the interviewee's educational background, employment status at the time of the interview, the language(s) in which the interview was conducted and the organization or institution with which the interviewee was associated and under whose auspices the interview was conducted.

Int. ¹	Sex	Age ²	Year Diag. ³	Education (No. of yrs completed)			Employment status at the time of the interview	Language in which interview was conducted	Participating organization or institution where interview was conducted
				Pri.	Sec.	Tert.			
Int. 1	F	31	1998	8	4	0	Unemployed	English	WOFAK ⁴
Int. 2	F	41	1996	7	4	? (attended college)	Unemployed	English	WOFAK
Int. 3	M	44	1994	7	4	0	Unemployed	English	WOFAK
Int. 4	F	34	1995	8	4	0	Self-employed	English	WOFAK
Int. 5	F	32	2002	8	4	? (attended college)	Unemployed	English	WOFAK
Int. 6	M	33	2001	8	4	4	Employed	English	WOFAK
Int. 7	F	24	2001	8	4	0	Unemployed	Kiswahili	WOFAK
Int. 8	F	31	2004	8	4	0	Unemployed	English	MDH HIV Clinic ⁵
Int. 9	F	32	2000	8	4	2	Employed	Kiswahili	MDH HIV Clinic
Int. 10	F	45	2000	7	4	1	Employed	English	MDH HIV Clinic
Int. 11	F	28	2003	8	4	4	Unemployed	English	MDH HIV Clinic
Int. 12	F	44	1991	3	0	0	Unemployed	Kiswahili	MDH HIV Clinic
Int. 13	M	32	2003	8	4	6	Student	English	MDH HIV Clinic
Int. 14	F	42	1999	7	6	3	Employed	English	MDH HIV Clinic
Int. 15	F	28	1998	8	0	0	Unemployed	Kiswahili	MDH HIV Clinic
Int. 16	F	30	1996	8	4	? (attended university; studies uncompleted)	Self-employed	English	MDH HIV Clinic
Int. 17	F	33	1999	7	4	? (attended college)		English	MDH HIV Clinic
Int. 18	F	40	1999	3	0	0	Unemployed	Kiswahili	MDH HIV Clinic
Int. 19	F	44	2000	7	2	0	Unemployed	Kiswahili	MSF Belgium HIV Clinic, MDH ⁶
Int. 20	F	38	1998 ⁷	7	4	0	Unemployed (volunteer) ⁸	English	MSF Belgium HIV Clinic, MDH
Int. 21	M	32	2004	8	4	0	Unemployed	English/Kiswahili	MSF Belgium HIV Clinic, MDH
Int. 22	M	44	1997	? (attended)	? (attended)	0	Employed	Kiswahili/English	MSF HIV Clinic, MDH
Int. 23	M	36	2004	7	0	0	Unemployed	Kiswahili	MDH HIV Clinic
Int.	M	38	2003	7	0	0	Unemployed	Kiswahili	MDH HIV Clinic

24									
Int. 25	F	38	1996	7	4	0	Unemployed	English	MDH HIV Clinic
Int. 26	M	36	2003	7	4	0	Self-employed	English	MDH HIV Clinic
Int. 27	F	? (f) ⁹	2003	? (f)	? (f)	? (f)	Employed	English	MDH HIV Clinic
Int. 28	F	52	1987	7	0	0	Unemployed	Kiswahili	MDH HIV Clinic
Int. 29	F	50	1992	2	0	0	Unemployed (volunteer)	Kiswahili	MDH HIV Clinic
Int. 30	M	44	2000	7	4	0	Employed	Kiswahili	MDH HIV Clinic
Int. 31	F	44	2002	7	6	4	Employed	English	MDH HIV Clinic
Int. 32	M	36	2001	7	4	0	Self-employed	English	MDH HIV Clinic
Int. 33	F	63	2002	4	0	0	Self-employed	Kiswahili	MDH HIV Clinic
Int. 34	M	50	2003	? (f)	? (f)	? (f)	Employed	English	MDH HIV Clinic
Int. 35	F	32	2000	8	0	0	Unemployed	Kiswahili	MSF HIV Clinic, MDH
Int. 36	F	41	1997	7	4	0	Unemployed	Kiswahili	MSF HIV Clinic, MDH
Int. 37	F	40	1997	7	0	0	Unemployed	Kiswahili	MSF HIV Clinic, MDH
Int. 38	F	31	2003	8	4	? (attended college)	Unemployed	English	MDH HIV Clinic
Int. 39	M	41	2003	7	6	0	Unemployed	English	MDH HIV Clinic
Int. 40	F	45	2003	7	2	0	Self-employed	Kiswahili	MDH HIV Clinic
Int. 41	F	35	1996	7	0	0	Unemployed (volunteer)	Kiswahili	MSF HIV Clinic, MDH
Int. 42	F	32	2001	8	4	? (attended college)	Unemployed	Kiswahili	MSF HIV Clinic, MDH
Int. 43	F	36	2003	5	0	0	Self-employed	Kiswahili	MSF HIV Clinic, MDH
Int. 44	M	39	1994	7	0	0	Self-employed	Kiswahili	MSF HIV Clinic, MDH
Int. 45	M	50	2001	7	6	? (attended medical training school)	Unemployed	English	MDH HIV Clinic
Int. 46	F	? (f)	2004	7	0	0	? (f)	English	MDH HIV Clinic
Int. 47	F	31	2000	8	4	? (attended college)	Self-employed	English	MDH HIV Clinic
Int. 48	F	38	1997	7	4	Ongoing	Student	English	MSF HIV Clinic, MDH
Int.	F	44	2003	7	1	0	Self-	Kiswahili	MSF Belgium

49							employed		HIV Clinic, MDH
¹ Interview number									
² Age at the time the interview was conducted. This was calculated by subtracting the interviewee's stated birth year from 2004 (the year the interviews were conducted), with the assumption, unless an interviewee provided a month and/or a date of birth, that the interviewee was born on the 1st of January of their stated birth year.									
³ Year interviewee was diagnosed with HIV									
⁴ WOFAK: Women Fighting AIDS in Kenya, Nairobi									
⁵ MDH HIV Clinic: Mbagathi District Hospital HIV Clinic, Nairobi									
⁶ MSF Belgium HIV Clinic, MDH: Médecins Sans Frontières HIV Clinic at MDH									
⁷ Disclosed 1998 as the year she "started living positively"; declining to disclose date when she learnt/was given a clinical HIV diagnosis.									
⁸ (Volunteer): Interviewee volunteered with an HIV organization, for which she received some remuneration or material return. The interviewee self-designated their volunteer work as their occupation.									
⁹ (f): Fault with audio-recording device, which meant the data here was not captured and was thus missing during the transcription process.									

b) Pre-interview

i. Interview Structure and Style

Structured interviewing was initially selected as the format most suitable to allow PLWHAs to consider the very specific issues which part of this research tackles while allowing the interviewer to monitor the direction that the interviews took.⁵ Pre-determined questions allow interviewees, for instance, to engage with the nuances of human rights and the ideas associated with them. However, I also was conscious that due to the sensitivity of some questions, particularly those relating to HIV/AIDS, I could influence the nature and order of questions but not necessarily the nature, depth or length of responses offered. And this, in any case, as mentioned earlier, may not be desirable in an exercise which seeks to investigate the subjectivities of respondents. This is indeed the approach I was inclined to adopt, a relaxed manner with the interviewee as long as the main question was addressed. As such, the resulting approach was a semi-structured approach, in light of the dual objectives of the interviews discussed earlier, which was able to accommodate those interviewees who might consider the interviewing process cathartic. For example, at the end of his session, interviewee 34, asked if he had anything to add, replied: “Personally, I feel that the interviews that one has, especially on one’s care, are very important because they assist not only the interviewer but also other people who might need to know the problem others face... So I feel happy with this kind of interview, that there someone who is caring for others, not only for me but for the others in future.” This relaxed stance, it was considered, might bring balance to an interviewing technique criticized for subordinating the respondent and imposing an “unnatural” relationship between interviewer and interviewee.⁶ However, as mentioned earlier, whether the interviewing process can ever be a fair exchange or entirely meet interviewees’ expectations is questionable, and was highlighted by interviewee 48, who alluded to interview-fatigue among PLWHAs and expressed disappointment about how the end-product of research was utilized. She appeared to have participated in other similar processes saying:

⁵ Burgess, Robert G., *In the Field: An Introduction to Field Research* (London: Unwin Hyman, 1984), at 101

⁶ *ibid.* See also Oakley, Ann, *The Sociology of Housework* (Oxford: Blackwell, 1985) at 226 and 228

You know we've been interviewed by so many people and then we get discouraged. I don't know if you realized that I was very reluctant because I just think we're fed up with the so many interviews. They are not benefiting us. They are benefiting you because you're the one who wants to get the information. Because you're supposed to interview me and come back to me and tell me, 'this is what is happening'. But what happens is that you people come, interview us and disappear. You only look for us when that need arises. I hope I haven't been hard on you.

As my findings remain unpublicized beyond my small academic team, her 'interview-and-disappear' prediction appears accurate; however, I hope to correct this once the research is complete, and indeed feel duty-bound to do so.

A looser approach to interviewing also enabled me to take advantage of unexpected opportunities for data collection. For instance, where interviewees deviated somewhat from the expected response particularly in relation to the human rights section of the questions, it was sometimes possible to glean a considerable amount of relevant but unsought information; a prime example of this will be seen in the next section when the design of the interview questions is analyzed. Such material contributed significantly to the general context. Further, this approach proved beneficial where it became necessary to adapt my framing of specific questions in order to help a respondent engage with the essential aspect of a question.⁷ It indeed suited the complex and multi-layered subject of this research and it is the style that Lee Harvey is arguably advocating when he warns that "[p]rescribing in advance how to collect data inhibits the research endeavour."⁸

In addition to the structured questions, I also decided to conduct my interviews face-to-face. One clear benefit of this was that it allows the interviewer to rectify immediately any misunderstanding or misinterpretation of the questions. Moreover, this more personal approach lent itself best to the sensitive subject matter, allowing researcher and interviewee to form a bond, however short-lived, which may in turn

⁷ For instance, when asking interviewees to consider the practical benefits of having a right to healthcare, I would try and get them to think of the question less abstractly: often I would rephrase it by saying, "If I came to you and told you, 'Jane, you have right to healthcare,' do you think there would be any practical benefits in this for you?". This was partly to emphasize the desired individual perspective. Also, I was hoping to emphasize that what I was looking for was their response to a statement like that when there may be nothing more in the way of action or deeds to back it up. In this sense, one may argue that I was giving such a question a very specific interpretation but it was the one I wanted respondents to consider and I sometimes felt that this emphasis brought me closer to that objective.

⁸ Harvey, Lee, *Critical Social Research* (London : Unwin Hyman, 1990) at 8

encourage the latter to respond more fully and openly.⁹ Even some of the suggested disadvantages this method proved well-suited to interviews with PLWHAs, because while it may require more time and resources than, say, telephone or email interviewing, the addition to the process of what Judd, *et al*, call “interviewer effects” can be utilized positively.¹⁰ For example, they suggest that the rapport that may develop between interviewer and interviewee, which enhances data quality, may also induce the interviewee to submit responses which they perceive will fulfil the researcher’s expectations or personal characteristics, such as sex. However, this risk can be managed and indeed manipulated to work in the interviewer’s favour: for instance, although my interview questions never asked how an interviewee had contracted the HIV virus, some interviewees, almost all of them women, volunteered this information. In all these cases, the infection had happened through sexual contact with their partners, and in one through rape. It is unlikely that interviewees would have offered such information to a male researcher yet such information, despite being surplus to the interview’s requirements, offered a unique insight into the complex psychosocial effects of HIV/AIDS from the perspective of the infected person and provided the context for a key strand in my analysis. Other researchers have written about similar advantages especially in studies where sex or ethnicity is a key element.¹¹

This latter element, of especial interest in a multi-ethnic country like Kenya and analyzed more broadly throughout this research, deserves further comment in relation to the conduct of the interviews. The interviewers were not asked to disclose their ethnic identities because ethnicity has often been an inflammatory subject in Kenyan socio-political interactions and I was concerned that if an interviewee was explicitly asked to disclose this information she might at best wonder about the

⁹ But as researchers such as Ann Oakley point out, however, that there is a fine balance to be struck between being “friendly but not too friendly.” For a successful interview “must have all the warmth of a personality exchange of a conversation with the clarity and guidelines of scientific research....[t]he contradiction at the heart of the textbook paradigm is that interviewing necessitates the manipulation of interviewees as objects of study/sources of data, but this can only be achieved via a certain amount of humane treatment. If the interviewee does not believe that he/she is being kindly and sympathetically treated by the interviewer, then he/she will not consent to be studied and will not come up with the desired information.” (Oakley, Ann, *Housewife* (Harmondsworth: Penguin, 1976), at 222 and 223

¹⁰ Judd, Charles M.; Smith, Eliot R.; and Kidder, Louise H., *Research Methods in Social Relations* (Orlando: Harcourt College Publishers, 1991), at 219

¹¹ See, for instance, Burgess (n 5), at 104

relevance of this information in the context of an interview ostensibly about HIV and human rights, and at worst assume that the interviewer meant to draw certain, possibly negative, conclusions from this detail. An explicit question about ethnicity may also cause the interviewee to wonder about my own ethnic identity (she perhaps viewing such disclosure as reciprocal) and how, were it to be provided, its correspondence or difference with her own might influence the information she chose to provide, how she provided it, or my interpretation of the information she provided, as well as her opinion of me or indeed my opinion of her. All in all, I concluded that any inquiry into an interviewee's ethnic identity would taint the interviewer-interviewee interaction and thus be counterproductive.

It must be noted, though, that sometimes interviewees did bring up the issue of ethnicity unbidden, and when this happened and their comments were significant to the wider discussion with which this research deals, this was noted and the comments analyzed. It must also be mentioned, of course, that a speaker's ethnic identity may become obvious to the listener based on her pronunciation of English or Kiswahili words. A more explicit revelation of an interviewee's ethnic identity occurred in the case of one respondent (discussed later in this chapter in note 35) who, struggling with answering her questions in English or Kiswahili, resorted to her ethnic mother-tongue, which her daughter then translated. However, I was not conscious of such information having any personal bearing on the process of interviewing any respondents, and certainly not in the analysis of the information collected from them.

ii. (In)Access and AIDS

Conducting interviews with PLWHAs in Kenya posed certain in-built challenges; the issue of gaining access cannot therefore be dealt with cursorily, as some studies have tended to do.¹² While the last few years have seen greater willingness by the

¹² *ibid.*, at 38. Burgess gives an example of his own research experience in a school: "First... access is not a straightforward procedure. Indeed, in the school, different approaches had to be made to individuals at different levels in the organisation. Access, therefore, involved negotiation and renegotiation. Secondly, that access influenced the kind of investigation that could be done and the position that I could take. Finally, that access occurred throughout the research process and as such

government and the media to highlight the plight of PLWHAs, AIDS-related stigma¹³ is still common, stemming largely from prevalent sexual and gender norms. Certain sexual behaviours, as well as intravenous drug use¹⁴, an emerging route of HIV transmission in Kenya, are frowned upon. Stigma is central to understanding how the psychosocial aspects of HIV/AIDS, the construction of subjectivities and the development of notions of entitlements intersect. Susan Sontag explored this theme, asserting that “the unsafe behaviour that produces AIDS is judged to be more than just weakness. It is indulgence, delinquency...”¹⁵ An individual’s HIV status, real or imagined, may lead to unfair treatment and thus stigma leads to discrimination. Many PLWHAs therefore prefer to keep their HIV status secret, making harder the task of identifying and interviewing them; indeed, several of my eventual interviewees articulated their ongoing concerns about stigma. One female respondent, interviewee 11, illustrated both her personal experience of stigma and discrimination as well as a lucid awareness of its source:

For one, if you look at HIV-positive person, everyone looks at them like an immoral person. They’ve forgotten that they could be born with it, they could have tampered with some razorblade or sharp object, it could have been a rape, blood transfusion, but because the society is not educated about it, everyone perceives you as an immoral person. So you become an outcast.... When they see you, they say, “That one is immoral; she moves around with a lot of men.” You really need to have strong character to get out of that kind of a state and stay positive. Also, about HIV victims who don’t want to talk about it because of the kind of society we have- I have preached in so many places myself but I had heard people say, ‘oh, this is a Christian. She used to preach to us but it seems she was also immoral.’

The question was therefore how to gain access to willing PLWHAs who were sufficiently confident to disclose their HIV status to a relative stranger, and who could also candidly relate what were likely to be painful or bitter experiences, as demonstrated by interviewee 11, cited above. The plan was to speak to between forty and fifty PLWHAs, a sample size large enough to offer the possibility of varied

generated other problems involved in doing field research (that is, selecting interviewees and observing situations).” (at 45)

¹³ The Joint United Nations Programme on HIV/AIDS, UNAIDS, defines stigma as a “‘process of devaluation’ of people either living with or associated with HIV/AIDS.” (UNAIDS, *UNAIDS Fact-sheet: Stigma and Discrimination*, 2003, at http://www.unaids.org/html/pub/publications/fact-sheets03/fs_stigma_discrimination_en_pdf.htm, accessed 25th November 2003) This issue is dealt with in greater detail in Chapter 6 of this thesis.

¹⁴ *ibid.*

¹⁵ Sontag, Susan, *AIDS and Its Metaphors* (Harmondsworth: Penguin, 1990), at 25.

and illuminating views on the relevant issues while still accommodating the limited time and resources at my disposal.

Given the possible shortage of willing interviewees, the most expedient method was, and indeed proved to be, interviewing any and all those interviewees to whom my contacts introduced me and who agreed to participate in the study. This meant that interviewees of any background or characteristic might be included. However, as will be detailed shortly, the vast majority of interviews took place at a hospital which catered for many residents of the nearby informal settlement or slum, Kibera, Africa's largest.¹⁶ This may account for the overwhelming proportion of respondents who alluded to a low-income background. There were no explicit questions on income or earnings, which, though useful, might have created more complications than they were worth.¹⁷ Respondents were instead asked whether they were currently employed, although many also referred generally to the (often dire) state of their finances.

There were certain benefits, imposed arbitrarily by prevailing circumstances, in talking to respondents who had possibly experienced poverty, but any resulting advantages were nevertheless accidental. As is often the case, the location of my research broadly pivoted on the places or institutions I was best able to establish contacts and obtain permission to conduct my research.¹⁸ Fundamentally, given the requirement of PLWHAs and the fact that, despite assumptions, HIV infection cannot instantly and conclusively be diagnosed from sight, I had to target places where I was certain of finding PLWHAs who were aware of their HIV status.

iii. Research and Ethics

Hospitals and clinics were the most obvious places where PLWHAs might go for treatment; however, these institutions have acquired reputations for unwieldy

¹⁶ See BBC, 'Nairobi slum life: Escaping Kibera,' 15th October 2002, at <http://news.bbc.co.uk/1/hi/world/africa/2297279.stm>, accessed 1st September 2010.

¹⁷ Among my concerns was that respondents would not always have had a ready answer to this, especially for those with unsteady sources of income; that they may be regard the matter as private; and that they may provide the answer which they feel is least likely to jeopardize the possible receipt of remuneration, which may be an expectation particularly among those who may have been through a similar process. See note 26 below.

¹⁸ Burgess (n 5), at 59

bureaucracies and tardiness in granting permissions for research. This is perhaps especially true of government establishments: in a preliminary inquiry about a typical process, a member of the administration staff MDH in Nairobi, where the vast majority of the interviews (42) were eventually conducted, was emphatic that proper procedures, beginning with permission from Kenya's Ministry of Health to conduct the research, be followed for the sake of the hospital's reputation as well as the protection of patients' privacy.¹⁹ Thus there appeared to be at least three layers of access and consent: the Ministry of Health, MDH and the potential interviewees themselves.

While delays in gaining approval for research can be criticized and need not be the consequence of thorough checks, such safeguards are imperative to protect already vulnerable interviewees. Indeed, there have been highly publicized incidents questioning the government's ability to do this, especially when the institutions in questions are based overseas. One such case, mentioned by at least one interviewee, involved allegations of irregularities surrounding research conducted by Oxford University on residents at Nairobi's Nyumbani Children's Home, an orphanage for AIDS orphans.²⁰

After my initial contact with the Ministry of Health, I was assured that this was the only permission required at ministerial level to conduct my research at MDH, although it is often the case that further permission may be required from the Ministry of Higher Education, Science and Technology. The Ministry of Health's permission was obtained on 5th April 2004 following a number of abortive meetings with the official in charge, and was granted subject to conditions such as further internal checks by MDH's Ethical Committee.²¹ However, I was given verbal permission by an MDH official to commence my interviews even before an Ethical Committee was assembled to review my proposal. Reasons for this were never given, and I was too grateful for anything that might expedite the process to complain. No

¹⁹ Preliminary Inquiry with Mbagathi District Hospital Administration Officer, 3rd March 2004

²⁰ Okweba, Arthur, 'Renowned Nairobi Orphanage in Suspect Study', *The Daily Nation*, 18th October 2001.

²¹ There was a further condition about the consumption of the end product, that is, the thesis, to which both the Director of Medical Services in the Ministry of Health and the hospital were to have access.

Ethical Committee was ever convened during the five weeks that I was at the hospital and, to the best of my knowledge, none ever was. Moreover, I was determined that despite clearances from the Ministry of Health (written) and MDH (verbal), I would, out of respect to would-be interviewees, also impose my own ethical checks²²: I introduced myself and the nature and purpose of my research to each prospective interviewee to ensure her decision on whether to proceed was an informed one.²³ Further, any interviews would be terminated at any point if the respondent so requested.²⁴ Such assurances may have contributed to MDH's administration's lax approach towards convening an Ethical Committee to assess my research request but it is worrying that less scrupulous persons might gain similar access to vulnerable PLWHAs purely on the basis of verbal assurances. The original list of questions also included the interviewee's name. In hindsight, this question should never have been included, to further safeguard the interviewees' anonymity and privacy. I subsequently compensated for this shortcoming by ensuring that all interviews were allocated a numbering system which corresponds to the sequence of interviews, by which they are referred to in the thesis. This protects even those respondents who volunteered such information at the time but who might view such disclosure differently with the passage of time.

Although most of the interviews were conducted at MDH, I had first opted for a different method of accessing PLWHAs. Following consultations with members of PLWHAs' support organizations at the International Conference on AIDS and STIs in Africa (ICASA) in Nairobi in September 2003, I became convinced that such organizations would be the best place to access possible interviewees. Not only were their clients more likely to be open about their HIV status, they were also likely to be familiar with the interview process and so, perhaps, more forthcoming with their opinions. I contacted a few of them and although in principle they did not object to the idea of interviewing their service-users- as long as the PLWHAs themselves consented- the actual process of arranging the interviews proved harder, with

²² See Gray, Joni N.; Lyons Jr. Phillip M.; and Melton, Gary B., *Ethical and Legal Issues in AIDS Research* (Baltimore: The Johns Hopkins University Press, 1995), at 34.

²³ *ibid.*, at 38-9.

²⁴ Indeed, one would-be interviewee, having agreed to speak to me, declined to proceed after I had informed her that the interview would be audiotape recorded, a choice that is discussed later in the chapter.

organization representatives appearing reluctant to allow access to their clients as the reality of the process crystallized. Whether this unwillingness was based purely on the desire to protect clients' privacy remained unclear. Care had been taken to explain the nature and purpose of my research in as much detail as possible to ensure that each organization knew that my work was a probe into the opinions and views of their clients and that membership in their particular support organization was incidental. As such, my research was neither an investigation into the workings of these organizations nor into the criteria for membership, if this was indeed the concern. (The latter, some MDH respondents would later claim, was sometimes based on ethnic identity (see Chapters 7 and 8).) In the end, I was able to arrange some interviews with one organization, WOFAK (who despite the name, has mixed-sex clients), with whom I had established the best contact and who were the only ones willing to make the time to speak to me and to avail clients for interviewing.

iv. 'Gatekeepers'

The process of gaining access is multi-layered and multi-dimensional. It requires the researcher to balance her investigative agenda with the demands and concerns of her interviewees and, as in the case of this research, their "gatekeepers", that is, "those individuals in an organisation that have the power to grant or withhold access to people or situations for the purposes of research."²⁵ Although these middlemen are crucial when conducting research into an area such as HIV/AIDS, where many interviewees prefer to remain hidden, that same reliance on their power to grant some initial access means they can unduly influence the research process, as will be seen shortly.

The seven WOFAK interviewees were specifically chosen by my contact there, the Program Officer (who also insisted that they were 'paid'²⁶), which I did not consider

²⁵ Burgess (n 5), at 48.

²⁶ He suggested a figure of Ksh. 200 (approx. GBP 1.30 or USD 2.60 at the time) as suitable and I agreed, as it was one which I my resources could accommodate. Subsequently, I offered this amount to all my interviewees at the end of the process, though some declined the offer. I did not advertise the reward when attempting to procure respondents: the figure would only be affordable given a small number of respondents and, further, I did not want to put off possible respondents who might decline to participate so as not to create the impression that they were either destitute (although they may, in fact, be) or that they were solely motivated by financial reward.

ideal.²⁷ It had been hoped the interviewees would be randomly selected based on availability and willingness to participate. There were two principal concerns about pre-selection: firstly, it was unclear why or by what criteria the Program Officer had chosen these particular individuals. Secondly, I did not want him to select only those clients whom he thought would be better informed about the issues raised in the questionnaire, perhaps for the prestige of the organization. My concern here was that this may colour any discussion I may engage in about how, if at all, contact with NGOs like WOFAK might affect PLWHAs' awareness of, and willingness to articulate, entitlements, and do so using a human rights framework. Indeed, explicit comments by respondents throughout the research suggested the influence of NGOs in promoting human rights vocabulary and ideas among PLWHAs. But the WOFAK clients did not appear more obviously rights-aware than subsequent interviewees.

It was unclear if the respondents were briefed in advance, although their responses were varied and appeared natural and sufficiently untutored. However, I was cautious not to voice my doubts about this for the sake of maintaining cordiality and possibly negotiating a further increase in interviewees.²⁸ However, opting not to voice anxiety on a matter that possibly concerned the nature and quality of information I might glean further illustrates the power a gatekeeper can exert on the research process as well as the data collected. This group of seven became my 'test group', as explored shortly, and based on the experience of interviewing them I was able to make some alterations to my interview questions and interviewing approach.

In addition to interviewing WOFAK's clients, I had also hoped for permission to observe any group sessions that the organization might host, having been informed that experts were sometimes invited to speak on a range of relevant topics. Previous subjects had included human rights and it would be interesting to observe the techniques that human rights professionals employed to make this information accessible and useful to non-experts but also to record how the clients reacted to it. However, permission was declined on the basis that a stranger's presence, even a

²⁷ I attempted to allay any concerns he may have had by detailing the nature of my research and allowing him to review the questionnaire. This proved to no avail.

²⁸ This strategy seems to have had some success as I was originally granted access to five interviewees, before two more were made available for interviews.

non-participating one (which I had suggested to enhance my anonymity) might be too intrusive and hence inhibit the clients from fully participating. These are reasonable considerations; I agreed that my research objectives must not supersede or obstruct a process aimed at assisting the clients. In addition, it has been noted that involvement by a researcher which hinders the naturalness of those being observed is sometimes counterproductive to the research itself.²⁹

Unable to secure more interviewees at WOFAK, I focused attention back to hospitals, particularly to MDH, where contact had already been established. The ethical issues pertaining to sensitive research at a government institution such as this is discussed later in this chapter. For now, it is important to note the role of the nurses and social workers at the MDH HIV clinic, who were crucial to gaining access to patients at this centre and at the Médecins Sans Frontières (MSF) Belgium unit based at the hospital. Not only did they assist with the logistics of the research (the head nurse at the HIV clinic suggested and permitted the use of a vacant room, adjacent to the clinic, for the private conduct of the interviews) but their excellent rapport with the patients greatly facilitated the procurement of interviewees. They volunteered useful suggestions on how to approach would-be interviewees and their experience enabled them to anticipate and remove some of the barriers that might discourage patients from participating while also ensuring they were comfortable with, and not inconvenienced by, the process.

For instance, the head nurse had grown concerned that my initial method of introducing myself to the patients assembled in the waiting area might put off potential interviewees, despite my efforts to be discreet by approaching one or two patients at a time. Indeed, there were those who sat in the adjacent- and sometimes merged- TB queue who were keen, when mistakenly approached, to emphasize that they were not part of the HIV queue and therefore, presumably, not infected with the virus. This is despite the high incidence of HIV prevalence among those with TB infection in Kenya³⁰; the TB patients are likely to have been aware of the links

²⁹ Judd, *et al* (n 10), at 270.

³⁰ Kenya ranks among the countries in sub-Saharan Africa with a high levels of HIV testing among people with TB, with 79% notified TB cases testing for HIV, up from 60% and 2006. (WHO/UNAIDS/UNICEF, *Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the*

between the two illnesses, which was by then common knowledge. Their vehement denial once again reflects concerns about the stigma surrounding AIDS. The head nurse rightly perceived that requesting the patients' participation in the privacy of their clinic session might yield more interviewees and she suggested taking up the initial task of mentioning my research to the patients while she saw them for their check-up, during which she would encourage them speak to me afterwards. Further, she suggested casually introducing me to those who had arrived early for their clinic sessions (while the waiting area was still relatively empty) and requesting them to speak to me about my work before the clinic started, assuring them that their place in the queue would be secure until the interview was done. Indeed, some patients had previously declined to speak to me for this reason, though it was often easier to convince them to be interviewed before or while they awaited their clinic appointment rather than afterwards when many had other competing activities such as collecting prescriptions. The endorsement of a trusted person seemed to encourage many patients to participate. In fact, its failures were down to human error, with the nurse, for instance, sometimes forgetting to mention my project to her patients.

The role of the MDH staff in the access hierarchy was further embedded by the informal relationships, alongside the formal, official ones, which existed between them and a number of the patients interviewed. One respondent, interviewee 36, for example, listed a particular social worker as one of those helping to provide for her health requirements, based on financial assistance she had occasionally sought and received from him, although this was likely not part of his official remit and would have had to come out of his own pocket. She said: Drugs it is MSF [that is providing me with them], the rest I beg for help. For example, to get to hospital, I might ask [the social worker] to help me with Ksh. 50." Other respondents, such as interviewee 3, also compared favourably the quality of care offered by MDH nurses with others elsewhere: "If I am taken to Kenyatta [National Hospital] I fear I won't last a week. The nurses there haven't the courtesy to handle people. It is better I was taken to

Mbagathi where the nurses have respect.” I was thus able to benefit from the trusting relationship between staff and patients.

With the MSF Belgium patients, my key contact was a social worker attached to the unit, who often initiated the process by introducing me rather vaguely to his clients thus: “This is one of our colleagues here and she is doing some research, so maybe you can talk to her.” It was not an accurate description of my role at MDH and I felt it necessary, for the sake of clarity and honesty, to inform potential interviewees of my independence from MDH- as well as filling in the details of my research. However despite such clarifications, many interviewees continued to believe that I was allied to the hospital or MSF team, or indeed the government³¹ or an NGO, as seemed the case with interviewee 35, who may have based her remark that I, too, had a role to play in providing for her healthcare needs on just such an assumption when she said, “It’s the responsibility of people like you! So I am very glad that I met you! You can help me! You and my husband combined can help me! Because I think that these organizations especially, more than even my husband, are the ones with the ability to help me. My husband can then help a little.” First impressions about the researcher’s identity and role may outlive any subsequent elucidation offered to an interviewee. Peter Blau, referring to his own experiences remarked, “The members of the organization know, of course, that management has given permission to conduct the study, and this creates another problem. The observer cannot escape an initial identification with management, since the assumption is that management must have a direct interest in the study.”³²

At any rate, the social workers’ endorsement guaranteed at least the chance to introduce myself and my work and in all but one case, they then went through with the interview process. This interaction with the social workers confirms Burgess’s statement that “[t]he points of contact which the researcher has within an institution, organisation or a group will influence the collection of data and the subsequent

³¹ For instance, interviewee 30, when asked how she thought the government might help her meet her health needs alluded in her reply that I was somehow associated with the government machinery, or that I might wield some influence within government: “If you can put forward a report so that we may get help from them, that would be good.”

³² Quoted in Hammond, Phillip E. (ed.), *Sociologists at Work* (New York; London: Basic Books, 1964), 25

perspective that can be portrayed.”³³ Although contact with MSF Belgium’s clients had not been planned my rapport with the staff attached to them provided access to this group of potential interviewees. It also provided an opportunity to register the views of PLWHAs who were actively engaged with an NGO and who may be able to draw more directly from personal experience when responding to questions regarding the role of these actors. Further, it allowed a glimpse into a parallel universe where MDH HIV clinic patients, located just a few yards away in the same compound, were having to partly subsidize their ARVs (the cost was officially lowered a number of times during and after my interviews, as discussed in Chapter 6), while those in the MSF programme received them free. Which of their other needs and requirements persisted despite a respite from the expenses of ART? Access to the MSF cohort provided an empirical opportunity to examine this. Altogether, of the forty-nine interviews conducted thirteen comprised of the MSF Belgium PLWHAs.

v. Designing the Interview Questions

Several issues arose during the creation of the interview questions for the PLWHAs’ interviews that highlighted the wider challenges involved in conducting research on a sensitive topic like HIV/AIDS, and which contribute significantly to the substantive discussion in this research about the construction of PLWHAs’ subjectivities and their perceptions about entitlements and rights. Further, as has been addressed at length earlier in this chapter, the dual objectives of the interviewing process meant there were inherent tensions at its heart which the design of the interview questions would have to contend with. Additionally, the interview questions design process drew attention to some of the difficulties associated with conducting research on human rights, where the standard terms of reference and their varied and contentious definitions may not be familiar to interviewees, a problem which, as is soon illustrated, is compounded when these terms require translation into an indigenous language. This suggests intrinsic problems within the human rights discipline, and obstacles to its rooting.

Language and Meaning

³³ Burgess (n 5), at 45.

To broaden the pool of possible interviewees, the interview questions had to be designed in both English and Kiswahili, Kenya's official languages. There are no figures available to suggest how many Kenyans are fluent in one or both of the languages, but the 74% of the population aged 15 years and over who are literate³⁴ will have encountered either one or both languages during their formal education. No version was prepared in any of Kenya's numerous indigenous languages; I calculated, correctly, the low risk of encountering a potential interviewee who could not communicate adequately in English or Kiswahili; indeed, there was only one such respondent.³⁵ The pitfalls of conducting interviews through a translator, even where one could be readily secured, were revealed on the one unforeseen occasion when this happened. It involved interviewee 33 (mentioned also in Chapter 1), whose interview illustrated problems not only with language but with attitudes about rights (dealt with in Chapter 8). The respondent, who had reached Standard 4 in her primary school education, was 63 at the time of the interview, and her daughter had accompanied her on her clinic session and into the interview. The respondent had difficulties understanding many of my questions and her daughter volunteered to act as interpreter, translating the questions into her mother's native Kikamba and relaying the answers to me in English or Kiswahili. Soon, however, it became obvious that some of the responses were the daughter's rather than the interviewee's, especially the imperative ones on human rights.³⁶

³⁴ Figure provided by the United Nations Population Fund (UNFPA) (UNFPA, 'Kenya', 2007, at <http://www.unfpa.org/profile/kenya.cfm>, accessed 15/09/07.

³⁵ She was interviewee 28, who when given the option of conducting the interview in either of these languages responded that she was most comfortable communicating in the indigenous language of Gikuyu. She was born in 1952 and formal primary school education up to Standard Seven. A considerable number of years had therefore passed since she was last enrolled in school and she may only have encountered either English or Kiswahili on an informal basis since that time. Although Gikuyu also happens to be my own indigenous language, I had in the past experienced difficulty in translating some of the key terms used the questionnaire, especially "human rights", without resorting to their English or Kiswahili translations or defining the term outright.

³⁶ For instance, the daughter tried to translate the question about whether the respondent had heard of the term 'human rights'; apparently unable to find a Kikamba equivalent for the phrase, she ended up having to use the Kiswahili term wholesale. As the daughter repeatedly tried to explain the question to her clearly uncomprehending mother, I could hear her trying to break down the term as she herself understood it: she used Kiswahili words like "*serikali*" (government) and "*mahitaji*" (needs). She seemed resolved not to concede that her mother could not understand the question. Their exchange continued, in which her daughter said "no" after certain responses from her mother (thus filtering the responses before they got to me), before she finally translated a response which I would say was almost certainly hers rather than the interviewee's: "The government should help those in need like myself, in the same way as it has been doing by providing the medicine." I followed this with a request for examples of human rights the interviewee may have heard of or knew; although I was aware that the response would be very skewed and would most likely be the daughter's rather than the

The practical application of the questionnaires was revelatory: for instance, the English version of the phrase ‘human rights’ appeared widely familiar, with even those with a stated preference for a Kiswahili interview often claiming to know it rather than its Kiswahili equivalent. Interviewee 37 is a good example, and like several others chose to conduct the interview in Kiswahili but referred to the words ‘human rights’ in English. When I initially mentioned the phrase in Kiswahili, she repeated the question and said, “You mean ‘human right’? She then proceeded with her response. Interviewee 42 also switched between Kiswahili and English when making the statement: “I know that ‘human rights’ is the right of human beings, the way a human being deserves to be treated, whoever they may be.” When speaking the words “the right of human beings” she reverted to her original Kiswahili, including when using the words ‘human’ and ‘right/s’ separately or in a different order; this indicates that it was well within her vocabulary capability to discuss the phrase ‘human rights’ in the Kiswahili language that she had initially chosen to conduct the interview. That she should break off into the English specifically to utter the phrase ‘human rights’ reinforces the notion, addressed shortly, that it is perhaps in the English that it has gained most popularity.

Indeed, one respondent, interviewee 36, who preferred to take the interview in Kiswahili, appeared to perceive the Kiswahili translation as the realm of language purists, saying: “I have heard [of the phrase] but I don’t understand it. You know with Kiswahili, sometimes you hear certain terms and vocabulary like *‘haki za kibinadamu’* and if there is no one there to explain to meaning, you wouldn’t know what they mean.” The broad familiarity may be explained by the increased public debate about human rights and the popularization of its terminology; yet the particular familiarity with the English phrase may also be symptomatic of the exclusivity of the discourse, which does not adequately embrace those outside professional, mainly-NGO circles for whom this is often the operating language. And though political events and active civic education may have since somewhat altered this latter situation and the

interviewee’s I thought there may be something to be learned regardless. Indeed, when the daughter translated the question to the interviewee, I heard words like “government” crop up again, as well as the sentence “taking care of your needs,” which I was able to make out later when I listened to the interview tape because it was a mixture of Kiswahili and Bantu words, similar to my native Kikuyu.

Kiswahili phrase probably gained more currency, the interviews here offer evidence of how language, knowledge and social and political dislocation intersect. As Harvey notes, the core of critical social research is the

idea that knowledge is structured by existing sets of social relations. The aim of a critical methodology is to provide knowledge which engages the prevailing social structures... Indeed, it is arguable that for a critical methodologist, *knowledge is critique*. ... Knowledge is a dynamic process not a static entity. Knowledge is not a bucket into which grains of information are dropped in the hope that they somehow coalesce into some kind of explanation of the world. For critical methodologists, knowledge is a process of moving towards an understanding of the world of the knowledge which structures our perceptions of that world.³⁷

Further linguistic challenges arose in the translation of other key terms of reference, with 'healthcare' being a prime example. To be sure, the choice of the word, in English or Kiswahili, was conceptually problematic, for the reasons highlighted in the Introduction. While using the phrase the 'right to healthcare' may have been the simpler alternative, in practice it also presented a difficulty: among the WOFAK test group, for instance, interviewees 3 and 1, who in previous questions had mentioned certain aspects of healthcare in association with rights, seemed, however, unsure about placing healthcare in the context of human rights when later asked more specific questions on the matter. Both interviews were conducted in English:

Interviewer: What are some of the Human Rights you've heard of or you know?

Interviewee 3: Like, to have access to medicine is a human right.

Later:

Interviewer: It has also been stated by some people that there is a human right to healthcare- have you ever heard about a human right to healthcare?

Interviewee 3: There is, yeah. It's like someone can be forced to go to hospital... I don't know whether I am getting you.

...

Interviewer: Some people have stated there is a link between the issue of health generally and that of human rights. Have you thought much about this issue or have you not heard much about it?

³⁷ Harvey (n 8), at 2-4

Interviewee 1: Well, as a human, anyone can fall sick- anyone. So you're supposed to be taken care of well if you're sick so I think it is related to human rights.

Later:

Interviewer: It has also been stated by some people that there is a human right to healthcare- have you ever heard about a human right to healthcare?

Interviewee 1: [Hesitation] Not really.

One could draw several conclusions from this discrepancy: interviewee 3 may not have heard about a right to healthcare as he claimed. Alternatively, he may have heard about it but could not explain precisely what it entailed. He may also not have associated access to medicine with the wider issue of healthcare. It was likely, too, that both interviewees may not have understood the meaning of the word 'healthcare'. I had automatically, and erroneously, assumed that my interviewees would have a working- and roughly similar- definition of the word, despite the fact that none of them were likely to have English as a mother tongue, including those who preferred an English interview. It would be highly unlikely, of course, that any interviewees made the kind of academic distinctions between 'health' and 'healthcare' explained in Chapter 1, which are themselves debatable. In fact, the only respondent in the test group to have intimated at a broad interpretation of the term, more akin to that applied to a right to *health*, was one who had admitted that she had only begun to perceive a linkage between health and human rights as the question was being posed to her. She (interviewee 7) said, "I've not heard much about but just as you were saying it, I do think there is a connection between health and human rights. Because if you see something like slums, people have the right to live in a good shelter and in slums there is a lot of congestion, which allows diseases to breed. Like TB, diarrhoea."

Matters were compounded by the Kiswahili questionnaire: while there is a Kiswahili word for 'health' it would not have made a translation of the phrase the 'right to health' and the concepts it tries to capture any clearer or less absurd, as Leary points

out, to a layperson. But there is also no singular equivalent for ‘healthcare’.³⁸ A choice had to be made on the translation which would best facilitate the inquiry. In effect, the twenty-two Kiswahili-speaking interviewees- that is, those advanced to this section of the interview- faced questions which had small but crucial differences to those interviewed in English, and it is difficult to gauge what the original question lost or gained in the process. The phrase I settled on was ‘*haki ya kupata matibabu*’ which translates back into the English as the ‘right to receive treatment’. If the phrase the ‘right to health’ is vague and unspecific and the ‘right to healthcare’ more precise but also open to interpretation, the ‘right to receive treatment’ can be said to be even more definite yet even this, too, is ambiguous in its scope. The effects of this translation may be seen, for instance, in interviewee 41’s responses: while she would still have applied her own interpretation to the key terms, there were compelling signs that the more specific nature of the question had already narrowed down considerably the scope of such interpretation. In the following extract, I have also italicized the relevant terms within the responses and replaced ‘healthcare’ with ‘receiving treatment’, which is how she would have received the question:

- Interviewer:* In your opinion, what does the term ‘*getting treatment*’ mean to you?
Interviewee: It means that when you’re ill and have opportunistic illnesses, we are taught that you must see a doctor because small illnesses can become huge problems.
- Interviewer:* Have you ever heard about a *human right to getting treatment*?
Interviewee: Yes.
- ...
- Interviewer:* In your own words, what does a *human right to getting treatment* mean to you?
Interviewee: It means if you’re ill you must get treatment, whatever illness it is. Even if it’s malaria.

Such interviews illustrate the multiplicity of definitions and associations that accompany terms used widely across the field. They may be further proof that familiarity with the vocabulary of commonly applied rights, though it may aid laypeople to re-conceive and re-articulate their entitlements, as later chapters explore, does not on its own mean that laypeople begin to frame such notions in this language. This relies on more fundamental transformations in how one views her wider relationships to others in the human rights dynamic and the attendant privileges and obligations. The interviews also underline the variation in information

³⁸ The Kamusi Project, *The Internet Living Swahili Dictionary*, Kamusi Project USA and Kamusi Project International, <http://www.kamusi.org/?q=en> (accessed 06/03/12)

possessed by researcher and interviewee and the unevenness of their relationship, where the former may often be an expert on the subject and the latter a laypeople. The interviewer's instinct is often to apply the lexicon of her milieu, which may provide the only terms of reference within which to frame the study. As with terms like 'healthcare' or 'human rights' the lack of adequate alternatives or equivalents compounds the problem and may result in having to define the term to the respondent first, which may be counterproductive to a study aimed precisely at discovering the extent of an interviewee's knowledge of that topic.

Such limitations in language which compel a researcher to impose her own terms and definitions could be interpreted as a subtle attempt to legitimize exactly that which she seeks to investigate. This in turn augments the researcher's position and her field, and widens the investigator-respondent fissure not just within temporal space of their engagement but also in the spheres of power that the two occupy. Interviews such as those above also raise deeper questions about how language and knowledge interrelate and might shape the deeply subjective notions of entitlements and rights. Moreover, they provide a window into the social factors that determine the distribution of knowledge, as Chapter 6 explores in reference to biomedical knowledge.³⁹ Many of these factors are also replicated in patterns of poverty and lack of access to socio-economic goods.

A further area where translation into Kiswahili may have altered the meaning or tone of key terms was in the series of questions designed to gauge notions about entitlements. In the English interviews, the simple use of the word 'should' in a question sufficed to tease out information about respondents' perception of agency vis-à-vis particular actors and the extent to which respondents felt they could influence their actions. Apparently innocuous terms like 'should' and 'duty' might turn into 'compel' (perhaps even 'force') and 'job', respectively, depending on interviewees' interpretations when translated back into the English. This changes the meaning, asking Kiswahili language respondents to contend with what often proved to be a rather startling notion of *forcing* the government to take certain actions. This

³⁹ Berger, Peter and Luckmann, Thomas, *The Social Construction of Reality: A Treatise in the Sociology of Knowledge* (Harmondsworth: Penguin, 1967)

could also be responsible for some of the responses where interviewees felt strongly that NGOs, whose role was often perceived as merely voluntary, should not or could not be compelled to help. Yet even these distorted responses usefully revealed the depth of asymmetry in power that several respondents perceived in relation to the State or NGOs.

Sequencing

As a general rule, questions should be worded in as clear, simple, specific and neutral a manner as possible and ordered to suit their sometimes sensitive nature. It was a much more subtle process than anticipated and, once again, some of the challenges it posed go beyond a methodological analysis.

The first set of questions was designed to be simple close-ended ones of fact to ease the respondent into the interview. They sought the interviewee's age and sex profile and the year they had contracted the HIV virus. I had also included a question on whether the respondent had developed AIDS, which might be a good early indicator ARV use. However, this question often proved confusing to the WOFAK test-group, with several of the interviewees giving an "I don't know" response.⁴⁰ The question was thus discontinued as the information it sought could be accessed more explicitly later in the questionnaire. In addition, such a seemingly ambiguous question so early on disrupted the flow and prevented the interviewee from settling.

The next set of questions was subjective and focused on interviewees' health needs, including where they located the obligation for meeting these needs. It is during this sequence that many interviewees began to offer very detailed and articulate answers and they sounded noticeably more relaxed, as the audio-tape transcriptions revealed. These questions offered the most obvious opportunity for respondents to register any grievances about living with HIV/AIDS in Kenya and the best chance for the cathartic function discussed earlier, with the more detailed responses also proving the most helpful. For instance:

Interviewer: Whose duty is it, in your view, to provide for your requirements?

⁴⁰ As interviewee 2 put it: "Well, that's a technical question...I don't know when you rank someone as having developed full-blown AIDS because you bank on CD 4 count and if it's that one, there are people who are having CD4 count of 1 and they have resurfaced from that state. So, it's confusing."

Interviewee 3: First of all the government should provide- if the government provides me with employment, indirectly they have provided me with all these other needs. So that will cover most of the things. Like the ARVs nowadays, the government is supposed to give these because I hear that there are some donors giving out money. But the government still continues doing research- I don't know how the research will really help. And they are using the money for ARVs for this. They are laying strategies... they do this in the big hotels! But this won't help. Already people are hard-up. They know so-and-so is in need- the hospitals already have records, everywhere there records. Why do another research to get the records?

Locating these questions at this point in the overall sequence proved generally successful and this was crucial because the next set of queries included some probative ones which throughout the interviews discomfited even the most uninhibited respondents; reticent respondents became even more minimalist in their responses afterwards.

The first in this sequence of questions asked for respondents' opinions regarding the cost of ART. A potentially broad topic for comment, I chose to introduce the question from the perspective of a relatively recent and momentous development which was widely reported in the media: the Kenyan government's announcement in September 2003 that subsidized ARVs would be introduced at government District Hospitals. This was intended to focus respondents' minds on a specific event before leading onto further questions on pricing as well as the efficacy of the government's policy. I opted for flexibility here, applying an unenforced filter for this part of the questioning so as not to curtail interviewees who responded that they had not, in fact, heard of the announcement.⁴¹ While filter questions have their merits, the rule on their use should not be absolute and should be weighed against the benefits of obtaining

⁴¹ In a matter that goes back to the dual-objective tension discussed earlier in this chapter, I debated on whether, before introducing the substantive element of the question, it should be preceded by a filter one, which is designed to accommodate "don't know" responses and remove the assumption made by many researchers about respondents possessing ready-made answers on various subjects. If I opted for this technique, I should ask interviewees whether they had heard of the government's plans, with those who responded in the positive proceeding to the substantive part of the question, unlike those who responded in the negative, who, ideally, would never be asked about it. In fact Judd, *et al*, even suggest that the respondents who had claimed, as they might in this particular case, to have heard about the government's policy, should have additional checks imposed to ensure the veracity of their responses, by asking them to explain a further detail about such a policy (Judd, et al (n 10), at 242) Hence, one might end up with a two-pronged filter question in an effort to weed out opinions that were formed on the spot and which could not therefore be said to be an interviewee's carefully considered or deeply-held view.

responses to certain questions. Indeed, some of the on-the-spot answers they are designed to eliminate were given and accepted, and had some interesting and useful information to offer, such as interviewee 7, quoted on pg 83, above. Interviewee 14 also seemed to make up her mind on the spot when asked if she had heard of a right to healthcare, but proceeded to give coherent, consistent answers:

Interviewee: I think every citizen has a right to healthcare.

Interviewer: So you've heard about this right?

Interviewee: I don't know how I came to hear about it! I think I'm just aware!

Another respondent, interviewee 25, who frequently interacted with NGOs said:

I've never heard about this [right to healthcare] but although I've never heard about it, I know there is because they are about fighting for the rights for accessibility of drugs. If human rights can come in to fight for the drugs to be accessible, in District hospitals, I know they can succeed. They have a lot of strength to do it.

Her response is also noteworthy for being one of a number in which the interviewee appeared to conceive of human rights as people or organizations, a discussion which is expounded on in Chapter 8. Interviewee 32 was unsure about what he may or may not have heard about a link between HIV and rights and when asked if he thought there should be one he said: "There *should* be." Not only was it important to find out what PLWHAs thought about the government's policy on ARVs, it was also crucial to offer them this chance to relate their own experiences, if any, of the implementation of this policy, as the subsequent substantive questions invited them to do. Even the responses of the MSF Belgium PLWHAs were useful, although a number of them had not heard about the government's ARV roll-out plan. Their opinions on the ARV costs still borne by their non-MSF counterparts contributed to the debate because, though often formulated on the spot, they were always filtered through their own experience of free ARVs supplied by MSF Belgium. The questions therefore invited them to comment on an alternative reality which but for good luck- as it often turned out- they themselves might inhabit.

As I had anticipated some problems, beyond the linguistic ones noted earlier, with responses to the human rights questions, they were positioned in what was, in effect, the second part of the questionnaire. Indeed, as seen in the Introduction, many interviewees found aspects of these queries especially taxing and it was noted that

several of them felt their inability to answer some of the questions, or, more accurately, that their “don’t know” responses were inadequate. I always introduced this section of the interview questions before plunging into the questions because, having thus far only examined the health requirements of PLWHAs, a discussion on human rights, a topic on which many respondents may not consider themselves experts or immediately link with HIV/AIDS, may appear unrelated and disjointed. As has been mentioned, this poses potential problems in that it arguably marshals interviewees’ towards the topic, subtly suggesting it as the ‘correct’ way of conceptualizing and analysing subsequent questions. Yet a lack of cohesion within the interview questions risks irritating or confusing the respondent⁴², whose continued participation in the interview process I desired. Therefore, despite having informed interviewees at the beginning of the process that some of the questions would be human rights-related, I would remind them of this at this point by saying, “As I mentioned earlier, I would also like to ask you about your thoughts on the issue of human rights.” This served to flag up the slight change in content- an accommodation which, again, owed to the dual-objective tension- and also introduced a possibly challenging topic in a manner that reassured the respondent that it was her opinions on the issue that were being sought, whatever they may be, rather than answers which they might perceive as being either right or wrong.

It is vital that no assumptions are made about nature and extent of knowledge that ordinary people may possess on the topic of human rights, although, as will be seen shortly, some presuppositions may persist, however unwittingly. To mitigate this the series began with very basic questions: whether respondents had heard of the term ‘human rights’, what they understood these words to mean, examples of human rights they had heard about and from where they had heard about them. There were several ambiguous responses which were sometimes left at that if I apprehended a danger that pushing for precision might be counterproductive, causing the interviewee to withdraw or become less forthcoming with successive answers. However, some gentle prodding occasionally resulted in an answer. The example of interviewee 7 will be recalled from the Introduction: after saying she had heard of the phrase ‘human rights’ she initially hesitated when asked to define it saying, “This is a

⁴² Judd, *et al* (n 10), at 245.

difficult question and you know explaining it is very hard.” But following the reassurance that she did not have to provide a text book definition she volunteered, “It means treating someone like they are a human being. You treat them the way that you would like to be treated yourself.” Indeed, the notion that an answer is unsatisfactory may often be imposed by the respondent herself, leading to unfortunate self-censorship.

This sequence of queries progressed to explicit questions about the possible nexus between human rights and HIV/AIDS about which, again, no assumptions were made, hence the filtering here of responses. This technique was employed and enforced here because for those interviewees who may admit to not having heard the term ‘human rights’ it would be futile to pursue questions about whether the interviewee had considered any link between human rights and HIV/AIDS. The filter question read: “Recently, we have been hearing people talk about human rights in relation to HIV/AIDS. Have you thought much about this issue or have you not heard much about it?” This construction serves to minimize any embarrassment that a respondent might feel about a response in the negative by “explaining it away” and ensures that “not knowing enough to have an opinion [is] implicitly excused in the wording to encourage respondents to answer truthfully.”⁴³ Although Judd, *et al*, recommend such a device especially where a response may be considered “socially undesirable”, and the audio-tapes confirm a distinct discomfort on the part of those respondents who had not contemplated any links between HIV/AIDS and human rights, it is unclear how much they viewed such an admission as being merely embarrassing rather than “socially undesirable”. However, it cannot be discounted that wording the filter question this way presented interviewees with an ‘acceptable’, ready-made, legitimate answer in itself and some did in fact respond by simply using the same words: “No, I haven’t heard about it”.

The next set of questions listed various actors- local government officials, central government, local and foreign NGOs and others- and sought the interviewees’ perceptions as to whether they could and should assist in meeting respondents’ healthcare needs. Amongst the WOFAK test group, most of those who replied that

⁴³ *ibid*, at 248.

any of these actors could help them also voluntarily supplied examples of the ways in which they could do so, which prompted me to ask the same of subsequent interviewees who did not volunteer this information; this is a good example of how respondents can help shape and improve interview questions and shows the advantages of keeping the process of its creation as fluid and flexible as possible.

For those who answered the previous human rights questions in the negative, this would be the last set of questions based on opinions and beliefs. For those who answered in the positive, these questions were followed by others that focused more specifically on the relationship between human rights and health.

The sequence of questions on human rights and health(care) presented the greatest challenges. Firstly, filtering was applied again here, so that respondents who had not heard of or thought about the stated link between the two did not answer any further questions in this set. For those who responded in the positive, there followed questions about their source for this information, whether they thought there was indeed such a link and what it might be.

Three points are worth mentioning here: firstly, I avoided saying that such a statement had been made by experts due to a genuine concern that this might persuade some interviewees to claim that not only had they heard of such an assertion but that they also concurred with 'the experts'. Thus my query began: "Some people have stated that...", and did not specify who these people were.

Secondly, interviewees were asked to consider the stated link between health and rights prior to being asked whether they had heard of a 'right to healthcare'. This was mainly because while it was important to learn whether at a basic level interviewees' thought there was a nexus between the two subjects, I wanted to avoid using the contentious phrase 'right to healthcare'. While the academic debate surrounding the attempt to delineate the scope of a right to health is ongoing, the questionnaire, by constructing simple and specific questions, must seek to minimize any confusion on the part of respondents, who may not have had the opportunity to consider such theoretical disputes.

Thirdly, there was a worrying hesitation among the first couple of WOFAK respondents when it came to addressing queries in this section of questionnaire, which may have partly been the cause and symptom of the afore-mentioned presumption about a common definition or interpretation of the word 'healthcare'. I became increasingly concerned that this may hinder subsequent interviewees from surviving the 'right to healthcare' filter and responding to the vital set of questions that followed. Having noticed his increasing difficulty with the question, I made an on-the-spot decision to ask interviewee 3 of my test group to define the term 'healthcare' first:

Interviewer: In your own words, what does a human right to healthcare mean to you?

Interviewee: (Hesitates.) According to the government your life is not yours! For example, if you were attempting to commit suicide.

Interviewer: Maybe it's easier to start like this- what does 'healthcare' mean to you?

Interviewee: (after some hesitation) There is individual healthcare and there's majority healthcare... (hesitates). At least each and every individual can get healthcare, medicine.

Interviewer: Do you think that people have a right to this?

Interviewee: Yes, they do.

The additional questions in this case did perhaps distort his responses, and the reference to access to medicine as a right, in particular, could be viewed as leading despite an arguable inference that medicines came within his definition of 'healthcare'. Indeed, as the questioning progressed the respondent's responses became more tentative. But I did not feel that this voided the interview as the objectives of the research were, again, much more broadly defined. Indeed, interviewees subsequent to those in the test group were asked to define the term 'healthcare' before being asked whether they had heard of such a right.

Some respondents did in fact appear, like the one above, not to have heard about such a right and simply joined the dots to come up with the perceived 'correct' response on the spot. Indeed, for interviewee 47, the decision to ask respondents to define the term 'healthcare' first before asking questions about such a right seemed

to have the desired, but also the feared, effect: it served to jog her mind about an answer but she also seemed to have decided about it on the spot⁴⁴:

Interviewer: In your opinion, what does the term 'healthcare' mean to you?

Interviewee: It means being able to afford your medical needs.

Interviewer: It has also been stated by some people that there is a human right to healthcare- have you ever heard about a human right to healthcare?

Interviewee: Yes there's a right to healthcare! Because if you think about the medical bill that you incur when you get sick, you automatically just get better! And like these medical cover companies, like AAR [a private healthcare company], they never cover us.

To an extent, I partly hoped for this due to frustration about the lack of progress in this important part of the questionnaire. Indeed, I felt that such an outcome may be justified in some cases, as some respondents appeared to describe, in all but name, healthcare and a right to it. The approach may not have always been helpful and procuring a definition of healthcare first did not, in fact, seem to help ring any bells for some respondents. Nevertheless, their answers were useful in illustrating the varied definitions that PLWHAs attached to the term healthcare, as seen in the Introduction, information that would not otherwise have been acquired.

Only those interviewees who responded that they had heard or thought about a link between health and human rights were then asked specific questions about the right to healthcare (definition, benefits, perceived beneficiaries and benefactors, etc). There were additional questions on respondents' perceptions about any role for government in providing healthcare. Initially this question had been intended only for those interviewees who volunteered responses to this effect, to them to expound further on this pivotal issue. However, I deemed it sufficiently useful to invite all respondents who had progressed to this stage of the interviews to consider it because it may provide critical insights into individuals' perceptions of their relationship with, and the functions of, the State. It was succeeded by an equally important query on perceptions about the affordability of such healthcare expenses.

While asking all interviewees to consider the role of government in healthcare provision might be open to charges of implanting suggestive ideas into the minds of

⁴⁴ However, it must be said that despite the strong impression she gave of having immediately formed her responses, they are consistent with those she had given throughout the interview, reinforcing the earlier argument in favour of a flexible approach to on-the-spot responses.

those who had not previously appeared to hold such views, these were the last questions based on interviewees' opinions or beliefs and their responses at this point could not affect the substantive aspects of their interviews. Additionally, this approach is in accordance with the guiding principle that the interviews should be used to collect as much information and as many diverse answers as possible from the narrow sample size. Restricting interviewees to commenting only on those ideas they already held and not inviting them to explore other perspectives when it was expedient and did not distort the rest of the interview, and might in fact enrich the analysis, would be to waste the interviewing opportunity.

In Retrospect...

The set of interview questions used for this research could have been improved by altering the sequencing of the key question 'How or from whom did you hear about these human rights?'. Transcription of the audio-tapes revealed that I occasionally failed to pose it to some respondents, although they often inadvertently addressed it elsewhere. This momentary lapse was most likely a reaction to the sudden disruption in the interviews when several interviewees' confidence appeared to diminish following the preceding question about examples of rights they had heard of. In hindsight, it would have been better to locate the crucial question earlier in the sequence, perhaps immediately after inquiring about respondents' familiarity with the term 'human rights'. This would have preserved the momentum that had often built by this stage and likely minimized the possibility of overlooking it. Moreover, this would have reflected the real information that the question was intended to glean: how interviewees had come by their knowledge of human rights in general rather than how they had heard about the examples of human rights they supplied.⁴⁵

The interview questions could also have been used to collect additional, vital data on the role of traditional medicines in Kenya's healthcare system, an issue whose full importance revealed itself only during the post-fieldwork research process. Although the issue was addressed anyway, further reading underlined the widespread

⁴⁵ Again, I was only able to identify this as a recurrent problem during the transcription process, as it happened relatively few times and intermittently. I do not believe it affected the success of the interviews on this particular question as the responses fell within a particular and established range, as Chapter 8 shows.

relevance in Africa of traditional medicine for those with little or no access to formal healthcare. It would therefore have been beneficial to seek respondents' views about it, including whether they had ever sought the services of alternative medical practitioners. Undoubtedly, similar challenges to those discussed earlier, such as setting out a definition and scope for the key terms of reference, would have applied to the inclusion of questions on traditional medicine. Further, inquiring into the subject may have proved even trickier as the 'choice' of traditional medicine, often the only available and accessible option, is sometimes perceived as emblematic of ignorance and backwardness, particularly amongst those in rural areas. In the event, I think the discussion undertaken in Chapter 6 was more than adequate but would have been greatly enhanced by interviewees' explicit responses on the matter.

c) The Interviewing Process

i. Audio-taping

Despite the lengthy transcription work required, the interviews were all audio-tape recorded to ensure that the information provided was captured as delivered and would be available for review if later required. Indeed, the concern that I would not always be able to simultaneously receive and process all the information provided by the respondents was well-founded and the recordings become useful for identifying inconsistencies in some interviewees' answers.⁴⁶ Moreover, as seen above, they also helped identify my own interviewing errors, some of which I was able to correct when I reviewed an interviewing session in advance of the next. A further crucial advantage in audio- or visual-recording is that they offer interviewers the chance to record elements of the interaction that may be otherwise missed, such as an interviewee's change in demeanour, from, say, tension to ease or vice versa.⁴⁷

Audio-tape recording was largely successful but for two issues: firstly, some respondents initially expressed discomfort with this aspect of the process. After some

⁴⁶ For example, interviewee 13 said he saw a link between health and human rights he said and then claimed not to have heard of a right to healthcare. However, on listening to his interview later, I noticed that he had indeed explicitly mentioned a "right to healthcare" as one of the examples of rights he knew in an earlier question. He may have misunderstood the later question but I was unable to pick this up during the actual interview.

⁴⁷ Thomson, Rachel, *Researching Sexuality in the Light of AIDS: Historical and Methodological Issues* (London: Tufnell Press, 1990), at 19.

assurances about confidentiality, and, indeed, the correction on more than one occasion that audio-recording did not (also) mean visual-recording in this case, all but one agreed to proceed. Secondly, faulty technology, revealed during transcription, meant the taping device sometimes skipped or did not clearly capture some sections of interviewees' responses. However, this happened only on four occasions and the effect on the value of these interviews, specifically and generally, was negligible.

ii. Ensuring the Interviewee's Welfare

It is imperative that respondents are comfortable during the interviewing process, and with PLWHA subjects there were additional aspects to this: firstly, the stigma surrounding HIV/AIDS means that many respondents' self-image may be quite negative and they might feel that they are already on the defensive even before the interview itself has begun. For some, this might be the first time they were speaking at any length about their illness and it is necessary to reassure them that any information divulged would be held confidentially by the researcher. Gray, *et al*, opine that confidentiality attached to the disclosure of HIV test results must apply to other personal information given during an interview focussing on the respondent's HIV status, such as how one may have contracted the virus (see discussion below). They assert that in providing sensitive information the respondent cedes control over it and therefore divulging it, even when no harm occurs, would be an infringement of the respondent's dignity.⁴⁸ Interviewees' concerns about privacy and confidentiality may be illustrated by the fact that of the 49 interviews conducted, only 9 gave their full names, with another 12 giving just one (the more anonymous Christian or ethnic) name.

Secondly, and even more importantly, as PLWHAs, the respondents were suffering from what is often a debilitating illness. While most interviewees appeared physically fit others were visibly unwell but still agreed to be interviewed. What prompted this decision on their part is unclear and they were never asked out of respect and a reluctance to presume their state of health. However, the onus is on the interviewer

⁴⁸ Gray, *et al* (n 22), at 11.

to be continually vigilant of the respondents' immediate well-being despite during the interview.⁴⁹

iii. Not Asked, but Told

From the beginning, I was clear that interviewees would not be asked about how they had contracted the HIV virus. There were a number of reasons for this: firstly, not all may know the answer to this question. Secondly, this information was not deemed crucial. Although certain responses might illuminate some interviewees' social, cultural and economic backgrounds, other less intrusive questions would have achieved the same purpose. Thirdly, and more importantly, even those who knew how they had contracted the virus may not want to share this information or they might feel compelled to lie: they might be suspicious that the interviewer may use this information to draw adverse conclusions about their morality, something that many interviewees later revealed they had often had to endure. The interviewer must try to anticipate which questions may thwart the smooth progress of an interview or even cause the interviewee to abandon it altogether.⁵⁰

In the event, some interviewees, mainly women, did volunteer this information in the course of the interview, perhaps in order to dispel any questions, suspicions or assumptions they thought I might have about their moral choices and to ensure that I was aware of their 'innocence' in the matter. This revealed a crucial aspect of their subjectivity which, it is argued in this research, may influence how some PLWHAs constructed their sense of entitlement to healthcare and other socio-economic goods. As such, seemingly neutral and non-judgemental questions as to fact elicited long and occasionally unnecessary but revelatory responses. Interviewee 30 is a good example:

Interviewer: When did you find out that you were HIV positive?

Interviewee: I used to be married. I lived with my husband but I could tell he was not trustworthy... Later, I noticed he was getting ill. Every time I suggested we should go to hospital, he would abuse me and say it was not necessary. He continued getting ill. His relatives started to claim that I was bewitching him. In hospital he was admitted, he was very ill. At that time, I had not noticed any symptoms myself. So I

⁴⁹ To persist with the process in the face a respondent's visibly deteriorating state would be unethical. Indeed, I decided to abandon one of my interviews when the respondent, a lady who had agreed to be interviewed, lapsed into a lengthy bout of coughing.

⁵⁰ Judd, *et al* (n 10), at 247.

followed up the doctor and asked him, 'how come my husband has been here 3 days and yet he has not improved?'. The doctor asked me what my husband had told me and I said he had not said anything to me. We came back home and I was given some medicine to be giving to him according to instructions. ...But I started not feeling well and I went to hospital. [W]hen the doctors at the hospital told me that my husband had HIV, I told them that I too wanted to be tested. I was and it was discovered that I, too, was HIV positive... This was in 2000.

Later, she revealed in an unrelated question how she contracted the virus but also tellingly indicated that she shared in the common view that associates HIV/AIDS with promiscuity, even though she too seemed to have been a victim such views:

Interviewer: What do you think about [the government's initiation of an ARV cost-sharing scheme]?

Interviewee: Even I agree that we should pay something small. Because if you provide humans with something for free, some people will start treating this illness as if it is a joke, a game. If you hear about the way some people contract this illness, they put themselves in risky situations. For example, I can swear that from the moment I got married, I have never been with anyone else other than my husband. When I think about it I am so bitter, so bitter. Even in my area my family, my brothers, they support me because they know I am not the kind of person who moves around with men. Some people may laugh at you and ask how else then you got the disease but these are the prostitutes who carry out their business in secret.

iv. Language and Accents

The way I used language proved instrumental to removing or creating barriers between me and the respondents. Ability to converse in Kiswahili, particularly for those who chose to be interviewed in this language- indeed, the presentation of this option to all respondents- meant they were aware that we had a local language in common. I could also understand their terms of reference as well as the colloquial words or slang they used. With English interviewees, I tried to keep to simple terms where possible and found from the first few interviews that I rarely read the out verbatim some of the questions in precisely the way they had been framed in the questionnaire.

I also found that I naturally reverted to my Kenyan accent, many characteristics of which had naturally become muted during my lengthy stay in the UK, and significantly blunted the foreign influences in my speech. Although the acquired twang may in fact occur naturally, there is often a perception of pretentiousness in Kenyan society

about Kenyan-born nationals who have travelled and/or lived abroad and who then adopt a foreign (normally British or American) accent, especially when they speak English. But even more reasonable is a presumption that anyone who has been, resides or studies abroad must have access to the kind of financial resources that are available only to a minority of Kenyans. I was very aware that this latter issue might alienate some of my interviewees, many of whom, as earlier noted, appeared to come from very poor backgrounds. It was important that such assumptions were not allowed to affect responses or, indeed, respondents' willingness to participate, and every effort was consciously or subconsciously made to counter the notion that I was outsider. One cannot underestimate the role that one's demeanour, language and overall presentation affects the personal dynamic that forms between interviewer and interviewee.

v. Relating the Personal

Although I sometimes gave examples of my personal experience of AIDS in the family, I had planned not to disclose such information in order not to detract from the respondents and their stories. Yet I found that I set aside this rule during my very first interviewing opportunity with the WOFAK respondents, whom I initially met as group to introduce myself and explain the purpose of my research before I conducted the one-to-one interviews. I may have felt compelled to do so to help shed the impression of an 'outsider' and instil a sense of solidarity with people from whom I hoped to coax some deeply personal information. I used a similar approach during a group discussion at MDH. I would also occasionally mention it, haphazardly, during some individual interviews where I thought it might be useful. For example, I wanted interviewee 29, who had said only the government could help meet the healthcare needs of PLWHAs, to consider if other actors that might play a role:

Interviewer: Do you think other people can? For example, we had a relative who was HIV+ and we used to raise money to take her to hospital so we helped her in that small way to get treatment, so it may not just be the government. What do you think about this?

Interviewee: The way I see, with your family, it is not always like that with families. There are others who will leave a person to die without offering any help. So it should be part of the law, not just voluntary otherwise some people will not want to get involved.

d) Post-interview Reflections: The (un)Objective Researcher

My involvement in AIDS advocacy was one reason behind my choice of research subject. Having co-founded and run a youth AIDS awareness network over a decade ago, I sometimes adopted public positions regarding the affordability of ARVs and was critical about the slow or counterproductive responses of governments like Kenya's and other actors. Researchers with prior self-declared public agenda have sometimes been accused of lacking objectivity when they attempt to conduct research into these areas of interest: witness, for instance, the criticisms levelled against the reputed feminist Oakley's research on housework.⁵¹ She has argued that "in most cases, the goal of finding out about people through interviewing is best achieved when the relationship of the interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship."⁵² She criticizes the fundamentals of the interviewing process itself, questioning the masculine perspective from which are drawn textbook notions of what constitutes "proper" interviewing methods.⁵³ These ideas enforce the notion of interviewing as a perfunctory, question-and-answer process of data-collection.⁵⁴ I confess to approaching my task with many such ideas in mind but also that the actual interviewing process disabused me of the notion that adhering to these textbook 'rules' was practicable or effective.

My research was also significantly influenced by the human rights focus of my university studies. Indeed, I was often conscious of the need sometimes to negate the knowledge I had acquired as a student- for instance when setting the questionnaire- to avoid making certain presumptions about respondents' knowledge. This was not entirely successful: for example, my expectations that interviewees would automatically attach to government the obligations for meeting their healthcare needs turned out to be exaggerated; interviewees' conceptions of the dynamics of obligations and privileges were more nuanced than the simplistic human rights theories of my education would have it.

⁵¹ Harvey (n 8), at 224, noting Oakley (n 9)

⁵² Oakley (n 9), at 229

⁵³ *ibid.*, at 226

⁵⁴ *ibid.*, at 225

A further related issue flagged up by the interviews was how laypeople perceived their needs within the broader context of entitlements and/or human rights claims. The anticipation, as a human rights student, that respondents might see or begin to see the possible human rights implications of their highly articulate responses about their medical needs influenced my attempts to simplify and clarify the questionnaire. a researcher's academic or professional background inevitably influences the process of gathering information but this may somewhat vitiate the objectivity intended by such an exercise. Indeed, it is difficult, if not impossible, for a researcher to claim total objectivity in her work: neutrality, Oakley and others argue, is futile; "participation demands alignment."⁵⁵

Consciously or subconsciously, then, the interview questions when wielded by one with an interest in the subject matter may become not just a means to gather information but as tool to pass on knowledge to interviewees. Thus it is unsurprising that some respondents, such as interviewee 16, requested I provide more information about human rights at the end of the formal interview. "I am so grateful to have met you," she said, "and now you're going to tell me about my rights! And please give me material about it as planning to be a preacher-cum-MP!"⁵⁶ Again, Oakley is critical of the notion that "properly-socialized respondents do not engage in asking questions back," and that the 'proper' response of the interviewer would be to parry- in many ways evade- interviewees' queries to avoid bias.⁵⁷ Indeed, this remained a concern, and I would wait till the end of the interviews to answer any such questions in order not to influence or render redundant the remaining ones. However simply I may have responded to these requests, in agreeing to do so I was actively staking a claim, alongside other actors such as the State, human rights activists and so on, and engaging in a deeply political act: attempting to shape the respondents' opinions- and their subjectivity- about a live, contentious issue and inculcate in them my own notions of it. The old AIDS advocate in me was keen that they should be made aware of what they were entitled to as PLWHAs, the

⁵⁵ See *ibid.*, at 237

⁵⁶ I had similar requests from a handful of other respondents. For instance, when asked to define 'human rights', interviewee 43 responded: "I may have heard of the words but I have forgotten. You'll have to tell me." Interviewee 35 said she had heard about human rights from the radio but, unable to offer a definition, asked me to tell her more about it.

⁵⁷ Oakley (n 9), at 224 and 225

discrepancy between their healthcare entitlements in theory and in practice notwithstanding, and that having expressed an interest in the subject they should not leave the interview uninformed about it.

Chapter 3: Land, Kinship and Patriarchy: Producing Subjectivity and Power in Pre-colonial Kenya

The experience of living with HIV/AIDS was a vital element in the construction of PLWHAs' subjectivities, as Chapter 2 highlighted. But it is only one of many. Moreover, attitudes towards AIDS and PLWHAs are themselves formed within the very particular social, cultural, economic and political environment in which they exist.

This chapter begins to map that complex and dynamic environment by looking at Kenya's pre-colonial period, and provides a vital prelude to the discussion in Chapter 4 on colonialism, the salient event in Kenya's recent history.¹ It illustrates how the values and attitudes of this period may shape not only contemporary subjectivities and notions of entitlement but also the patterns of risk to a very 21st Century epidemic: HIV/AIDS. Further, the examination of pre-colonial social and political organization explains how traditional conceptions and bonds of privileges and obligations influence modern perceptions about the relationship between the individual, her community and customary and State institutions.

These discussions are framed within three themes that this chapter identifies as central to social organization and the stratification of power in pre-colonial Kenya: land ownership, kinship and patriarchy. It is argued here that the rules, duties and rights which pertained to these systems not may only have a fundamental bearing on how the subjectivities of modern PLWHAs and Kenyans have developed but influence how the interviewees situate themselves in the wider social, economic and political grid, thus shaping their notions of entitlement. And crucially for the rights discourse, this chapter underlines the fact that these enduring customary systems and structures operate within conceptual and normative frameworks that are often at odds with fundamental human rights values. As such, one begins to see in this chapter the foundations of the paradoxes about rights and entitlements explored in latter empirical chapters, and the groundwork for, among other things, the

¹ The British declared Kenya a colony in 1895 which it remained until independence in 1963.

postcolonial analysis of the relationship between the individual and the State developed in the following chapter.

Such analyses must, however, be prefaced by an acknowledgement that Kenyan cultures are not homogenous; nevertheless, there are broad similarities in the way in which traditional power was organized to facilitate and sustain particular models of resource ownership and transfer, kinship and patriarchy. Each of these aspects has a dual role in the discussions to come: firstly, because each was a key component in the organization of power, each represents a key site for the contestation of that power to this day. Each has therefore been crucial in shaping the kind of individual and State that has emerged, and, as a result, the way the human rights debate has evolved in Kenya. Secondly, the three elements shed light on the distribution and control of resources in Kenya, which is germane to the realization of socio-economic rights. They reveal how patterns of wealth and poverty and disparity, key determinants of health, are produced.

Firstly, though, it is necessary to comment briefly on the challenges for a researcher in obtaining a clear and accurate account of Africa's pre-colonial history. In particular, how this issue, too, is central to the question of how identities and subjectivities are constructed, particularly in a postcolonial context where indigenous African historians challenged the long-standing exclusion of indigenous populations from describing their own histories and experiences unmediated by external observers and experts.

1. Recording Pre-colonial History and Constructing Identities

Many African societies have oral traditions which predate colonialism by four or five centuries, as well as archaeological and linguistic sources that provide a picture of Africa's more ancient past.² Despite its importance in revealing and transmitting information over generations, oral traditions have various limitations as a record of history which vitiates their reliability even more than the written. Charles Ambler decries, for instance, the restricted perspective of the past that popular histories, especially those of dominant groups, offer. He highlights a tendency to edit out the

² Spear, Thomas, *Kenya's Past: An Introduction to Historical Method in Africa* (London: Longman Group Ltd, 1981) at xix

conflicts and discrepancies that characterize the inevitable intercourse between groups, and to “reduce complicated processes of movement and social formation to a few clean lines on a map.”³ Such versions lack the very texture that illuminates the complex process of transformation that this chapter deals with. Yet oral traditions are integral to manufacturing the shared myths around which communities often cohere and from which they draw distinct identities. One of many black African historians to emerge in the more permissive postcolonial era, breaking the monotony of the study of Africa and Africans by a uniformly white contingent of anthropologists, historians and other Africanist scholars⁴, was Gideon S. Were, whose studies focussed on Western Kenya. Questioned on the legitimacy of oral traditions as sources of history he is quoted as stating:

Tradition was not simply something sentimental or theoretical, or merely dead dogma but, rather, a relevant and practical aspect of the life of the community which was handed down from generation to generation and which was, therefore, a living embodiment of the past and present... It is this factor which gives the traditions authority and relevance as a historical source, in contradiction to ordinary fables or plain mythology.⁵

These protean traditional myths are important in helping a community accommodate new events in its historical narrative while side-stepping any inconvenient inconsistencies. Spear writes that “[t]he remembered past is seen as a reflection in the present of an idealized heritage in such a way as to support the maintenance of current institutions and values as a timeless historical heritage.”⁶ While this supports some anthropologists’ contention that oral traditional myths were more reliable as accounts of a community’s present rather than its past, in this context this is still an essential purpose: they mirrored a community’s (idealized) image of itself, as well as the image it wanted to project to outsiders.⁷ This flexibility of ‘memory’, as it were,

³ Ambler, Charles, *Kenya’s Communities in the Age of Imperialism: The Central Region in the late Nineteenth Century* (New Haven; London: Yale University Press, 1988) at 9

⁴ As Mahmood Mamdani writes, “What is called African Studies was in reality a study of natives by settler intellectuals.” (Mamdani, Mahmood, *When Does a Settler Become a Native: Reflections of the Colonial Roots of Citizenship in Equatorial and South Africa*, University of Cape Town Inaugural Lecture, 13 May 1998, at http://hrp.bard.edu/resource_pdfs/mamdani.settler.pdf (accessed June 23 2009)

⁵ Ochieng’, William R., (ed.), *Historical Studies and Social Change in Western Kenya: Essays in Memory of Professor Gideon S. Were* (Nairobi: East African Educational Publishers, 2002) at xii

⁶ Spear (n 2), at 47

⁷ Spear mentions Malinowski as a proponent of the view that oral traditions say more about the contemporary political interests of a group, as such accounts are skewed to accommodate change. He also references Claude Levi-Strauss, who stressed on the symbolic role of traditional myths as indicators of “universal patterns of human thought that transcend specific cultures and historical traditions.” (ibid)

did not begin with the attempt to make sense of the colonial experience.⁸ As will be seen in the next chapter, it is a quality that postcolonial States have exploited to self-mythologize and self-legitimize and to engender a national consciousness. All these points should be kept in mind as various sources are applied.

II. Themes in Pre-colonial Patterns of Power

a) Land: Access and Control

The issue of land ownership in former African colonies is complex and nuanced. In Kenya, as with most agricultural-based economies, land is the main commodity in production. An earlier draft of Kenya's new constitution recognized it as the country's "primary resource and the basis of livelihood for the people."⁹ The diverse agricultural sector still contributes a considerable 25% of Kenya's gross domestic product.¹⁰ It provides, directly or indirectly, 80% of employment, more so for the nearly 60% of the rural population.¹¹ There is a well-documented link between land ownership and individual and household income, as the discussion in Chapter 5 will underline, and hence between access and control of this key resource and the ability to afford nutrition, healthcare and the other necessities mentioned by PLWHAs. This

⁸ Makau Mutua states, "[t]he oral tradition common to most of Africa had its own imprecision even before its interruption by the forces of colonialism." (Mutua, Makau, *Human Rights: A Political and Cultural Critique* (Philadelphia: University of Pennsylvania Press, 2002) at 74-5)

⁹ Chapter VII, "Land and Property", Art. 77(1) of the Harmonized Draft Constitution, published November 17 2009, read: "Land is Kenya's primary resource and the basis of livelihood for the people, and shall be held, used and managed in a manner which is equitable, efficient, productive and sustainable." (Committee of Experts on Constitutional Review (CECR), *Harmonized Draft Constitution of Kenya*, 17th November, 2009, a copy of which is published on the website of The Local Democracy, Peace and Human Security, University of the Western Cape, at <http://www.ldphs.org.za/resources/local-government-database/by-instrument/constitution>, accessed 12/03/10). This provision did not survive into the final draft in this form though the Art. 60(1) of the new constitution does reiterate the same guiding principles. (Chapter Five, 'Land and Environment', at 41-2. Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010*, 2010, Kenya Law Reports (www.kenyalaw.org), accessed 10/12/13. (Published by the National Council for Law Reporting, with the Authority of the Attorney General)

¹⁰ Figure from the World Bank, 'Kenya Country Brief', 2010, at <http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/KENYAEXTN/0,,menuPK:356520~pagePK:141132~piPK:141107~theSitePK:356509,00.html>, accessed 10/02/10

¹¹ Statistics for the agricultural sector's contribution to national GDP and employment, from a paper by Karanja, Mercy, 'Water Management in Kenya', International Federation of Agricultural Producers (IFAP), at www.ifap.org/issues/waterspeech_mk.pdf, accessed 02/03/05. Statistics for rural population from Food and Agriculture Organization (FAO), 'FAOStat', 2005, at <http://faostat.fao.org/faostat/form?collection=Population.LTS&Domain=Population&servlet=1&hasbulk=0&version=ext&language=EN>, accessed 02/03/05

reaffirms the correlation between Kenya's endemic socio-economic inequalities and the patterns of ownership of, or access to, land.

Further, land, or unequal access to it, has been a long-standing source of conflict in Kenya, most recently following the 2007 elections (which left 1,133 people dead and approximately 350,000 internally displaced), an issue fuelled in part by the common practice of land grabbing by the ruling elite.¹² Over the years, land became a key asset in the patronage system that still underpins many political relations in Kenya¹³, accentuating its incendiary potential, as discussions around it during the constitutional reform process of the last decade illustrate.¹⁴ It evokes powerful emotions and gaining ownership of it has become something of an obsession with most Kenyans.¹⁵

At a more subtle level, land continues to define ethnic groups as much as, say, their customs and practices, and quite literally puts them on the map, as records of pre-colonial Kenya demonstrate. It irresistibly anchors the notion of community, and citizenship was traditionally founded on access to land, binding members in the real sense of a shared physical space and in the metaphysical of common goals and interests.¹⁶ Stephen Ndegwa quotes with approval Kivutha Kibwana's observation that "individuals had a community share in or the rights to benefit from land.... Members' entitlement to land was based on the fact that the individual belonged to a

¹² See Commission of Inquiry into Post-Election Violence (CIPEV), *Republic of Kenya Report of the Commission of Inquiry into Post-Election Violence*, 2008, at http://www.kenyalaw.org/Downloads/Reports/Commission_of_Inquiry_into_Post_Election_Violence.pdf, accessed 10/03/10, from which these figures are drawn (at 305 and 362). See also Southall, Roger, 'The Ndungu Report: Land & Graft in Kenya,' *Review of African Political Economy*, 103, March 2005, pp.142-51; Anderson, David and Lochery, Emma, 'Violence and Exodus in Kenya's Rift Valley, 2008: Predictable and Preventable?' *Journal of East African Studies*, Vol. 2, No. 2 (2008), pp. 328-343; Committee of Experts on Constitutional Review (CECR), *Final Report of the Committee of Experts on Constitutional Review*, 11th October 2010 (Nairobi), at 25.

¹³ See Okoth-Ogendo, H.W.O., *Tenants of the Crown: Evolution of Agrarian Law and Institutions in Kenya* (Nairobi: Acts Press, 1991), at 147.

¹⁴ CECR, *Final Report of the Committee of Experts on Constitutional Review* (n 12), at 9.

¹⁵ See Karanja, Perpetua W., 'Women's Land Ownership Rights in Kenya,' *Third World Legal Studies* 109 (1991), pp. 109-136, at 111

¹⁶ Angelique Haugerud notes: "Access to rural land is one means by which rural residents, as well as seasonal and longer-term migrants, maintain local and descent group affiliations." (Haugerud, Angelique, 'Land Tenure and Agrarian Change in Kenya,' *Africa: Journal of the International African Institute*, Vol. 59, No. 1 (1989), pp. 61-90, at 62)

particular group.”¹⁷ In most cases the entire group was involved in the collective defence of its territorial integrity.¹⁸

Akinyi Nzioki asserts that this link between land and identity is founded on the former’s durability and permanence.¹⁹ Its importance is underlined by the efforts of various ethnic groups to cement in their historical narrative their spiritual association with it.²⁰ This is the case despite the fact that the groups themselves are less the monolithic units they purport to be and more artificial constructs of colonial politics.²¹ However, there are more doubts beyond the obvious ones about such an account of divine rights, as linguistic archaeological evidence rebuts many claims to such continuous ownership.²²

Whether a group used land for cultivation, grazing or hunting and gathering, controlling territory was crucial to its success and survival.²³ Elsewhere, Jomo Kenyatta, later Kenya’s first president, emphasizes the social, political, economic and spiritual importance of land to the Gikuyu.²⁴ As groups expanded and migrated from their traditional territories they often interacted for trade and other purposes. And

¹⁷ Ndegwa, Stephen N., ‘Citizenship and Ethnicity: An Examination of Two Transition Moments in Kenyan Politics,’ *American Political Science Review*, Vol. 91, No.3 (1997), pp 599-617, at 608

¹⁸ Kenyatta, Jomo, *Facing Mount Kenya: The Tribal Life of the Gikuyu* (London: Mercury Books, 1961) at 21

¹⁹ Nzioki, Akinyi, ‘The Effects of Land Tenure on Women’s Access and Control of Land in Kenya,’ in Abdullahi A. An-Na’im (ed.), *Cultural Transformation and Human Rights in Africa*, (London: Zed Books Ltd, 2002) at 223

²⁰ See Shipton, Parker, and Goheen, Mitzi, ‘Understanding African Land-Holding: Power, Wealth, and Meaning,’ *Africa: Journal of the International African Institute*, Vol. 62, No. 3 (1992), pp. 307-325, at 309. See also Mkangi, George C., *The Social Cost of Small Families and Land Reform: A Case Study of the Wataita of Kenya* (Oxford: Pergamon, 1983) at 28

²¹ Ndegwa (n 17), at 600-1

²² For example, Spear writes that the land currently occupied by the Gikuyu had been occupied by other peoples before their arrival (Spear (n 2), at 59- 60). Indeed, it would appear that some versions of the Gikuyu legend of creation do, in fact, accommodate the notion that not all the land occupied by the Gikuyu came directly from God. But even these accounts find ways of conveniently ‘doing away’ with those from whom the Gikuyu acquired these additional lands, presumably to pre-empt any future claims (Kenyatta (n 18), at 21). Spear’s version of the Gikuyu’s interaction with the Gumba suggests it was less amicable than Kenyatta’s (Spear (n 2), at 54) Their fate, like that of others, may have been assimilation or marginalization, explained away by supernatural “disappearance” in the creation legend of Kenyatta’s childhood.

²³ Spear writes, for example, of the Iloogolala, a pastoralist tribe hounded out of their traditional lands and forced into assimilation by their conquerors, thereby “disappearing”. (Spear (n 2), at 64). Terrence J. McCabe also writes that the expansion of the Turkana in northern Kenya also involved a similar process of assimilating those they encountered and even their “extermination”. (McCabe, Terrence J., *Cattle Bring Us to Our Enemies: Turkana Ecology, Politics and Raiding in a Disequilibrium System* (Ann Arbor : University of Michigan Press, 2004), at 98)

²⁴ Kenyatta (n 18), at 21

although disputes over land might lead to conflict²⁵, land could also be a valuable commodity in trade, lubricating such interaction.²⁶

It is difficult to apply a Western framework of property ownership to the mainly unwritten, multilayered, customary laws of land tenure in pre-colonial Kenya.²⁷ Indeed, the differences between the British and Kenyan conceptualization of land ownership and use were exploited to justify the alienation of Africans from their land at the start of the colonial project, with colonial officials asserting that “since Africans owned land only in terms of occupational rights, it followed that unoccupied land reverted to the territorial sovereign.”²⁸ The narrow Western definition of ownership is unsuited to the range of rights to land in operation, namely: “tenure (land holding rights), ‘usufruct’ (rights to use land), ‘freehold’ (holding exclusive rights but transferable), and ‘ownership’ (cash valued land with title for individual or group.”²⁹ Customary land rights carried different and intersecting- though sometimes competing- obligations and entitlements but the notion of communal of land ownership has been fiercely rejected.³⁰ Karanja asserts that only insofar as customary land tenure guaranteed access to land for all and did not vest title to individuals (as was the case in the West) could such a land tenure system like the Gikuyu’s be said to be communal; only lands with particular cultural functions like shrines, salt licks and grazing lands were in fact held communally.³¹ A strong social adhesive was thus

²⁵ The Maasai, for example, were pastoralist and engaged in battle with other pastoralists like the Turkana and Pokot during the early 19th century, as the pressure for fertile land increased. (Spear (n 2), at 64)

²⁶ For instance, the Okiek, a hunter-gatherer group, were able to sell land to the Agikuyu, who, having adopted cultivation, were in need of ever more farming territory. (ibid, at 61). As seen in n 22, above, however, such a method of land accretion is then conveniently airbrushed out of the Gikuyu story of origin.

²⁷ See, for instance, Okoth-Ogendo (n 13), at 17. See also Nzioki (n 19), at 225; Shipton and Goheen (n 20), at 307-8; Republic of Kenya, Ministry of Lands, *Sessional Paper No. 3 of 2009 on National Land Policy* (Nairobi: Government Printer, August 2009), at 6 and 7

²⁸ Okoth-Ogendo (n 13), at 11

²⁹ Nzioki (n 19), at 225. See also Karanja, P. W. (n 15), at 124-5

³⁰ Kenyatta writes of the Gikuyu land tenure system: “[communal ownership of land] presupposes that the land belonged to every Dick and Harry in the community. This could not be the case for... the land did not belong to the community as such, *but* to some individual founders of the various families who had the full rights of ownership and the control of the land.” (Kenyatta (n 18), at 30). Mkangi writes of similar ideas contained within the land tenure system of the Wataita, in which the community was the *de jure* owner of the land, with *de facto* ownership devolving downwards. It was in the context of social relationships that a man came to ‘own’, through his status or social position (by virtue of first occupancy, purchase, conquest or inheritance). (Mkangi (n 20), at 29 and 31.) See also Nzioki (n 19), at 226 and Shipton and Goheen (n 20), at 311-12

³¹ See Karanja, P. W. (n 15), at 112 and 113

required to allow group members with only limited claims, and, by inference, power, to feel that they had sufficient vested interests in it to defend it. To be sure, their lesser but by no means unimportant claims to the land- to cultivate it, reside on it- must somehow be guaranteed if this sense of common interest was to be invoked. Consequently, the key to understanding the enduring notion of a shared interest in the land and its value and the other assets it now underpins, despite the uneven rights it encompasses, lay in understanding the nature of kinship ties, which radiated outwards from the family to the tribe, and their privileges and obligations. It is this sense of shared interest within the ethnic group that ruling elites have sought to exploit at key moments in Kenya's postcolonial history.

Kinship is one of the common aspects of the systems of tenure in Kenya, with members of the same ancestry usually involved in holding land in common³², and the relative abundance of the resource before colonialism undoubtedly further facilitated inter-family or inter-clan harmony.³³ However, the kinship emphasis on collective over individual welfare did not always prevent the inevitable competition associated with the exploitation of any finite resource.³⁴ Such tensions were soon exposed and compounded by the imposed shortage caused by the wholesale alienation of land by white settlers during the colonial era.³⁵ The issue of access to land would become a key grievance in the struggle for independence. Today's ruling elite, most of which consolidated their positions and acquired their enormous land-based wealth in the post-independence period, now face increasing scrutiny and criticism.³⁶

³² Spear (n 2), at xxii. See also Maxon, Robert, 'Agriculture,' in Ochieng', William R. , (ed.), *Themes in Kenyan History* (Nairobi: Heinemann Kenya, 1990) at 29

³³ *ibid.*, at 24

³⁴ One such struggle occurred amongst some Maasai sub-groups in the early 19th century, as each attempted to expand territorially. The victors increased their stock of herds and land while the losers had to serve them while they waited to accumulate enough property in order to reassert themselves. (Spear (n 2), at 64)

³⁵ Nzioki (n 19), at 218

³⁶ Mr Uhuru Kenyatta, Jomo Kenyatta's son and currently the Kenyan president, gave the coastal peoples vast tracts of land several years ago, which his family had acquired after independence, amidst questions about how such wealth had been attained. A journalist with *The Daily Nation* wrote, "Neither the Kenyatta family nor Parliament can be called *socialist*. The Kenyattas cannot qualify not so much because they are so rich but more because the way they acquired their wealth raises eyebrows. Moreover, the Kanu chairman has never uttered a single word advocating a national redistribution of wealth. And Uhuru Kenyatta belongs to that same Parliament which always seeks to perfect a legislative machine for popular robbery." (*The Daily Nation*, 'Fifth Columnist: On Kimunya, Socialism and Land Grabbing', 15th May 2005). The coastal region has "the largest single concentration of landless indigenous people living as squatters." (Republic of Kenya, *Sessional Paper No. 3 of 2009 on National Land Policy* (n 27), at 43)

Patriarchy, explored later in this chapter, is the other common element in traditional Kenyan systems of tenure. Generally, women only enjoyed access to land through their association with their husbands or male relatives. This asymmetry in privileges, it has been pointed out, should not belie women's special status as the conduits by which property passed down the lineage to sons, ensuring that they benefitted in their capacity as wives.³⁷ Patrilineal succession was rationalized as preserving wealth within the kin group. Women were expected to marry and leave the family unit of their birth to join another. But the male right to succession carried a duty to provide for other family members.³⁸ Customary land tenure systems emphasized inclusion rather than exclusion of kin but Karanja rightly critiques this generalization for obscuring the manner by which each sex gained access and the gender roles which entrenched notions about what privileges could be enjoyed. Men were recognized as 'owners' through the manual work they undertook in clearing the bush for use, while women's roles entailed cultivating it *after* it had been acquired.³⁹ And despite having total control over the limited parcels they were allowed access to as unmarried, single or divorced women, and the right to determine what to do with any food surpluses produced, their land rights remained unequal to men's rights.⁴⁰ These restrictions on women's control of land is reflected in the language used to conduct the dialogue on land rights:

[T]he terms "use" and "control" of land, when applied to women's dealings with land, define their usufructuary interests and relate exclusively to subsistence production and the supply of labour. Market production, the power to make decisions on how much land is to be allocated to what use and the power to alienate, the main hallmarks of ownership, all remain outside the realms of women's control. Without further qualification, the terms "use" and "control" of land then become questionable epithets in defining women's rights to land because they exclude the need for acquisition of title and the benefits that flow from ownership exclusively.⁴¹

³⁷ Karanja, P. W. (n 15), at 116-7

³⁸ Kameri-Mbote distinguishes the responsibilities that come with 'succession' and 'inheritance': the former "denotes the passage not only of the property of the deceased but also the obligations to which he was subject and the status held in society. The heir on the other hand gets a share of the property but is not under a similar obligation." (Patricia Kameri-Mbote, 'Gender Dimension of Law, Colonialism and Inheritance in East Africa: Kenyan Women's Experiences', *International Environmental Law Research Centre (IELRC) Working Paper 2001-1*, at <http://www.ielrc.org/content/w0101.pdf>, accessed 12/10/05.

³⁹ Karanja, P. W. (n 15), at 115

⁴⁰ *ibid*

⁴¹ *ibid*, at 124-5

The correlation between land ownership or control and the distribution of power along kinship, gender or other lines, is historical. Kenyatta underlines the overwhelming social and economic dependence of the poor on the (Gikuyu) landowners from whom they might acquire limited rights.⁴² This power imbalance was expertly exploited by the traditional chiefs whom the colonial administration co-opted into its service, and who remained a tool of State suppression at local level long into independence.⁴³ As will be seen in Chapter 4, many of those with traditionally limited access to resources, particularly young men, saw in the social reshuffling of the colonial period an opportunity to establish power bases for themselves outside the old, restrictive structures, thereby undermining them.⁴⁴

Indeed, the latter colonial era saw the beginning of major transformations in the systems of land tenure in Kenya involving land ownership by the State and the individualization of land title.⁴⁵ As Chapter 5 explores in detail, individual land titling is particularly pertinent to an analysis of the pattern of HIV infection in Kenya and the capacity to realize socio-economic rights. Some groups, such as the historically pastoralist Maasai, were less equipped than the farming Gikuyu and Luo to take advantage of the new system.⁴⁶ Nor did the demands of State bureaucracy that land litigation entailed favour the uneducated and jobless.⁴⁷ As will be seen, today's multiple, incoherent, often incompatible systems of land tenure⁴⁸ restrict the rights of millions, particularly women, to own or access land; meanwhile, "the best arable land

⁴² There is even specific vocabulary to denote the landowner or the titleholder (*moramati*), whose superior status was often upheld in land rights disputes brought before elders' councils, and the individual with cultivation and building rights (*mothami*) or one who merely had cultivation rights (*mohoi*), which further embeds and legitimizes this cleavage. The latter owed certain strict obligations to the landowner, including helping him do certain chores on the property, and they could be evicted from the property and their rights to the land withdrawn if they failed in these obligations. The landowner was thus in a position to deprive his tenants of their economic livelihoods. (Kenyatta (n 18), at 34-5)

⁴³ Ndegwa, Stephen, 'Citizenship Amid Economic and Political Change in Kenya', *Africa Today*, Vol. 45, No. 3/4 (1998), pp 351-368, at 354

⁴⁴ Bayart, Jean-François, *The State in Africa: The Politics of the Belly* (London; New York: Longman, 1993) at 112-3

⁴⁵ Ikdhah I., Hellum A., Kaarhus R., Benjaminsen T.A. and Kameri-Mbote P., 'Human Rights, Formalisation and Women's Land Rights in Southern and Eastern Africa', *Studies in Women's Law No. 57* (July 2005), at 85. The Swynnerton Plan (published in 1954) was ostensibly aimed at creating employment, boosting productivity and income through the introduction of title deeds which farmers could use to access credit and buy farming equipment. (Nzioki (n 19), at 236.) See also Haugerud (n 16), at 63

⁴⁶ Ndegwa, 'Citizenship and Ethnicity: An Examination of Two Transition Moments in Kenyan Politics' (n 17), at 608

⁴⁷ Haugerud (n 16), at 82

⁴⁸ Republic of Kenya, *Sessional Paper No. 3 of 2009 on National Land Policy* (n 27), at ix and 1

is concentrated in the hands of rich civil servants, business men, foreigners and multi-national corporations.”⁴⁹ Problems related to uneven ownership of and access to land are among the issues that the new Constitution hopes to address.⁵⁰

b) Kinship

The second of the dominant themes of pre-colonial life in Kenya which still greatly impact many individuals’ notions of selfhood is that of kinship. In Kenya, social organization was founded upon age-grade (which, with rituals such as circumcision, marked the entry into adulthood⁵¹), cemented by geographical location and kinship networks.⁵² Kinship bound family or clan groups together by blood or marriage. However, the concept of kinship adopted here reflects not only its essential if restrictive meaning of a set of relationships founded on sexual reproduction but includes, too, a vital socio-cultural element by which power and obligations and privileges were distributed. The term is used to denote “a working system linking human beings together in an orderly arrangement of interactions, by which particular customs are seen as functioning parts of the social machinery.”⁵³ The interrelation between the two aspects of kinship, the extent to which one is necessarily predicated on the other and other theories of kinship have been dealt with eloquently and in greater detail by other writers.⁵⁴ Indeed, others have questioned the existence of kinship, arguing that it is a flexible concept whose meaning depends on the observer’s chosen definition.⁵⁵ Their work can only be acknowledged here as an analysis of their theories is not the primary purpose of this research.

⁴⁹ Karanja, P. W. (n 15), at 134. Karanja notes the ownership by the pineapple export company, Del-Monte, of millions of acres of land in Thika, near Nairobi, which has resulted in a “very large squatter population” around the pineapple plantation, arising out of the displacement of great numbers in Kiambu and Murang’a Districts. (at 134-5)

⁵⁰ Art. 60(1)(f) vows as one of its principles of land use and management to enforce the “elimination of gender discrimination in law, customs and practices related to land and property in land.” (Chapter V, ‘Land and Environment’, Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010* (n 9)

⁵¹ See, for instance, Kenyatta (n 18), at 115

⁵² Spear (n 2), at 75

⁵³ Radcliffe-Brown, A.R., ‘Introduction,’ in Radcliffe-Brown, A.R., and Forde, Daryll, (eds.), *African Systems of Kinship and Marriage* (London: OUP, 1960) at 3

⁵⁴ See, for instance, Morgan, Lewis H., *Systems of Consanguinity and Affinity of the Human Family: Smithsonian Contributions to Knowledge, No 17.* (Washington, D.C.: Smithsonian Institution, 1870). See, too, Schneider, David M., *A Critique of the Study of Kinship* (Ann Arbor: The University of Michigan Press: 1984) and Needham, Rodney (ed.), *Rethinking Kinship and Marriage* (London: Tavistock Publications, 1971)

⁵⁵ See generally Schneider (n 54)

For the narrower task at hand, while blood or marriage were the common ties within a kinship group, the concept was adaptable to changes in affiliations so that it might include individuals born outside the group.⁵⁶ And herein lay a salient point about kinship and other social bonds: in defining the behaviour patterns of their members these networks also provided a framework for the obligations and privileges which governed their relationships. This is especially pertinent to a discussion on individual perceptions about entitlement to resources belonging to one's family or kinship group in order to meet healthcare needs. Later chapters reveal that many PLWHAs appeared to claim entitlements to help from their families or relatives based on obligations they felt still governed their respective relationships, although others were doubtful if or to what extent they could rely on these ties. Historically, too, there were voluntary self-help groups consisting of members of the same age-group, sex or inter-village clans, formed to assist each with such tasks as cultivation or building; these were the roots of the *Harambee* concept, that is, the "collective and cooperative participation of a community in an attempt to fill perceived needs through utilization of its own resources."⁵⁷ In the modern context, a more diffuse network might be involved. For instance, interviewee 18 spoke of "...elders who support those in need and ... nuns [who also] raise money for those who are ill in their homes and they take them to hospital. So in the villages, people have formed their own groups to look after the poor."

Makau Mutua views the existence of kinship and other social obligations as irrefutable proof of an African "fingerprint" embedded in modern human rights ideals, disproving claims that such ideas are counter-intuitive to African traditions. In a discussion developed in the last chapter, he writes:

As Josiah Cobbah correctly explains, the naming of individuals within the kinship structure 'defines and institutionalizes' the family member's required role. These roles, which to the Western outsider may appear to be only of morally persuasive value, are 'essentially rights which each kinship member customarily possesses, and

⁵⁶ Spears writes: "Kinship did not merely define one's circle of associates. It was also defined by them it acted as a passive idiom to describe social relations.... Kinship, then, defined patterns of behaviour more accurately than it did groups of blood kin. This flexibility of idiom allowed individuals constantly to redefine themselves and to change and adapt their social allegiances through time." (Spears n 2), at 76). Kenyatta also underlines the fluid, opportunistic nature of notions of kinship. (Kenyatta (n 18), at 14)

⁵⁷ Ngau, Peter M., 'Tensions in Empowerment: The Experience of the "Harambee" (Self-Help) Movement in Kenya,' *Economic Development and Cultural Change*, Vol. 35, No. 3 (Apr., 1987), pp. 523-538, at 524

duties which each kinship member has toward his kin.' Expressed differently, 'the right of one kinship member is the duty of the other and the duty of the other kinship member is the right of another.'⁵⁸

Other writers, too, apply modern rights analogies to these traditional African relations. Radcliffe-Brown expounds on the jural element in these social interactions, providing a useful perspective on the foundation of notions of entitlement within the kinship set-up.⁵⁹ Though transplanting such contemporary concepts and their meanings to another era can be problematic it is not deleterious to the core task here, that is, exploring the role of kinship ties in the construction of notions of obligation and entitlement. For instance, Radcliffe-Brown refers to claims which one member of the unit might make obliging another to perform certain actions as 'positive duties'; 'negative' ones were selected deeds proscribed among certain members of the kinship network. Similarly, he differentiates 'personal rights', which governed the relationships between, say, husbands and wives and parents and children, from rights "against the world", used especially in regards to property, which in many African societies included "possessive rights" of husbands over their wives and children.⁶⁰ The choice of rights language thus helps to illuminate the nature of these bonds; "[r]eferences to duties or rights are simply different ways of referring to a social relation and the rules of behaviour connected therewith."⁶¹

The terminology commonly used in kinship research also provides insights into the nature obligations arising from these bonds. For instance, Lewis H. Morgan's oft-quoted work in the 19th century, introduced the idea of the classificatory system of kinship, where terms which referred to lineal relatives were also applied to some collateral relatives.⁶² In some communities where such a system exists, one's father's brother may be accorded the term "father" or one's mother's sister referred to as "mother", and so on.⁶³ Radcliffe-Brown quotes with approval Sir Henry Maine's view that, "the effect of the system is in general to bring within your mental grasp a much

⁵⁸ Cobbah, Josiah, 'African Values and the Human Rights Debate: An African Perspective,' 9 *Human Rights Quarterly*, Vol.9, No. 3 (1987), pp. 309-331, quoted in Mutua (n 8), at 83

⁵⁹ Radcliffe-Brown and Forde (eds.) (n 53). See generally Radcliffe-Brown's introductory chapter.

⁶⁰ *ibid*, at 11-2

⁶¹ *ibid*, at 11

⁶² See, for instance, White, Leslie A., 'What is a Classificatory Kinship Term?', *Southwestern Journal of Anthropology*, Vol. 14, No.4 (Winter, 1958), pp. 378-385

⁶³ See also the Gikuyu kinship system, in which the older or younger brothers of one's father, are referred to as "elder father" or "younger father", respectively. (Kenyatta, (n 18), at 14)

greater number of your kindred than is possible under the system to which [the British] are accustomed”, adding that the classification system is also “used as a method of dividing relatives into categories which determine social relations as exhibited in conduct.”⁶⁴

Whether narrowly or broadly constituted, kinship ties locked their members into an often complex, well-honed (although not always uncontested) set of norms and conventions, duties and privileges, and the effects on social structures of colonialism and its aftermath is crucial to understanding how human rights concepts are absorbed and internalized at grassroots level. One of the central notions that underpins human rights theory, for instance, is the individual-State relationship of duties and rights. Traditional social organizations, too, had sophisticated, entrenched systems of obligations and norms in which individuals were part of an ethnic public whose relations were moderated by powerful customary institutions whose authority, though reduced, remains today particularly in the rural sphere. In such a context the State may not be perceived as providing the sole- or even the primary- institutional framework, raising issues about conflict and co-existence, which will be analyzed in Chapters 4 and 8. What is noteworthy for now are the perceptions about obligations and entitlements that these multiple allegiances nurture in Kenyans, which are far from the simple rights-holding individual/duty-bearing State dynamic that the human rights equation posits.

The overall picture, therefore, is one of sprawling social networks and connections, each branching out to link household to clan to the wider ethnic group. Being able to locate one’s place in the network was thus essential⁶⁵; for while there were certain duties involved, there were also entitlements and every link was a potential source of support for the individual who could claim it in need.⁶⁶ An individual’s social connections themselves became a vital currency and a source of power.⁶⁷

⁶⁴ Radcliffe-Brown, in Radcliffe-Brown and Forde (eds.) (n 53), at 8-9

⁶⁵ Kenyatta (n 18), at 2

⁶⁶ Spear (n 2), at 76

⁶⁷ As Spears writes: “Among societies where everyone had rights to land so that no one could control productive resources and where no centralized political institutions existed, power was a function of one’s influence over people. The more extensive one’s personal networks, the more people one could mobilize in a dispute, and the larger one’s village, the greater prestige and power one enjoyed in village, clan and social affairs. Elders who succeeded in amassing a large personal following were

c) Patriarchy and Gender Disparity

Patriarchy, whose literal meaning, as Patricia Kameri-Mbote points out, is the rule of the fathers,⁶⁸ underpins much of social, political and economic life in Kenya. It enabled wealth, power and status to be held primarily by the males in the community and to be passed down patrilineally. It also bound women's identity and selfhood to their male relations, making them virtual chattels first of their fathers, then their husbands. This has consequences on women's perceptions about the nature of 'the individual' at the heart of human rights theory, but may also impact on their views about the scope of their entitlements. For example, one PLWHA interviewed for this research based her dependence on NGOs for her ARVs in part on the absence of spousal support: "If [MSF] weren't here I don't know how else I could get the drugs.... I don't have a husband; I used to be married in Kangundo [in Eastern province] but when my husband died my in-laws deserted me." (Interviewee 19)

It would be impossible to map individual subjectivities and notions of entitlements and rights in historical and modern Kenya without looking at this system and the resulting gender disparity. The problem is acknowledged in the new Constitution, which underlines the significance of redressing gender inequality and inequity⁶⁹, but as Maria Nzomo and Kameri-Mbote argued in their recommendations for the Draft Constitution of 2003, nothing short of social engineering will be required to transform this ideal into a reality.⁷⁰ Yet this theme is pertinent to the AIDS epidemic, with disproportionately high number of females, especially young ones, infected.⁷¹

widely respected in informal councils, while those who failed were largely ignored." (Spear (n 2)). See also Mkangi (n 20), at 31. He notes that "a man without social relationships was a man without land."

⁶⁸ Kameri-Mbote, Patricia, 'The Land Has Its Owners: Gender Issues in Land Tenure Under Customary Law in Kenya,' *IELRC Working Paper, 2005-9*, International Environmental Law Research Centre (IELRC), at <http://www.ielrc.org/content/w0509.pdf>, accessed 20/12/09, at 1

⁶⁹ Gender is referenced often in the new constitution: for instance, Art. 27(8) provides that members of any State bodies instituted to redress imbalances caused by past discrimination on the basis of such factors as sex shall not comprise of more than two-thirds of the same gender (Chapter IV, "The Bill of Rights"). Also, as noted earlier, gender discrimination is also outlawed in reference to land policy in Chapter V on "Land and Environment" (Republic of Kenya *Laws of Kenya: The Constitution of Kenya, 2010* (n 9))

⁷⁰ Nzomo, Maria and Kameri-Mbote, Patricia, 'Gender Issues in the Draft Bill of the Constitution of Kenya: an Analysis (Contribution for the Constitution Review Commission of Kenya),' *IELRC Working Paper 2003-1*, International Environmental Law Research Centre, at <http://www.ielrc.org/content/w0301.pdf>, accessed 21/11/09, at 14

⁷¹ Among 15-24 year-olds, females are 4 times as likely as males to be HIV-positive (2.7% to 0.7%). (NACC and NASCOP, *The Kenya AIDS Epidemic Update 2011*, (Nairobi, Kenya: 2012) at

One of the most enduring self-identity constructs is that which defines the notions of 'masculinity' and the 'femininity' and gender roles in African society. The discussion in this part of the chapter is based on some of the common themes among Kenya's diverse ethnic groups. Firstly, however, a methodological point must be underlined: there is often a marked imbalance between researching and recording the social, economic and political lives of men and those of women in pre-colonial Kenya. This somewhat affects the quantity and quality of sources available on gender roles and women in general during this period, as writers such as Beth Maina Ahlberg and Ulrike von Mitzlaff note.⁷² The predetermined importance of males in pre-colonial societies was guaranteed by patriarchy and their roles within them viewed as superior to those of females. Additionally, many accounts show that unlike women, men were conceived as individuals with clearly defined and separate identities. Women's roles were only to be appreciated within the context of their families or communities and their identities were immutably tied to those of their male associates; it is a discussion that will be further developed here and in Chapters 5 and 8.

It must be noted, too, that most, if not all, African societies adopted rigid positions on gender and sexuality, with little or no recognition of alternative sexualities.⁷³

http://www.unaids.org/en/dataanalysis/knownyourresponse/countryprogressreports/2012countries/ce-KE_Narrative_Report.pdf, accessed 12/12/13, at 24)

⁷²Maina Ahlberg, for instance, notes that while there are several sources for researchers on, say, the political roles of Gikuyu men after the universally important initiation ceremony, little detail exists on their female counterparts. (Maina Ahlberg, Beth, *Women, Sexuality and the Changing Social Order: The Impact of Government Policies on the Reproductive Behaviour in Kenya* (Philadelphia: Gordon and Breach, 1991) at 62). Von Mitzlaff lists the absence of women in existing literature as an obvious limitation on her research on Maasai women. But she also implicates anthropologists themselves as they have overall control of the direction and methodology of their research. (von Mitzlaff, Ulrike, *Maasai Women: Life in a Patriarchal Society: Field Research Among the Parakuyo Tanzania* (München : Trickster Verlag ; Dar es Salaam: Tanzania Publishing House, 1994) at 10 and 11). Although von Mitzlaff's research deals specifically with the Tanzanian Maa-speaking Parakuyo community, it is referred to here because the author draws on the work of others who have written extensively on their counterpart Kenyan Maasai communities.

⁷³ See Oliver Phillips, '(Dis)Continuities of Custom in Zimbabwe and South Africa: The Implications for Gendered and Sexual Rights,' *Health and Human Rights: An International Journal*, Vol. 7, No.2 (2004), pp. 82-113. Kenyatta writes, for instance: "[T]he practice of homosexuality is unknown among the Gikuyu. The freedom of intercourse allowed between young people of opposite sex makes it unnecessary, and encourages them to acquire experience which will be useful in married life." (Kenyatta (n 18), at 162). Further, he states, "any form of sexual intercourse other than the natural form, between men and women acting in a normal way, is out of the question. It is considered taboo even to have sexual intercourse with a woman in any position except the regular one, face to face." (at

Individuals were either male or female and their prescribed sexuality necessarily hetero, and it was on this premise that their identities and roles within society were set. This rigidity persists today⁷⁴: it restricts an open debate on homosexuality and the prevention of HIV transmission through sex between men difficult, if not impossible, despite anecdotal evidence of both phenomena.⁷⁵ Certain practices such as sanctioned sexual relationships with young girls and widely-condemned practices such as female circumcision, common in many societies, raise interesting questions about how modern attitudes towards sexuality were formed. For now, however, these must be viewed from the perspective of traditional societies, for whom they bore little or no controversy.

Women's main function in traditional Kenyan societies centred on their reproductive capability. Children had great material value, extending the kinship chain and augmenting group status. This was also potentially the greatest source of women's power as Maina Ahlberg and Oboler emphasize.⁷⁶ There was also higher ritual status accorded to fathers in households with a male first-born. A girl-child is also a valuable asset for the extension in kinship ties and bridal wealth she brought with marriage,

161). Of the Parakuyo Maasai, Von Mitzlaff writes: "Homosexuality, as the term is defined for our society, is not the custom with the Parakuyo. I do not know, however, whether and to what extent adolescent Parakuyo might have sex with members of the same sex."(Von Mitzlaff (n 72), at 128, footnote 1)

⁷⁴ See, for instance, the hysteria that has greeted recent reports about an alleged marriage in the coastal region of Kenya. (BBC, 'Kenya Chiefs Block Mombasa "gay wedding,"' 11th February 2010, at <http://news.bbc.co.uk/1/hi/8511321.stm>, accessed 10/04/10). See also *The Daily Nation*, 'Two Kenyan Men Wed in London,' 17th October 2009). The reporters note that "The marriage has raised a storm among Kenyan residents in the UK who have described it as 'unnatural and socially unacceptable'." See also reports of a bill currently being debated in Uganda which proposes to make homosexuality a capital offence. (*The Observer*, 'Anti-gay Bigots Plunge Africa into New Era of Hate Crimes,' 13th December 2009, at <http://www.guardian.co.uk/world/2009/dec/13/death-penalty-uganda-homosexuals>, accessed 10/04/10). The article quotes David Bahati, the Ugandan MP who presented the bill, as saying, "Learned behaviour can be unlearned. You can't tell me that people are born gays. It is foreign influence that is at work." It condemns "'ungodly' donor countries, including the UK, Sweden and Canada, who are "bent on forcing homosexuality on Ugandans".

⁷⁵ UNAIDS, *Policy Brief: HIV and Sex Between Men*, 2007, at http://data.unaids.org/Publications/IRC-pub07/JC1269-PolicyBrief-MSM_en.pdf?preview=true, accessed 15/10/06. UNAIDS further cites unprotected sex between men as a growing drivers of HIV infection in Kenya, estimating that it accounts for about 15% of new infections in Kenya. (UNAIDS, *Global Report: UNAIDS Report on the Global AIDS Epidemic, 2010*, 2010, at http://www.unaids.org/documents/20101123_GlobalReport_em.pdf, accessed 12/12/10, at 30). And although it, combined with shared use of contaminated injecting drug equipment and unprotected paid sex account for an estimated 33% of new infections in Kenya (at 30), only 0.35% of spending on HIV prevention is targeted at these crucial groups, with international funding accounting for virtually all the mount (at 65). This underlines the exclusion of such groups from the public sphere.

⁷⁶ Oboler, Regina Smith, *Women Power and Economic Change: The Nandi of Kenya* (Stanford, California: Stanford University Press, 1985) at 27 and 67

the latter which facilitated her brothers' marriages. Thus her perceived significance is still attached to her male family members.

There were also disparities in the value judgements associated with masculinity and femininity: the former was idealized while 'female' traits were invariably regarded as inferior or undesirable, although not necessarily negative, as Oboler illustrates.⁷⁷ She reveals that femininity was not regarded as a completely different set of traits but rather more a "lack of the positive traits whose full measure defines real masculinity."⁷⁸ In a telling bias of its own, while the Nandi have a word for masculinity they lack one for femininity. Masculinity was therefore the designated reference point and femininity akin to an absence of character, or, as Oboler writes, it was simply assumed that women, among whom masculine values are also desirable, would fail to give them their full expression due to their innate inferiority.⁷⁹

And yet although 'masculine' characteristics were viewed positively by both sexes, the display by a woman of some of these traits may not be well-received. An assertive Nandi woman might be pejoratively known by a word that translates to "manly woman", signalling a potential conflict with expectations of respectfulness and subservience towards her husband.⁸⁰ Women appear to be in a no-win situation: disparaged for their apparently natural inability to be like their men but, similarly, branded as disrespectful and socially divisive if they failed to accept this condition of permanent disadvantage and adopted some masculine traits. As Sylvia Tamale observes, "[i]n Africa, it does not matter whether a woman is a successful politician, possesses three Ph.D.s and runs the most successful business in town; if she has never married and/or is childless, she is perceived to be lacking in a fundamental way."⁸¹ The focus was not on legitimising or imbuing value in female characteristics,

⁷⁷ *ibid.*, at 58. The fact that some of her anthropological investigations were conducted as recently as the late 1970s is a clear sign of the durability of many of these perceptions about what it means to be 'male' or 'female' and that many aspects of the gender identities constructed decades if not centuries ago, remain. See also Kenyatta (n 18), at 101)

⁷⁸ Oboler (n 76), at 62

⁷⁹ *ibid.* Only a few feminine characteristics amongst the Nandi are valued, such as pity and cleanliness (although even here, Oboler adds, being anything other than clean would be of greater shame to a woman rather to a man). (at 58-62).

⁸⁰ *ibid.*, at 62-3

⁸¹ Tamale, Sylvia, 'Gender Trauma in Africa: Enhancing Women's Links to Resources,' *Journal of African Law*, Vol. 48, No.1 (2004), pp. 50-61, at 52

or even challenging the dubious basis of these character assignments. This would change over time, especially with the injection into the discourse of notions of equality and rights. But, as Chapter 5 shows, equity and equality for women in relation to access to and control over resources, the key to attaining real autonomy, remains elusive; the consequences for the spread of HIV have been far-reaching.

The inculcation of the norms and roles traits outlined above formed the backbone of traditional education for young boys and girls with the ultimate goal of instructing individuals about their position within the social structure and their obligations to others within the community. These lessons, which started early in childhood and continued well into adulthood, could not be taken for granted.⁸² A significant part of the learning process involved the imitation of elders as well as play-acting.⁸³ One crucial aspect of it was the inculcation of norms on sexuality and family life. For many groups the age-grading system provided the framework for this developmental process, which was punctuated by events such as initiation and marriage. The centrality of sex education in an individual's development is clear from the elaborate rules and rituals that accompanied it. Yet it would appear that a number of communities, while attaching great value to sexual purity before marriage, were also careful to provide compromises for youngsters who wished to experiment with their sexuality, as was- and is- natural at this age.⁸⁴

Some communities, such as the Maasai, even made provisions for sexual relationships outside marital bonds: relations between women and men of their husband's age-set

⁸² Kenyatta (n 18), at 106; Odwar Agak, John, and Odwar Agak, Hellen Atieno, 'Indigenous Education Among the Luo', in Ocheing' (ed.) (n 5), at 84 and 86)

⁸³ Kenyatta (n 18), at 102 and 101); Odwar Agak and Odwar Agak (n 72), at 85); Von Mitzlaff (n 72), at 30.

⁸⁴ The Gikuyu, for example, in furtherance to the "spirit of comradeship and group solidarity before marriage" had *ngweko*, or fondling, a carefully orchestrated act in which unmarried boys and girls were permitted to engage in acts that fell just short of penetrative sex...by mutual arrangement a girl may allow her lover to have fuller intercourse, trusting that incomplete penetration would safeguard against the risk of conception, but such behaviour is absolutely against the tribal law and never takes place between casual lovers. If it does happen, which is rare, the law punishes it by imposing social stigma upon the offenders." (Kenyatta (n 18), at 158-159) Among the Maasai, too, sexual relations between unmarried girls and morans (members of the warrior class), regardless of whether they are married or not, are authorized. The Nandi also expected courting couples to satisfy each other sexually, but, like the Gikuyu, without engaging in full, penetrative sex. (Von Mitzlaff (n 72), at 90).

⁸⁴ Oboler (n 76), at 90

were all considered legitimate, and this may still be the case among some.⁸⁵ This indicates that the process that precipitated the eventual abandonment of these more relaxed attitudes to sex and sexuality began and proliferated with the Christian and Victorian moral values introduced during colonialism. The effect of this change, of course, was not the end of centuries of cultural norms on sexual activity outside marriage, but that such practices gradually became socially unacceptable and were effectively driven underground. As von Mitzlaff writes, “women converted to the Christian religion, for example, have tried to forbid their daughters from premarital sexual activities. Some mothers also deny that their daughters have sexual activities before circumcision.”⁸⁶ The effect of Christianity to sexual relations in Kenya was and remains profound: indeed, the myth of sex as a taboo subject in African societies appears to be a more recent development than is widely believed. The denunciation of sexual interaction outside these strictly-defined parameters and reclassification of previously acceptable behaviour as counter-normative has had a devastating effect on how individuals and communities approach sexually transmitted illnesses such as HIV/AIDS and those who contract them, as later chapters will demonstrate. The intersection of such taboos and ongoing traditional practices such as widow-inheritance among the Luo or even the afore-mentioned wife-sharing among the Maasai age-set mates creates barriers for the kind of open and honest debate about sex that is vital to curbing HIV infection.

Despite the concessions made by certain communities on sexual matters, there was, as mentioned earlier, an undoubted value placed by many on sexual purity, that is, the avoidance of full penetrative sex or sex outside the socially-prescribed parameters, at least during initiation and/or marriage.⁸⁷ But here again there was greater emphasis on chastity in girls than boys, the latter for whom there was no method of verification.⁸⁸

⁸⁵ Von Mitzlaff (n 72), at 128

⁸⁶ *ibid*, at 129

⁸⁷ Among the Nandi, virginity at initiation, ascertained by old women in the community, was rewarded by several ceremonial privileges. Premarital pregnancy and especially the birth of a child outside marriage was disapproved of, to the extent that such a child was supposed to be killed as soon as it was born. (Oboler (n 76), at 94-5).

⁸⁸ It must be noted that a perforated hymen is not in itself conclusive of penetrative sexual intercourse in women. Oboler, though noting some legitimate sexual acts between courting couples does not mention any expectations of virginity for men among the Nandi, except to say that a warrior who impregnated a girl received a severe beating from his age-mates and may be fined for his

All the above demonstrates the corporate value attached to sexuality, but especially to female sexuality. The public notification and celebration of a girl's virginity underlines the difference between the two. This has two significant implications: firstly, the fact that sex and sexuality were of public interest in traditional and, arguably to a considerable extent, modern- Kenyan societies exposes a fundamental difference between attitudes here and in the West. This is important because not only do Western notions on sexuality disproportionately dominate the global discourse due to the sphere's cultural, economic and political reach⁸⁹ but so do their political and philosophical ideas about individual rights, in which sex and sexuality is regarded as falling within the private sphere. The tension between these two perspectives is critical: on the one hand, persistent cultural norms emphasize and promote (heterosexual) marriage and procreation as the principal avenue for furthering the lineage and family, the primary social and economic unit. The body, through which this collective goal is to be achieved, cannot be a private domain. Its expected yield- children- has a public utility, and so, too, does its functions. And yet the individual at the heart of human rights must be autonomous, and fundamental to this is the ownership of one's body.⁹⁰ The sexual domain perhaps embodies best that autonomy and many commentators on sexual rights strongly argue that they cannot be delinked from other rights.⁹¹ Highlighting the convergence of the development discourse and sexuality, they argue that where an individual's right to control her own sexuality is constrained so are other rights.⁹² Further, recognizing the right of women

transgressions. (ibid) But arguably this is punishment for impregnating the girl rather than engaging in full sexual intercourse. The Gikuyu, too, tested girls rigorously to ensure they were virgins at initiation and again at marriage, where the results of such an exercise were publicized to both the girl's parents and those of her prospective husband. (Kenyatta (n 18), at 136 and 173)

⁸⁹ See, for instance Lewis, Jill and Gordon, Gill, 'Terms of Contact and Touching Change: Investigating Pleasure in an HIV Epidemic,' in Cornwall, Andrea; Correa, Sonia; and Jolly, Susie (eds.), *Development with a Body: Sexuality, Human Rights and Development* (London, New York: Zed Books, 2008).

⁹⁰ See Veil, Simone, 'A Personal Perspective on Human Rights and Health,' *Health and Human Rights: An International Journal*, Vol. 2, No. 3 (1997), pp. 91-94. She argues that public health objectives, which have traditionally prioritized society over the individual, must be reassessed so that they consider and protect "the rights relevant to the sphere of private life. To move in that direction, the human rights of women must be taken into account." (at 93). See also Oliver Phillips on attempts in colonial Zimbabwe to curb the sexual autonomy of married women through legislation. (Phillips (n 73), at 88-9)

⁹¹ See generally Cornwall, Correa and Jolly (eds.) (n 89)

⁹² See Correa, Sonia, and Jolly, Susie, 'Development's Encounter with Sexuality: Essentialism and Beyond,' in Cornwall, Correa and Jolly (eds.), *ibid*

as individuals means recognizing their presence and role in the public space, from which they have traditionally been excluded.⁹³ As Tamale notes:

The public sphere represents men and is the locus of socially valued activities such as politics and business, while the private is representative of domestic activities centred around the family. The former represents society, while the latter represents culture. Women are confined to (read trapped in) the domestic arena-a space where men rule over them as heads of the family-while men spend most of their time in the public realm.⁹⁴

Indeed, the emphasis in history of women's subordination has been used to galvanize their confinement in the private domain.⁹⁵

The education of generations of girls by their mothers, aunts and grandmothers can be seen in this light, with its emphasis on domesticity- marriage and motherhood- as the epitome of fulfilled womanhood.⁹⁶ The cumulative effects of such instruction were present in this research in a number of interviewees' responses. Further, some highlighted the persistence within their belief system of the notion that compliance and a subdued sexuality were emblems of good womanhood. It was an ideal which a number of PLWHAs either aspired to or felt they embodied as part of their subjectivity. A PLWHA must navigate all these conflicts with the added factor of social stigma attached to HIV/AIDS, because of which she may be censured for presumed sexual deviancy. And even while she may desire to embrace a human rights frame of reference with its positive messages of individual and sexual autonomy, of the validation of her self-worth and dignity, she must contend with the social and cultural context in which she experiences her daily life and whose values have been long ingrained. These conflicts will be explored further in latter chapters.

Secondly, the contrasting attitudes towards male and female sexuality, in which the former were granted greater independence in the legislation of their sexual affairs, exemplify the collective ownership of women's sexuality. Its preservation, or lack thereof, is viewed as having consequences on the wider society. The notions of 'honour' and 'respect' attached to a sexually pure female who at initiation and/or

⁹³ Fraser, Arvonne S., 'Becoming Human: The Origins and Developments of Women's Human Rights,' *Human Rights Quarterly*, Vol. 21, No. 4 (1999) pp. 853-906, at 859

⁹⁴ Tamale (n 81), at 52

⁹⁵ Fraser (n 93), at 860

⁹⁶ Tamale (n 81), at 51-2

marriage bore none of the outward signs of illicit interference, imputable to her parents and her family, underscore this. This illustrates the entrenchment of the female body and sexuality into the society's idea of its own identity. Society's purity appears to be invested more in its women; sexual impurity in men, conveniently harder to prove, does not seem to implicate similarly their wider community. If no such proof, positive or negative, can be found on the male body, then none can be imputed to the community.

Nevertheless an aspect of male sexuality can be said to attract a similar kind of corporate investment: his virility. His ability to father children or even take on more than one wife or sexual partner, are signs of his- and therefore his kin and community's- vitality.⁹⁷ This creates social pressure on men to assert their sexuality- to 'be men'- by engaging in behaviours that may be reckless or aggressive and which carry serious sexual health consequences for them and their sexual partners. It is in this context that violence against women and the spread of HIV infections to wives or long term partners by men who use commercial sex workers or have multiple sexual partners can be seen.⁹⁸

Several female PLWHAs interviewees for this research expressed a sense of grievance at this discrepancy in societal norms which promote a restrictive ideal of female sexuality, urging them to be faithful to their spouses while condoning sexual promiscuity in men despite the cost in lives to wives or female partners:

If you hear about the way some people contract this illness, they put themselves in risky situations. For example, I can swear that from the moment I got married, I have never been with anyone else other than my husband. When I think about it I am so bitter.... Even in my area my family, my brothers, they support me because they know I am not the kind of person who moves around with men. Some people may laugh at you, asking how else then you got the disease, but these are the prostitutes who carry out their business in secret. Here the nurses tell us it is good to tell other people about this disease and preach about it. But when I go to my District hospital and I see people there I think that no matter how much you tell people, they will never listen. You see a man taking someone's young daughter, the next time you see her she is in hospital and she is ill. You ask, what is wrong with such a person? (Interviewee 30)

⁹⁷ Kenyatta (n 18), at 178-9. Indeed, impotence or barrenness in either party were grounds for annulment of marriage. (at 184)

⁹⁸ UNAIDS urban data in Kenya estimates that about 62% of PLWHAs are in long-term relationships and that about 44% of new HIV infections through heterosexual transmission occur within marriage. (UNAIDS, *Global Report: UNAIDS Report on the Global AIDS Epidemic, 2010* (n 75), at 30)

Interviewee 5 emphasized the prevalent dichotomy between ‘good’, faithful, married women and ‘bad’, licentious, presumably unmarried ones:

It’s not the way people put it that those who are infected are harlots, prostitutes and so on. It’s not like that. Some of us, since we were born, maybe you have only had two boyfriends, maybe even one, in all your life. Some of us, since you got married, you settled, but this thing just got into your house.

Interviewee 10 distinguished ‘good’ women/wives from ‘bad’ men/husbands:

...[S]ome people... if they hear you are HIV-positive you’re just someone who was a loose person, and it is not that way. Especially us women, you are married lady, you’re with your children. It is these men we are married to that go look for this thing and bring it to you. We women we are very, very, very, very innocent. Very innocent.

In these responses, reviewed in later chapters, wives stridently assert their chastity (even though one of them can hardly bring herself to blame her husband explicitly, perhaps out of embarrassment, loyalty or deference: “this thing (HIV/AIDS) got into your house”), for there is still great currency for women in upholding- or seeming to uphold- these norms. While there are certain privileges to be enjoyed by those who adhere to society’s sexual rules and so exemplify the best of the community, serious repercussions await those who operate outside its strictures and attempt to carve out of the collective interest in sexual affairs a private, independent space.

The notion of errant male sexuality and a chaste female one is one that a number of female respondents appeared to subscribe to. And while such notions are still popular today, they are not uncontested. The issue of how to tackle HIV incidence within married couples is much-debated.⁹⁹ Some human rights experts such as Nzomo and Kameri-Mbote have proposed legal recognition of “mandatory but guaranteed testing [for] HIV/AIDS before solemnizing marriage,” as part of a wider agenda to give women greater sexual and reproductive autonomy.¹⁰⁰ But others oppose involuntary testing as violation of individual rights and a potent tool for discrimination of PLWHAs.¹⁰¹ Yet others note the potential conflict between respect

⁹⁹ See, for instance, BBC, ‘Should HIV testing be mandatory?’ 30th March 2006, at <http://news.bbc.co.uk/1/hi/world/africa/4850996.stm>, accessed 29th May 2009.

¹⁰⁰ Nzomo and Kameri-Mbote (n 67), at 5

¹⁰¹ See, for instance, a Human Rights Watch report condemning involuntary HIV testing in the Dominican Republic, despite the practice being illegal in the country. It notes that HIV-positive women have been denied work or been dismissed as a consequence and test results been publicized. (Human

for PLWHAs' rights- rejecting policies that may aggravate stigma and discrimination- and what may ultimately be practical and possibly successful prevention strategies. Elizabeth Pisani decries "the predictable, knee-jack comments about a violation of ethics, about protecting people's right not to know if they were infected, and their right not to tell anyone else if they did know," and talks of challenging the "sacred cow of 'only voluntary confidential testing'", especially in light of the increasing potential for counselling and treatment now found in many countries, including Kenya.¹⁰² Other commentators suggest alternative approaches to bridge these dilemmas, such as increasing availability and accessibility of VCTs or conducting routine testing, a policy endorsed by the WHO.¹⁰³

All of the above sets up a debate on the role of gender and sexual norms within a human rights framework which formally recognizes only autonomous individuals whose social goods are to be accessed through the State, which in Kenya's case, retains many of the patriarchal impulses that motivated pre-colonial societies and which the colonial State little intervened to alter.¹⁰⁴ One detrimental manifestation of this, explored in detail in Chapter 5, has been the government's failure to address the problem of gender inequity regarding access to land. Women are disadvantaged by State-sponsored individual-titling policies which combine with culture, customary laws of tenure, and other factors including capitalism and the prevailing global social inequalities to institutionalize male control of this key resource.¹⁰⁵ Another of these factors, colonialism, which altered but in other ways entrenched the patterns of traditional power distribution discussed here, is reviewed next.

Rights Watch, 'A Test of Inequality: Discrimination Against Women Living With HIV in the Dominican Republic,' *Human Rights Watch*, Vol. 16, No.4 (B) (June 2004), at <http://www.hrw.org/sites/default/files/reports/dr0704.pdf>, accessed 12/10/10; at 7

¹⁰² Pisani, Elizabeth, *The Wisdom of Whores: Bureaucrats, Brothels and the Business of AIDS* (London: Granta Publications, 2008), at 169 and 171)

¹⁰³ London, Leslie, 'What is a Human Rights-Based Approach to Health and Does it Matter?,' *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 65-80, at 66

¹⁰⁴ Oliver Phillips notes that "emancipate African women from what they perceived to be 'primitive' and oppressive structures of kinship was rapidly replaced by a recognition that their authority was based on the cooperation of African chiefs and headmen." (Phillips (n 73), at 87)

¹⁰⁵ Karanja, P. W. (n 15), at 111

Chapter 4: The Colonial Legacy

Chapter 4 continues to map the complex environment in which PLWHAs' subjectivities and notions about entitlements and notions about rights are hewn. Building on the discussions in Chapter 3, it introduces into the landscape the experience of seven decades of colonization. It examines how this event, with its multiple and sometimes contradictory aims, contributed to these key issues. In particular, this chapter analyzes continuities in the colonial and AIDS discourses, illustrating the persistent dominance of the themes of race and power in shaping individual and collective subjectivities. Significantly, the colonial period saw the introduction of the State, thus parachuting into the existing hierarchy of power a new entity to rival the customary. Crucially, the introduction of the State also heralded the haphazard construction the African legal subject and the attempt to delineate her rights. Here lie the roots of the binaries at the heart of Mahmood Mamdani's bifurcated State theory: civil and customary, citizen and subject. The issues they raise frame this research. As this chapter shows, from the outset there was a clear racial demarcation between the legal and political identity of the native and settler: the former was a subject only, confined to the customary realm, while the latter alone occupied the civil domain, a citizen with rights from the State. As Mamdani argues, the boundary, though now deracialized, persists. Yet, as several interviewees' responses for this research illustrate, the modern Kenyan is arguably less a citizen *or* subject and more a citizen *and* subject. This chapter contends that this dual membership of a national and ethnic public, and perceptions about the roles, legitimacy and values of State and customary authorities significantly influence how individual PLWHAs identify themselves in reference to other actors. Consequently, the complexities and contradictions inherent in this duality not only help define individual subjectivity but arguably their notions about health-related entitlements.

Before we explore these discussions, however, it is worth making a preliminary point about the characters of the citizen and subject, whom Mamdani employs in his analysis of the development of subjecthood, law and rights in the colonial and postcolonial periods. It may be possible to argue that Mamdani uses the

citizen/subject dichotomies as 'ideal types', theoretical tools developed by Max Weber.¹ Understood as such, the citizen and subject do not, indeed can never hope to fully encapsulate the varied reality of the social, cultural, political and economic lives of the white settlers and indigenous Africans. Arguably then, in deploying these characters, Mamdani may have been distilling into the 'citizen type' and the 'subject type' the general aspects of their complex lived experiences, with particular emphasis on the more extreme aspects, in order to highlight what separated the two groups and as such aid his analysis of the divergent fates of the citizen and subject. The consequence of this, of course, would be to mute the shades of grey that would define such a co-existence in reality.

To be sure, there is a basis in this argument, for even the colonial-era citizens and subjects, whose separation was so rigidly policed, inevitably encountered each other in the shared spaces which developed in order to facilitate various colonial objectives. One such objective was the servicing of the settler economy, which necessitated African labour and thus interaction between citizens and subjects. Mamdani explores this, for instance, in relation to South African migrant workers.² Nevertheless, as will be seen shortly, one insuperable concrete reality persists which transcends even these interactions: the fundamental racial divide that defined and separated citizen from subject. As Mamdani writes, the term 'native', evolved as "a blanket racial category.... The point was to cast the net wide enough to catch within its fold every person with any trace of African ancestry. The objective was to arrive at a racial definition, not a cultural one."³ For the citizens and subjects of the colonial period the greys are subsumed in the fact of their ineluctable racial identity.

For the deracialized postcolonial citizen-subject, however, this essential separation is negated. The urban/ rural boundary that divides the two is more fluid, thus arguably presenting greater scope for arguing that the citizens and subjects Mamdani describes in postcolonial context are more identifiably 'ideal types'. The accentuation of the extremes of their social, cultural political and economic lives becomes more

¹ See, for instance Watkins, J.W.N., 'Ideal Types and Historical Explanation' *The British Journal for the Philosophy of Science*, Vol. 3, No. 9 (1952), pp. 22-43

² Mamdani, Mahmood, *Citizen and Subject: Contemporary Africa and the Legacy of Late Colonialism*, Princeton, NJ: Princeton University Press, 1996) at 218

³ *ibid*, at 111

necessary to this phase of his analysis of the citizen and subject narrative, and he arguably has this in mind, in order to highlight their cleavage and facilitate his theory of the persistence of this duality in the postcolony. Indeed, it is this fluidity, the shades of grey within the postcolonial citizen-subject dichotomy, which the interviews for this thesis appear to reaffirm, as will be seen later. The above notwithstanding, Mamdani's theory remains fundamental to this research, and it provides an ideal conceptual tool for analyzing the development of the differentiated legal statuses of white settlers and indigenous Africans which evolved in colonial era and continued after independence, with crucial ramifications for the development not just of concept of the citizen(-subject) and the State, but also the rights and duties which bound them. This is what underpins the significance of Mamdani's thesis to this research.

I. Colonialism, the State and the Subject

The colonial enterprise embraced various, sometimes inconsistent, objectives, reflected in the shifting attitudes of the administrators of the Crown Colony of Kenya towards the indigenous population. These included 'civilizing' and evangelizing the black Africans, as well as commercially exploiting the new colony. The term 'civilization' is problematic and its definition elusive yet it is fundamental to the discussion here because it became the key criteria in deciding the legal status of indigenous peoples. Were they to be regarded as subjects within the law of the colony as well as equal citizens with rights and privileges equal to their settler counterparts? But, as will be seen, this catch-all term also resonates in contemporary debates about the objectives and processes of international development and the universalization of the human rights project, adherence to which is widely recognized as a criteria for international legitimacy among post-independence nations and an indicator of their 'maturity'.⁴

The term 'civilization' informed popular notions about Africa and Africans during the Scramble for Africa in 1884. It defines a certain standard of advancement in human

⁴ Indeed, Makau Mutua suggests that the mostly-successful efforts by European powers to broaden the reach of human rights standards and related Eurocentric ideas may be yet another 'civilizing' project in all but name (Mutua, Makau, *Human Rights: A Political and Cultural Critique* (Philadelphia: University of Pennsylvania, 2002) at 32, and elsewhere.

society.⁵ As with all value-laden terms, those who introduce, define, endorse and popularize their use invariably ascribe to themselves its positive aspects and to others its antitheses. So, too, with 'civilization': the white Europeans, who began to settle in Kenya at the close of the 19th Century, predictably had *more* of it than the black population. This ideology of European/white superiority continued to frame the paternalistic policies and laws of the colonial State throughout the period.⁶ And it endures in the psyches of many; this was perhaps best-illustrated by PLWHAs' responses regarding overseas development aid, some of which appeared to attribute an almost mythical status to foreign actors, as if their offers of assistance symbolized a higher, 'civilized' quality.⁷ This will be explored in greater detail in Chapters 6 and 7 when the role of donors and NGOs in financing ARV projects for PLWHAs is discussed.

The definition of civilization adopted by Europeans was an amalgamation of many ideas: it contained religious and moral components rooted firmly in Christian monotheism. The inculcation of Christianity and eradication of what were seen as the inferior morals of Africans everywhere therefore became an integral part of the colonial agenda, as pro-colonists such as Matthew Carey, writing in the first half of the 19th Century, demonstrate.⁸ African customs and practices such as female circumcision were a constant source of tension, with African writers such as Kenyatta condemning the patronising attitude of the British, whom, he argued, took a narrow

⁵ *Oxford English Dictionary Online*, www.dictionary.oed.com, accessed on 28/08/06.

⁶ Bruce Berman writes that as part of the "omnipotent" image that the influential Provincial Administration strived to project, the institution also used its extensive discretionary powers to reaffirm in the Africans "their sense of inferiority to and dependence on Europeans." (Berman, Bruce, *Control & Crisis in Colonial Kenya: The Dialectic of Domination*, (London: James Currey, 1990) at 204)

⁷ See Ekeh, Peter P., 'Colonialism and the Two Publics in Africa: A Theoretical Statement,' *Comparative Studies in Society and History*, Vol. 17, No.1 (1975), pp. 91-112, at 99. See also Bayart, Jean-François, *The State in Africa: The Politics of the Belly* (London; New York: Longman, 1993) at 61

⁸ Writing in favour of the establishment of a colony for freed slaves in Liberia 1832, Carey asserts that one of the strongest arguments is: "...spreading the blessings of civilization, morals, and religion among the natives in the neighbourhood of the colony [of Liberia], whom it has taught to depend on honest labour in the cultivation of the soil..." (Carey, Matthew, *Letters on the Colonization Society, with a View of its Probable Results... Addressed to the Hon. C.F. Mercer* (Philadelphia: 1832) at iv). Liberia is a very specific case, given the history of many of its inhabitants as freed slaves from Europe and the Americas. One of Carey's main contentions in favour of the colony, for example, was that its establishment helped curb the "nefarious" slave trade and offered the blacks the kind of opportunities they did not actually enjoy as slaves in the United States. However, many of his views on the issue of civilization are typical of other colonization debates: "The best criterion, however, by which to judge [the advances made by the freed slaves in colony of Liberia] is the progress they have made...Of the improvements in morals, and manners and habits..."

view of the offending customs without considering their wider social significance.⁹ Despite subsequent willingness to allow controlled expression of cultural uniqueness for pragmatic reasons, the caveat of European-defined morality remained.¹⁰ Africans were obliged to accept the colonizing mission as an effort to save them from themselves, their backwardness and their past.¹¹

Ultimately, however, the most fundamental element of the colonial definition of 'civilization' was the crude one of race. In this sense the question of whether the newly-colonized indigenes could ever gain admittance into the social, political, economic and legal space on an equal footing with white settlers was pre-determined.¹² The result was a split State- Mamdani's 'bifurcated State'-, a product of the deliberate processes and considered rationale deployed by the colonizers. The population itself was split into different administrative and legal spheres. Mamdani writes:

In the main... the colonial state was a double-sided affair. Its one side, the state that governed a racially defined citizenry, was bounded by the rule of law and an associated regime of rights. Its other side, the state that ruled over subjects, was a regime of extra-economic coercion and administratively driven justice.¹³

Mamdani, Mbembe and others successfully argue that these schisms both in the State and the subject have been substantially replicated in post-independence African countries such as Kenya, producing two publics instead of one. A number of

⁹ Kenyatta, Jomo, *Facing Mount Kenya: The Tribal Life of the Gikuyu* (London: Mercury Books, 1961) at 135

¹⁰ As Mahmood Mamdani writes, "The standard formulation ... required that customary law [in countries like Kenya or Malawi] be applicable if 'not repugnant to justice and morality.'" (Mamdani (n 2), at 115. In Kenya, the relevant legislation was East Africa Order in Council of 1897, at Art. 2. (Kameri-Mbote, Patricia, 'Gender Dimension of Law, Colonialism and Inheritance in East Africa: Kenyan Women's Experiences,' *International Environmental Law Research Centre (IELRC) Working Paper 2001-1*, at <http://www.ielrc.org/content/w0101.pdf>, accessed 12/10/05, at 2). Kameri-Mbote continues: "However, an African who had embraced Christianity was deemed to have technically abandoned African customary law and was therefore not subject to it," with little clarification of what laws applied to them instead (*ibid.*). As will be seen shortly, though, the issue was a foregone conclusion, with race being the immovable fault line along which the application of either customary law or modern English law was decided.

¹¹ Ekeh (n 7), at 97

¹² Achille Mbembe draws attention to the distinction made between colonizer and *native* or *indigene*, a word that means "a 'son or daughter of the soil,' not someone who has settled as a result of immigration or conquest." (Mbembe, Achille, *On the Postcolony* (Berkeley: University of California, 2001) at 28

¹³ Mamdani (n 2), at 19

comments made by interviewees intimate at just the kind of split publics that Peter Ekeh and Stephen Ndegwa explore, as will be seen later.

Before addressing the impact of the colonial discourse on the AIDS debate and the configuration of the State and citizen-subject, it is worth highlighting a couple of points about the notions of race and culture which so influenced the colonial government. Firstly, critiques of popular ideas about Africans and African-ness did not emanate solely from Africans themselves. Despite the wide subscription to views like Carey's above, some Europeans had questioned the hypocrisy that underlay presumptions of European cultural and moral superiority.¹⁴ Prevailing views on the treatment of indigenous populations, whether they should simply be regarded as mere objects upon whom certain acts, often violent, were performed for their alleged betterment, proved problematic in some quarters.¹⁵ Such objectification was difficult to reconcile with the perceived triumph of the abolition of slave trade which the British themselves claimed. Indeed, this development overlapped with European colonial ambitions, meaning that there had been an ongoing dialogue about the exploitation and maltreatment of non-white races long before Kenya became a colony.¹⁶

Secondly, the abolition movement, in effectively attributing qualities of 'humanness' to black slaves, exposed yet another incongruity in the attempt to define the term

¹⁴ A good example of this is William Howitt's *Colonization and Christianity: a Popular History of the Treatment of the Natives by the Europeans in all their Colonies* (London: 1838): He writes, "We have long laid to our souls the flattering unction that we are a civilized and a Christian people. We talk of all other nations in all other quarters of the world as savages, barbarians, uncivilized.... It is high time we examined, on the evidence of the facts, whether we are quite so civilized, quite so Christian as we have assumed to be.... What, indeed, are civilization and Christianity? (at 1, 2, 7, 14). Interestingly, though, Howitt does not appear to be contesting the superiority of the Christian-based European civilization, or even the colonial endeavour for the purpose of evangelising (at 13-14)); instead he appears to be reproving the Europeans colonizers for not representing Christianity's true values.

¹⁵ Mbembe explores the characteristic use of indiscriminate violence by colonial powers on indigenous peoples. He argues that it is precisely because these peoples were viewed as occupying the realm of mere objects or animals that such liberal use of violence was deemed permissible. (Mbembe (n 12), at 27)

¹⁶ Interestingly, many individuals and organizations who had been successfully advocating the abolition of the slave trade extended their attention to activities on the continent itself and the plight of Africans there. Here, organizations such as the African-Aid Society (AAS), set up in Britain in the latter half of the 19th Century to support freed slaves hoping to establish themselves in Africa, focused again on the task of "civilizing" them. AAS's stated objectives are: "to develop the material sources of Africa...; and to promote the Christian civilization of the African races; by which means the society believes that the annihilation of the slave trade will ultimately be accomplished." (African-Aid Society, *First Report of the African-Aid Society, July, 1860, to March 31, 1862* (London: African Aid Society, 1862), at 2-3.

'human': for human value in the slave or indigene was often limited to her potential rather than her existing state of being.¹⁷ Because her value is predicated on a future state which she may or may not achieve, depending on the opinion of her colonial arbiters, any rights she might possess by virtue of her humanness are either limited or a receding horizon.¹⁸ This feeds into questions about the legal subjectivity of black Africans in new colonies like Kenya, whether they, too, had any rights, or whether there was at least a space within the legal terrain of the new colonial State in which they might, in future, be recognized as citizens rather than mere subjects of the law. These issues will be addressed later in the chapter. For now, it is worth assessing the lasting effects of the colonization narrative on the HIV/AIDS debate that is the backdrop for this research.

II. Postcolonialism, Neo-Colonialism and the Political Economy of AIDS

The globalization of the campaign for free or affordable ARVs and the rights of PLWHAs, explored in detail Chapters 6 and 7, has been one of the most effective of recent years: the effects of the social and economic disparities across the world, embodied by the vastly differing outcomes for PLWHAs in the poorest (especially African) and richest countries, has resonated with many around the world. One of the critical issues was the international patents system, TRIPS (or the Agreement on Trade-Related Aspects of Intellectual Property Rights), that covers, among others, life-saving pharmaceutical products (as will be explored in Chapter 6). The pernicious effects of its strict application drew analogies with the racist policies of South Africa's

¹⁷ See AAS's statements, mentioned above, which emphasize the Christianization and civilization of Africans, suggesting the view of indigenous as somehow 'unfinished' and their value not fully realized without this intervention. Mbembe quotes Albert Sarraut, who spoke of natives as simply being "that 'unformed clay of primitive multitudes' from which colonization's task was to 'shape the face of a new humanity'." (Mbembe (n 12), at 28). Various authors have written on the objectification of the African and development of the notion or stereotype of the 'African'. The medical and scientific fields significantly aided this process, constantly producing knowledge geared towards understanding the nature of the 'otherness' of the African. See, for example, Vaughn, Megan, *Curing Their Ills: Colonial Power and African Illness* (Stanford, California: Stanford University Press, 1991; and Butchart, Alexander, *The Anatomy of Power: European Constructions of the African Body* (London; New York: Zed Books, 1998)

¹⁸ Charles William Hopley, for instance, estimated that it would take one to two centuries of "patient work on the African native" before he could be trusted to play a significant part in his own development. (Hopley, Charles William, *Kenya: From Chartered Company to Crown Colony: 30 years of Exploration and Administration in British East Africa* (London, 1970), at 195

apartheid regime, with “[pharmaceutical] companies act[ing] to maintain the rules of a system that denies the value of black lives in favor of minority privilege. The result in Africa has been murder by patent.”¹⁹

It was a dichotomy that was perfectly suited to campaigning, fitting as it did with well-established though rather crude narratives about the global economic system and modern humanitarian crises familiar to global audiences.²⁰ In these narratives, on the one hand, were often extremely poor Africans unable to meet their basic needs. On the other were a well-endowed amalgam of donors, development agencies and NGOs from the industrialized world, compelled to (well-publicized) action in large part by effective advocacy campaigns by individuals and civil society groups among their own constituents.²¹

However, there are disturbing parallels between the moral and narrative framework into which the contemporary HIV/AIDS crisis has been slotted and that which over a century ago had been used to legitimize the colonial enterprise. There are significant differences of context, of course: among them, firstly, the millions of dead and suffering gave unquestionable moral force to the anti-AIDS movement; by contrast, the policies of racism and economic exploitation that underlay the colonial enterprise exemplified its inherent moral bankruptcy. Secondly, post-independence Africans, despite the curtailment of rights that many endure, enjoy greater collective and

¹⁹ Booker, Salih and Minter, William, ‘Global Apartheid,’ *The Nation*, 21st June 2001 (<http://www.thenation.com/doc/20010709/booker/single> (accessed 15/07/09). They define global apartheid as “an international system of minority rule whose attributes include: differential access to basic human rights; wealth and power structured by race and place; structural racism, embedded in global economic processes, political institutions and cultural assumptions; and the international practice of double standards that assume inferior rights to be appropriate for certain ‘others,’ defined by location, origin, race or gender”.

²⁰ As Dennis Altman notes, “The common rhetoric around inequality in access to healthcare tends to reflect a rather simplistic analysis of imperialism, in which ‘developing’ countries are seen as powerless in [the] face of the dominant capitalist order.” (Altman, Dennis, ‘Globalization, Political Economy and HIV/AIDS,’ in Jeffrey Weeks, Janet Holland, Matthew Waites (eds.), *Sexualities and Society: A Reader* (Cambridge: Polity Press, 2003) at 191)

²¹ Indeed, Baxi explains the complexities of this process using a market analogy: “The raw material for human rights investment and consumer markets is provided by here-and-now human misery and suffering. However morally deplorable, it is a social fact that the overall human capacity to develop a fellowship of human suffering is awesomely limited... [The]human rights markets, no matter whether investor [e.g., governmental, corporate, community] or consumer [e.g., NGOs or funding agencies], are confronted with the problem of ‘compassion fatigue’. This is a moral problem, to be sure, but it is also a material problem....” (Baxi, Upendra, ‘Voices of Suffering and the Future of Human Rights,’ *Transnational Law and Contemporary Problems*, Vol.8, No. 2 (1998), pp.125-169, at 159)

individual agency and are therefore able to shape significantly their trajectories. So while the access to treatment and PLWHA rights movements in Africa are rightfully linked to external, globalized economic issues, a substantial role is also foreseen for Africans in their solution; the accomplishments of home-grown activists and NGOs seem testament to this. The reality and scope of such autonomy may be arguable but post-independence Africans are undoubtedly less directly susceptible to the whims of overseas imperial powers, certainly when it comes to the application of the corporal violence, through brute force or bonded labour, that was a leitmotif of colonialism.

But the discourse of dominance, exemplified by the colonial/indigene dynamic, has been less easy to shift even with issues as morally compelling as healthcare and HIV/AIDS, and is arguably reinforced with every humanitarian or public health crisis. The popular identities persist: the suffering black African, often perceived as author or catalyst of her own misfortune, is seen as helpless and in need of assistance; and the white European saviour compelled to ride to her rescue. Once again, intervention is the latter's duty and despite the former's resistance, it must be undertaken for her own good, even when the remedy may be detrimental: witness the Structural Adjustment Programmes (SAPs) of the 1980s and 1990s²² or the pro-abstinence policy of US President George W. Bush's Presidential Emergency Plan for AIDS Relief (PEPFAR), more of which in Chapter 7. And despite a noted lack of transparency and local accountability in the processes of foreign-based development actors, "[p]rescriptions of good governance are discriminatorily-and viciously-addressed only to states and communities outside the core Euro-Atlantic states," a sceptical Baxi notes.²³ Indeed, Celestine Nyamu-Musembi and Andrea Cornwall argue that overseas-based aid agencies, among the most vociferous advocates of the de rigueur rights-based approaches to development today, often underplay the highly politicized history of the colonial era because their own relationships to their beneficiary States are framed by this problematic history.²⁴

²² See, for instance, Mohindra, K.S., 'Healthy Public Policy in Poor Countries: Tackling Macro-economic Policies,' *Health Promotion International*, Vol. 22, No.2 (2007), pp. 163-169. See also Nzomo, Maria, 'The Political Economy of the African Crisis: Gender Impacts and Responses,' *International Journal*, Vol. 51, No.1 (1995-1996), pp. 78-102, at 82-3.

²³ Baxi (n 21), at 167

²⁴ Nyamu-Musembi, Celestine and Cornwall, Andrea, 'What is the 'Rights-Based Approach' All About? Perspectives from International Development Agencies,' *IDS Working Paper 234* (Institute of Development Studies (IDS): Brighton, Sussex, November, 2004), at 7

John Comaroff and Jean Comaroff analyze the ideological fervour of the influential civil society organizations (CSOs): the *'Idée'* of 'civil society' (discussed in Chapter 7), they argue, embraces terms that "have a highly charged history in a continent still struggling to extricate itself from a century of European rule; from a cultural imperialism styled, literally, as a civilizing mission, whose telos lingers on in the paternalism of both the 'charity business in Africa' and the ideologically saturated "development" industry."²⁵ L. Muthoni Wanyeki, writing shortly after the 2005 G8 meeting at Gleneagles, Scotland, echoed the imperative to locate these movements within Africa's recent history:

'[D]o-gooding'...is the only way in which [British aid organisations] are able to frame the discussion. History has gone out of the window. Yet the impoverishment of Africa is not ahistorical – it is the result of a political-economic positioning in the world that dates back beyond colonisation to slavery. ...The question then is how the debate around the G8 summit could have become such an ahistorical debate? What lies behind our push for the deals on aid, debt and trade is an immense awareness of our history. We may not talk about it. But we live with its continued presence every day. ... What lies behind their push is a desire to forget, ignore – or worse, deny – history. And thus it is possible for the debates to proceed with nary an African in sight.²⁶

Yet more issues surface which have resonance with the colonial experiences of many black Africans: the sensitive debate about the origin of the disease itself, believed by many to be central Africa, Joseph Conrad's very Heart of Darkness, but a debate in which many of those in the health sector would rather not engage. James Chin writes of his attempts to broach the issue: "I believe that 'mainstream' AIDS organizations generally accept Africa as the most likely origin of HIV, but they are all acutely aware of the international sensitivity this issue causes, especially among Africans. When and if asked about the origin HIV, these organizations state that the origin of HIV is irrelevant to the problems at hand...", that is, the prevention of infection and treatment and care of the infected.²⁷

²⁵ Comaroff, John L. and Comaroff, Jean, 'Introduction,' in Comaroff, John L. and Comaroff Jean, (eds.), *Civil Society and the Political Imagination in Africa: Critical Perspectives* (Chicago: University of Chicago Press, 1999), at 2

²⁶ Wanyeki, L. Muthoni, 'Poor Africa, Darling of the West,' *The East African*, 11th July 2005. Wanyeki was then-Executive Director of the African Women's Development and Communication Network (FEMNET)

²⁷ Chin, James, *The AIDS Pandemic: The Collision of Epidemiology with Political Correctness* (Oxford; Seattle: Radcliffe Publishing, 2007) at 27

Moreover, the HIV epidemic thrust onto centre-stage a controversial subject in colonial discourse: Western notions about African sexuality. To 19th Century Europeans, Africans were possessed of a rampant sexuality, which, alongside their 'unsanitary' customs and practices, was proof of an innate barbarity which further justified the European 'civilizing' mission.²⁸ The plight of Saartjie Bartmann, a Hottentot woman paraded around Europe as a freak of nature because of her physical features, uncommon in a European context, is a good example. Even her remains were a curiosity, "her genital matter fingered by inquisitive European men who believed that her pickled organs held secrets that would reveal the mysteries of the 'dark continent' of African female sexuality."²⁹

Some prominent Africans saw similar patterns of thought emerging in the way sub-Saharan Africa's HIV/AIDS epidemic was being characterized. In 2001, South African president Thabo Mbeki, who, as will be seen in Chapter 6, was rightly criticized for his response to the epidemic there, denounced those he said were "convinced that we are but natural born promiscuous carriers of germs, unique in the world. They proclaim that our continent is doomed to an inevitable mortal end because of our unconquerable devotion to the sin of lust."³⁰ Widely-reported sexual and cultural practices which have been blamed for fuelling the spread of the infection encourage the views that Mbeki denounces. An example is 'dry sex', the use of powders, papers, dry leaves, etc, to dry out and tighten the vagina prior to sex, apparently to heighten male sexual pleasure. Although more prevalent in central and southern Africa, it has been documented among commercial sex workers in Kenya and the economic imperative that often spurs it revealed.³¹

²⁸ Seckinelgin, Hakan, 'Time to Stop and Think: HIV/AIDS, Global Civil Society, and People's Politics,' in Glasius, Marlies, Kaldor, Mary and Anheier Helmut, (eds.), *Global Civil Society 2002*, (Oxford: Oxford University Press, 2002) at 113. See also, Vaughn, *op. cit.*, and Butchart, *op. cit.*, and UNAIDS, *HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes*, UNAIDS Best Practice Collection, 2005, http://data.unaids.org/publications/irc-pub06/JC999-HumRightsViol_en.pdf, accessed 10/03/10, at 8

²⁹ Holmes, Rachel, *African Queen: The Real Life of the Hottentot Venus* (New York, NY: Random House, 2007) at 112

³⁰ Quoted in Epstein, Helen, *The Invisible Cure: Africa, The West and the Fight Against AIDS* (New York, NY: Farrar, Straus and Giroux, 2007), at 150

³¹ A study in Meru in Eastern Province found that 36.1% of the 147 female sex workers interviewed participated in the practice because it often attracted a greater fee, with many personally initiating it and performing it without a condom although the vast majority of them recognized that it exposed them to greater risk of HIV infection. (Schwandt, Michael, *et al*, 'Anal and Dry Sex in Commercial Sex Work, and Relation to Risk for Sexually Transmitted Infection and HIV in Meru, Kenya', *Sexually*

Other practices considered risky, such as wife-inheritance and female circumcision, are more ingrained in cultural rituals among some communities, and the latter in particular, attracted strident British colonial opposition and equally vociferous support from the likes of Jomo Kenyatta.³² Even today, opponents of these practices are accused of cultural chauvinism and condemned as brainwashed African lackeys of the former imperial masters. While one Kenyan female MP publicly criticized in 2005 the forced 'female genital mutilation' of some schoolgirls in Kenya's north-west, a few months earlier some of her male counterparts, sensitive to how the issue might play out among their constituents, eventually fought successfully to have a proposal to abolish the practice excised from the then-circulating Sexual Offences Bill.³³

The above are only a few of the issues that converge in the AIDS debate, which, as Barnett and Whiteside point out, "mixes sex, death, fear and disease in ways that can be interpreted to suit the prejudices and agendas of those controlling particular narratives in any specific time or place."³⁴ Colonial notions about African sexuality have shaped the epidemic in Kenya and elsewhere in Africa in two ironic ways: firstly religious leaders and self-proclaimed guardians of African culture have cast themselves in opposite roles to those that Mbeki, above, appoints for them albeit with disapproval. Like the condom-burners in Nairobi's Uhuru Park they see themselves as the true and modern custodians of moral standards and the West, with its liberal sexual attitudes, as morally depraved. They exercise the formidable power of production and authentication of African identity (which amounts to power to certify candidates for the crucial, alternative site for citizenship and rights that is the customary). They reject as 'unAfrican' methods of HIV prevention which do not prioritize abstinence, seeing them as a Western attempt to subvert African moral probity. Unfortunately, this has created fertile ground for the rejection and stigmatization of PLWHAs, their infection perceived as manifestations of their moral depravity and therefore, according to some, deserved.

Transmitted Infections, 21st June 2006, at <http://sti.bmj.com/cgi/rapidpdf/sti.2006.019794v1>, accessed 21/05/08), at 7)

³² Kenyatta (n 9), at 131-134

³³ Beth Mugo, MP, 'FGM is Barbaric and Retrogressive,' Letter, *The Daily Nation*, 25th July 2005

³⁴ Barnett, Tony and Whiteside, Alan, *AIDS in the Twenty-First Century: Disease and Globalization* (Basingstoke, Hampshire; New York, NY: Palgrave Macmillan, 2006), at 71

Secondly, the Victorian attitudes towards sex and disease, largely promulgated by the missionaries who operated most of the early biomedical health facilities, shadow modern attitudes about sexually transmitted illnesses and hamper efforts to bring the epidemic out of the shadows in which it thrives. This point bears emphasizing: Vaughn observes that some Europeans interpreted as signs of lack of shame, uncontrolled and dangerous sexuality, and savage innocence Africans' readiness to present themselves for treatment for sexually transmitted illnesses.³⁵ Arguably, the success with which notions of shame became coupled with sex and sexuality is one of the colonial period's most enduring legacies: they have helped fuel the very AIDS epidemic in Africa at which many in the West throw up their arms in frustration. The secrecy and stigmatization which shame encourages leads many to resist HIV testing and the possibility of treatment.³⁶

Colonial ideas about African sexuality were only one element of the broader attempt to define and delineate the African subject. These efforts would find form, to devastating and lasting effect, in the language and processes of law.

III. Colonization and the Construction of (Legal) Subjectivities

The process of creating indigenous legal subjects was continuous and often contradictory: the former because the distinguishing elements persist³⁷, and the latter because, as Mbembe notes, the colonial State in its exercise of power retained its capacity to treat indigenous people both as objects and subjects of the law, a gap that he argues was never bridged. As a component of indirect rule, British law was deemed "too 'advanced' for the level of evolution reached by the Africans of

³⁵ Vaughn (n 17), at 150

³⁶ Only 37% of 15-to-49-year-olds in Kenya know their HIV status. (WHO/UNAIDS/UNICEF, *Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector, Progress Report 2009*, 2009, http://data.unaids.org/pub/Report/2009/20090930_tuapr_2009_en.pdf, accessed 10/04/10, at 22)

³⁷ Megan Vaughn briefly critiques of some theories on the notion and construction of the subject. Of particular relevance here are those in which the identity of the colonial subject, the African 'other', is based on established dichotomies of race, ethnicity, gender, sexuality, power relations (oppressor/oppressed) and so forth. She argues that in using the objectified definitions produced by the colonial apparatus to identify a postcolonial subject, one is necessarily reproducing rather than displacing these restrictive binary distinctions. (Vaughn (n 17), at 1-4)

Kenya...”³⁸ Thus, a plural system of law operated, which, as will be seen in later discussions, continued post-independence. White settlers alone comprised the citizens- the civil society- of the colonial State. In this realm, they enjoyed the rights and freedoms of modern civil law, including the limitation of State power.³⁹ The colonial administration clothed this differential treatment in familiar paternalistic language. Mbembe writes:

“As for the native, docilely caught up in the family guardianship, he or she can only think of his/her enfranchisement at his/her own risk and peril. For a native (or a protégé) cannot be a subject of law. Consigned unilaterally to a sort of minority without foreseeable end, he/she cannot be a subject of politics, a citizen. Since the notion of citizen overlaps with that of nationality, the colonized being excluded from the vote, is not being simply consigned to the fringes of the nation, but is virtually a stranger in his/her own home, the idea of political or civil equality- that is, of an equivalence among all the inhabitants of the colony- is not the bond among those living in the colony.”⁴⁰

The indigene would be governed through customary law, in a social and political sphere administered by the Native Authority; here she would be allowed to become a legal subject.

Customary authority in the rural areas was based in the local State.⁴¹ The colonial Native Authority, created to control the often violently resistant indigenous peoples⁴² and to better exploit the agricultural and human resources in the new colony, comprised the offices of remodelled chieftaincy, Native Tribunals and Local Native Councils; the first two were particularly instrumental in the formulation of customary law.⁴³ Their creation received legal assent through a succession of Native Authority ordinances from 1902 onwards.⁴⁴ The themes explored in the previous chapter, which bonded Africans to their ancestral land, kinship group and the patriarchal system, were employed by the colonial administration to emphasize their difference from the

³⁸ Berman (n 16), at 214

³⁹ Mamdani (n 2), at 109

⁴⁰ Mbembe (n 12), at 35. He describes the relationship of the native to the colonial State as one in which the State, in its infinite goodness, projects a sense protectiveness over the native, who is, as such, its protégé. This protectiveness, in reality, is just another reminder to the native of the State’s power over him: its ability to switch from benevolence to brutality feeds the image of awe and terror in the native.

⁴¹ Mamdani (n 2), at 23

⁴² About a third of the British Protectorate’s budget for the first nine years after its creation in June 1895 was sunk into military campaigns geared towards subjugating indigenous peoples either through force or diplomatic means (Berman (n 6), at 52)

⁴³ *ibid*, at 208

⁴⁴ *ibid*, at 54

white settler community and therefore justify the differential legal treatment. But although advertised as replications of traditional power structures to legitimize them to the Africans, their character, role and modus operandi was a hybrid of both the new and old, with the former increasingly supplanting the latter. The character and processes of these weak, co-opted chieftaincies and native authorities were considerably arbitrary, as the colonizers consciously sought, unsuccessfully, to “drag [them] into the muddle of amoral civic public politics...”⁴⁵ As will be seen later, an emergent African bourgeois class, whom the colonizers determinedly tried to subvert in the tried-and-tested British policy of ‘divide and rule’, exploited and thrived in this flux.⁴⁶

Two contradictory philosophies, both instrumental in the construction of subjectivities, provided the rationale for the creation of the Native Authorities: on the one hand, all indigenous peoples, because they are of one race, are lumped together to facilitate a uniform policy of exclusion.⁴⁷ The overarching idea is the reaffirmation of tradition as the source of legitimacy⁴⁸; longstanding cultural differences are suppressed, submerged under a collective label of ‘the native’ and presented as nullified. As Mamdani puts it, the policy “grounded racial exclusion in a cultural inclusion.”⁴⁹ Various actors were involved in this deliberate process of manufacturing new native identities.⁵⁰ Yet on the other hand, even while highlighting the homogeneity of the indigenous population, the Native Authorities and customary laws were allowed to be as distinct and variant as the specific ethnic groups to whom they applied. Mamdani again: “Customary law was defined in the plural, as the law of the tribe, and not in the singular, as a law for all natives. Thus there was not one

⁴⁵ Ekeh (n 7), at 104

⁴⁶ Ibid, at 103-4

⁴⁷ Mamdani writes: “...[N]ative was not used to mean a person whose life had historically been governed by the customary law in question, but as a blanket racial category.... The point was to cast the net wide enough to catch within its fold every person with any trace of African ancestry. The objective was to arrive at a racial definition, not a cultural one.” (Mamdani (n 2), at 111)

⁴⁸ Ekeh (n 7), at 103

⁴⁹ Mamdani (n 2), at 112

⁵⁰ John Comaroff describes just such a process by British colonists in southern Africa. The identity they created was distilled from “complex, drawn out historical processes” and “re-presented by the evangelists back to the Tswana themselves (in their schools, courts, churches, and other contexts)- and then to the whites of colonial South Africa.... ‘the Bechuana’ were portrayed as a people governed by the primal sovereignty of their ‘custom’”, with little account taken of the heterogeneity of their identity.” (Comaroff, John, ‘The Discourse of Rights in Colonial South Africa: Subjectivity, Sovereignty, Modernity’, in Sarat, A. and Kearns, Thomas R. (eds.), *Identities, Politics and Rights* (Ann Arbor: University of Michigan Press, 1995), at 217)

customary law for all natives, but roughly as many sets of customary laws as there were said to be tribes.”⁵¹

These deliberate policies underline the centrality of individual and collective subjectivity to (re)imagining notions of obligation, entitlement and rights. The right to shape subjectivity is part and parcel of power struggles. They also emphasize the fact that subjectivity is mutable and manipulable; as later chapters demonstrate, it is a characteristic that PLWHA rights advocates have exploited in their efforts to transform PLWHAs’- and by extension public- perceptions of HIV sufferers as undesirable members of society whose apparent violation of sexual norms may negate their claims to entitlements or rights.

The role and processes of the Native Authority and its State overseer, the Provincial Administration (PA), in constructing the customary sphere and exercising State power at the grassroots is germane to this research for two connected reasons: firstly, it offers crucial insights into the inculcation and evolution among indigenous Africans of notions about the State. The PA’s operations projected certain characteristics of the central State and its relationship with the individual, and many of these often negative attributes are still associated with the State today, as several PLWHAs’ responses demonstrate shortly. This analysis is all the more important because it provides a framework for understanding post-independence power relations and attitudes towards the idea of a citizen-subject with allegiances to the dual power-bases of the centrally-ran State and local, traditional authority. This is pivotal in gaining an appreciation for how messages about rights, duties and entitlements were internalized by indigenous Africans throughout the colonial and post-independence period. Secondly, it provides a glimpse into the cooption of Africans into the machinery of the State and the gradual breakdown of the traditional social structures described in the previous chapter.

Managing and containing the indigene involved not only the demarcation of the real space she occupied but the construction, too, of the legal and imaginary space of the customary. This latter process was one of the main arenas for colonial and

⁵¹ Mamdani (n 2), at 22

postcolonial Kenya power contests. Key actors included the chiefs who, along with the central State, which retained the right to expunge laws that it deemed “repugnant to justice and morality”, competed for the right to define what was customary.⁵² The colonial administration hoped that the co-operation of the traditional African institution of the chieftaincy would ease wider community resistance.⁵³ Yet the chieftaincy had been massively transformed in the colonial era: its military and economic authority had dwindled, with the colonial State dominating the former and the reconfiguration of market relations effecting the loss of the latter.⁵⁴ To this extent, even as it based its claims for legitimacy in the familiar, the customary, the new chieftaincy was effectively “almost wholly [a] creation of the colonial state.”⁵⁵

A potent new power underwritten by the might of the colonial State, it had the sole responsibility of moulding custom, the very foundation of this native sphere, a role previously shared with other traditional institutions such as councils of elders. As Mamdani observes, “[c]ustomary law thus consolidated the non-customary power of colonial chiefs.”⁵⁶ All these changes to the chieftaincy, as will be seen shortly, altered the relationship between traditional institutions and their subjects and bred distrust of institutions of authority.⁵⁷ Many local administration officials took advantage of their new-found powers to amass personal wealth. It was noted that “the first generation of chiefs [used] their positions to acquire mostly the traditional forms of wealth in wives, livestock, and land, although by the 1920s the richest aspired to automobiles, European-style clothing and houses.”⁵⁸ Chiefs also exploited their key role as arbiters of custom to authenticate those customary rights which augmented

⁵² *ibid*, at 115

⁵³ Berman (n 6), at 208-9. Among those tribes where power was vested in alternative institutions such as dominant clans, lineages or individuals, the colonial administration sought these out instead. The key was to invest newly-defined powers to pre-existing offices or authorities recognizable to the local population.

⁵⁴ Mamdani (n 2), at 122

⁵⁵ Berman (n 6), at 209

⁵⁶ Mamdani (n 2), at 122

⁵⁷ Kenyatta writes of the attitudes towards the new chiefs, now chosen by the colonial administrators: “The Gikuyu people do not regard those who have been chosen over their heads as the true representatives of the interests of the community. No one knows this better than the chiefs themselves.... The Gikuyu knows perfectly well that these chiefs represent a particular interest, namely, the interest of the British Government, and as such they cannot expect popularity from the people whom they help to oppress and exploit.” (Kenyatta (n 9), at 196)

⁵⁸ Berman (n 6), at 212

their positions, particularly over those of low social standing.⁵⁹ And as long as the flow of labour and production was not impeded and social control of the native population maintained, the colonial administration largely turned a blind eye.⁶⁰ Indeed, Mamdani writes of a shift in emphasis from “the search for good laws... to one for effective authorities.”⁶¹ The chieftaincy was therefore legitimately viewed as an extension of colonial power; under these circumstances, imposing custom was synonymous with imposing State power. A similar policy of prioritizing administrative over conflict resolution functions was exercised by the new-fangled Native Tribunals.⁶² Ghai and McAuslan argue that this created tensions in the legal system that survived the end of colonialism.⁶³ This rightly roots the weak popular support for postcolonial legal and other State institutions in the colonial era, accentuating their competitive relationship with ethnic or customary institutions.

Individually or collectively, the various arms of the Native Authority significantly influenced the early impressions of indigenous Africans about this new creation, the State. The exercise of power by local officials within or without their officially-prescribed limits would have sent certain signals to indigenous subjects. One was of the power of the State: indeed the PA, the authority most closely linked to the central State and therefore its most visible cipher in the native territories, was expected to

⁵⁹ Mamdani (n 2), at 122. Nevertheless, Berman states that these lucrative positions were not without their disadvantages: the new and sometimes contradictory roles of the colonial chief, as agents of control for the colonial State and representative of his people, placed immense personal and social pressure on some of them. Alcoholism and apathy were a common occurrence, with the chiefs’ tenure dependent on an Administration that was inclined to interpret some of the difficulties borne out of the newly-conceived roles of the colonial chief as incompetence on their part. (Berman (n 6), at 210)

⁶⁰ Berman, *loc. cit.* at note 52. Mamdani also gives some examples of the kind of rules that chiefs enforced as custom, which appear to be primarily geared towards easing the administration task of the colonial forces and helping sustain the economy. These include the payment of taxes and school fees and the maintenance of agricultural land. (Mamdani (n 2), at 123)

⁶¹ Mamdani (n 2), at 121. Indeed, Mamdani quotes Sir Frederick Lugard’s attempts at rationalizing this withdrawal into legal administration: he admits the real practical motive of the policy: “The separation of judicial and administrative power would be unnatural to the primitive African since they are combined in his own rulers.” He adds: “In a country recently brought under administration, and in times of political difficulty, occasions may arise when the strictly legal aspect may give way to expediency.” (at 125)

⁶² Native tribunals were a marriage of largely indigenous officials and procedures and the typical powers of sanction of a colonial system. (Ghai, Y.P. and McAuslan, J.P.W.B., *Public Law and Political Change in Kenya: A Study of the Legal Framework of Government from Colonial Times to the Present*, (Nairobi; New York: Oxford University Press, 1970) at 147) The extensive discretionary powers granted to the PA in the 1930 Native Tribunal Ordinance meant that they could continue to shape the emerging tribunals to fit the requirements of the colonial administration as they saw them. (Berman (n 6), at 214)

⁶³ Ghai and McAuslan (n 62), at 153

project its “key myths...: permanence, omnipotence and infallibility.”⁶⁴ Through the co-opted Native Authority, the colonial State had achieved such an overwhelming administrative control of the native populations by the time WWII began as to encompass the minutiae of their lives. Matters previously addressed within formal and informal traditional structures were diverted to the control of the remote colonial administration, further undermining traditional authority and social cohesion while alienating people from the institutions that governed them.⁶⁵

Secondly, the PA reflected the State’s paternalism, presenting it as guardian and protector of the indigenous population. But as Mbembe observes in quoting Albert Sarraut, this is yet another opportunity to display the power of the colonial State and exercise “‘the right of the stronger to aid the weaker.’ Colonial conquest, [Sarraut] specified, ‘is not the right, but the *fact* of one who is stronger; the true *right* of the stronger is the generous right that he assumes to help, assist and protect the weaker, to be his guide and guardian.’”⁶⁶ This protector image persists to this day. Asked if they thought the government should assist them in meeting their healthcare needs, some PLWHAs in this research even equated the government-citizen relationship to that of parent and child. Interviewee 14, for instance, declared that “[t]he government is our mother.”

To be sure, there were indeed tensions between the PA and the central colonial State, rooted in the former’s wide discretionary powers and the contradictory objectives of the broader colonial enterprise.⁶⁷ But the general message which

⁶⁴ Berman (n 6), at 204. There was no end to the practical tools made available to administrators to assist them in gaining a better ‘understanding’ of their indigenous subjects, for certain stereotypes of Africans generally, and others of particular tribes, were actively circulated: Kikuyus were regarded as intelligent and diligent but also “unstable and untrustworthy”; the Luo were “straightforward and stolid”; the Kamba “loyal and good-natured”; the Maasai were “the aloof ‘noble savage’”; the Giriama “backward and apathetic.” (at 206) The literary output from the members of white colonial society also reflects the widespread subscription to, and reproduction of these stereotypes: Christopher Wilson describes Africans as generally “lazy” and, without a hint of irony, prone to using brute force as the basis their power. Kikuyus are, once again, treacherous but now also prone to drinking. (Wilson, Christopher, *Before the White Man in Kenya: Abridged Edition of “Before the Dawn in Kenya.”* (London: McCorquodale, 1953)

⁶⁵ Mamdani (n 2), at 119 and 123. See Kenyatta for the types of disputes among the Gikuyu that would be addressed in traditional forums. (Kenyatta (n 9), at 214-230)

⁶⁶ Mbembe, *loc. cit.* at note 37. Upendra Baxi remarks, too, on the employment of the malleable language of rights by colonizing States to justify the politics of domination. (Baxi, *op.cit.*, at 135)

⁶⁷ The State’s and settlers’ need for cheap African labour to drive colonial production, explained earlier, and the especially brutal manner in which such labour was extracted, as well as harsh tax

filtered through to many Africans at the local level where they interfaced with State institutions would have been shorn of the subtleties of any power contests between the PA and the central State. The impression would have been that the rules applied by the local authorities emanated from or were backed by a powerful, remote source, the mystique being yet another exercise of power.

But despite promoting a caring image, Ann Beck notes the low prioritization by the colonial State of genuine development and improvement of indigenous welfare. She remarks upon its reluctance to allocate funds even to public health services for Africans, especially during the war years, which, except where they may serve a political purpose⁶⁸, were not seen as “necessarily revenue producing.”⁶⁹ Further, in the fulfilment of that civilization remit of the colonial enterprise, the State and other institutions like the church provided vocational training and a “literary” Western education. The starting point of this exercise, however, as Kenyatta notes, was always imperialistic and paternalistic, rejecting traditional modes of education and their philosophical objectives.⁷⁰ And despite growing demand from Africans for these services because of the opportunities they opened up in the new labour market, the State’s leadership role here was ultimately driven by its own demands and those of the settler community.⁷¹ Indeed, the emerging educated class of young ‘detrribalised’ African men was later identified as posing a serious challenge to the State-endorsed local authorities and wider State control, and education criticised as the tool by which

policies targeted at indigenous peoples, directed at neutralizing the considerable competition in labour and production that African peasant farmers, was condemned by the PA. (Berman (n 6), at 59) The PA saw the State’s response as potential catalysts for unrest amongst the native populations. They advocated the protection of some African economic enterprise, which was an integral part of the rewards aspect of their administrative system.

⁶⁸ Beck, Ann, *Medicine, Tradition, and Development in Kenya and Tanzania, 1920-1970* (Massachusetts: Crossroads Press, 1981), at 17

⁶⁹ *ibid*, at 10. She adds that “it did not help to point out that a part of the money spent on medicine was retrieved through “invisible returns by better labor productivity as the result of better health.”

⁷⁰ Kenyatta (n 9), at 126

⁷¹ Berman (n 6), at 225. Africans like Oginga Odinga, a central figure in the independence movement spoke of the deliberately divisive aim of educating Africans, as it “created a category of educated men who were easily tamed because they had lost their moorings within African society... ” (Odinga, Oginga, *Not Yet Uhuru: An Autobiography*, (London: Heinemann, 1967) at 68). This is an interesting comment from a man who benefitted from the system and who would become a key member of Kenya’s ruling elite and father of an enduring political dynasty, especially in light of Ekeh’s assertion that its Western-acquired education was the basis on which the African bourgeois class sought- and managed- to convince lay Africans that it could and should take over the reins of power from the white colonial government. (Ekeh (n 7), at 102). Like Odinga, he declares the educated African even more susceptible than the uneducated ones to colonial ideologies of legitimation. (at 100)

this menace had been unleashed.⁷² Some commentators also noted the negative effect that a more politically-aware class of African was having on the running of the settler economy.⁷³

Thirdly, the corruption and arbitrariness with which Local Authority branches applied their rules and dispensed their duties became yet another characteristic associated with the State, despite the State's ostensible claims of being bound by the rule of law.⁷⁴ Okoth-Ogendo notes, for instance, that Local Native Councils, "although controlled and manipulated by colonial administrations... left a permanent imprint on African political behaviour in that they were the first to institutionalize ethnicity as a criterion for political leadership and affiliation."⁷⁵ Native Tribunals, too, operated with limited supervision from, or rights of appeal to, centrally-ran judicial organs, for example, and the native experience of the State-sanctioned machineries of justice was thus often negative.⁷⁶ A report on Native Tribunals found certain procedures direct contraventions of basic legal principles, such as the imposition of non-indigenous penal sanctions for the violation of native criminal laws previously settled through compensation.⁷⁷ The use of favours and patronage to oil the local administrative machinery was widespread and encouraged unmitigated corruption.⁷⁸ While patronage had long been used to secure loyalty and co-operation in traditional African society, there was a significant difference in the use of bribery and corrupt

⁷² Berman (n 6), at 239-40

⁷³ A. J. Schwelm, advocating for more emigration of Englishmen to the colonies, wrote, "... [T]hanks to modern educational methods it quickly becomes clear to the natives that, so far as they are concerned, this type of colonisation [in which colonisers employ cheap labour to do the bulk of the manual work] is nothing but a modern system of exploitation of human beings, and they therefore steadily increase their demands, so that profits are necessarily reduced. In this connection the influence of Christian missionaries had made itself greatly felt... and this explains why in many parts of the world missionaries are to be found siding with the heathen native rather than with the Christian colonist." (Schwelm, A. J., *Some Thoughts on Colonization: An Address Delivered at the Royal Empire Society*, (London: Barker, 1932) at 9-10

⁷⁴ Mamdani (n 2), at 125

⁷⁵ Okoth-Ogendo, H.W.O., *Tenants of the Crown: Evolution of Agrarian Law and Institutions in Kenya* (Nairobi: Acts Press, 1991), at 161.

⁷⁶ Ghai and McAuslan quote a statement by Sir Barclay Nihill at the Africa Bureau Conference on Kenya and Britain in May 1956 in which he said, "I am not sure that the average African [in Kenya] has quite the same confidence that the British is there in order- not only to punish him- but to protect him. He is more likely to regard the whole system as just another government department that is there to join in the general power of coercion." (Ghai and McAuslan (n 62), at 173-4)

⁷⁷ Ghai and McAuslan, *loc. cit.*, at note 60. Ghai and McAuslan detail the failed efforts to reform the Native Tribunals, which were scuttled by successful demands from administrative officials for leeway in the exercise of their administrative duties.

⁷⁸ See variously Mamdani (n 2), and Berman (n 6). Also Ghai and McAuslan (n 62), at 152-3

practises by agents of the colonial government to augment their official income and strengthen their local powerbases. For the traditional structures which regulated patronage and which tied it to a broader system of duties and responsibilities within the clan or kinship group had been significantly decimated. Such a system rendered these practices an acceptable, perhaps even a necessary service to social cohesion. The colonial offices, however, had no wider obligations or social function beyond the private enrichment of the local agents and those within their “semi-official politico-administrative apparatus.”⁷⁹ Most African States, including Kenya, maintained this characteristic after decolonization and today “[l]ocal and state governments remain exclusionary in their norms and practices, and the rights and privileges they confer on the people.”⁸⁰

A fourth defining characteristic of the State, which is closely allied to the application of arbitrary, oppressive methods by its agents in the customary sphere, is the use of coercion. This significantly differentiated the encounter of State power between the citizens in the civil sphere and subjects in customary. Mamdani writes:

Customary law was never concerned with the problem of limiting state power, only with enforcing it. Liberal theory emphasized the double-sided character of the law, that while it came from the state it also restrained power. Power was said to be grounded in consent. State command was presumed to be rule bound, not arbitrary. This was the meaning of the claim that civil society was framed by the rule of law. None of these claims, however, sounded sensible where power sought to secure order through conquest, not consent.⁸¹

Mbembe further separates the violence applied by the State into three types: firstly, that used in its conquest of territory; secondly, that required to transform the original violence into a legitimizing, effective authority; finally, that necessary to maintain and spread this authority.⁸² And yet alongside this brutal reality is the fantasy sold by the colonial State not only of a free African subject, her autonomy enabled and guaranteed in the safety of the customary realm, but of a State that respected, encouraged and preserved that freedom.⁸³

⁷⁹ Berman (n 6), at 212

⁸⁰ Adejumo, Said, ‘Citizenship, Rights, and the Problem of Conflicts and Civil Wars in Africa,’ *Human Rights Quarterly*, Vol. 23, No.1 (2001), pp. 148-170, at 160

⁸¹ Mamdani (n 2), at 125

⁸² Mbembe (n 12), at 25

⁸³ It is a fantasy that finds appeal amongst some supporters of the colonial enterprise. Christopher Wilson, writing in 1952 at a time when the post-war clamour for the greater recognition of the rights

In reality, only the white, rights-bearing settler population in the civil sphere could make any real claim to be citizens: for while the perception of State power as rampant and selective in its magnanimity and malevolence took root in the customary realm, those in the civil realm experienced a form of State power that was bound and restrained by their civil laws. This bred feelings of resentment and mistrust about State officials, and doubts about the moral legitimacy of the State itself. The fact that the PA condoned methods which were so oppressive to so many meant that the character of the State as an avaricious entity beneficial only to a privileged few crystallized. Indeed, many PLWHAs' responses reflected such feelings about the conduct of the State both at the national and local levels. Their views regarding the central government's efforts to tackle the AIDS epidemic and related issues will be addressed in more detail in later chapters, and illustrate the enduring negative perceptions about State conduct. But many of them are similarly scathing about the local government officials, who represent the otherwise remote centralized State, such as the various agents like that colonial remnant, the PA.⁸⁴ It is therefore instructive to analyze opinions about village elders, chiefs, District Officers (D.O.s) and other local administrative officials, henceforth LAOs, who today embody the State at grassroots level.

of Africans- and colonial State repression- was at its peak says: "Some Africans are prepared wilfully to distort the picture of the past, with the object of influencing others towards a reaction against present conditions. These are the people who talk of the 'bondage' of British rule and shout for 'freedom' for Africans. They know that the African has never been so free as he is now under British Administration." (Wilson (n 64), at 2)

⁸⁴ There were controversial proposals in the Harmonized Draft Constitution of Kenya, 2009, to dissolve the PA in a new system of devolved government that would be established under the new constitution. (See Seventh Schedule (Article 312) Transitional and Consequential Provisions, Provincial Administration, 10(1), Committee of Experts on Constitutional Review (CECR), *Harmonized Draft Constitution of Kenya*, 17th November, 2009, on the website of The Local Democracy, Peace and Human Security, University of the Western Cape, at <http://www.ldphs.org.za/resources/local-government-database/by-instrument/constitution>, accessed 12/03/10; at 189). The office seems to have survived the constitutional process, however, although but is scheduled for massive restructuring under devolved government. (Sixth Schedule, Art. 262, Transitional and Consequential Provisions, Provincial Administration, at 186. Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010*, 2010, Kenya Law Reports (www.kenyalaw.org), accessed 10/12/13. (Published by the National Council for Law Reporting, with the Authority of the Attorney General). The Draft Constitution also envisaged roles for many of the offices currently under the umbrella of the PA: "[C]hiefs, the assistant chiefs and village elders may continue as such under the county governments as may be determined by each county government." (Art 312, 10(3)). A restructured office of paramount chief, better paid and with more responsibilities, also seems on the cards under the new Constitution. (See *The Daily Nation*, 'Scheme to Give Kenya Chiefs More Powers Unveiled,' 9th September 2010)

Although interviewees for this research had very particular health needs, an area which does not immediately appear to be within the purview of the PA, the modern PA's main functions are broad and open to interpretation. They include: "[p]romotion of statehood and nationhood; development coordination in the field; maintenance of law and order; dissemination and interpretation of Government policies; peace building and conflict resolution in the field; monitoring and appraising of performance of Government departments/officers in the field; publication of all Government documents; championing campaigns against drug and substance abuse; and coordination of state functions."⁸⁵ Moreover, the unprecedented involvement with the minutiae of people's lives persists at the lower administrative levels, so that the State in guise of the PA may become intimately familiar with details such as an individual's HIV-status, as will be seen, and other health matters, as well as more typical affairs like land or family disputes. So responses about how, if at all, LAOs might assist PLWHAs with their health problems are also linked to broader perceptions about the general functions of the State and its obligations to citizens.

Indeed some PLWHAs saw a clear path connecting LAOs to the central State and executive power. For instance, interviewee 44 saw LAOs as "the first people on the ground in the path that that leads to the president. So if there is any assistance, it should pass through them. And truly, if it is my right to be assisted, then they should be compelled to help me." Interviewee 18 spoke of

...village elders and chairmen who are in charge of the welfare of a village. They should be involved so that chief can liaise with them. These village elders are the ones who should know how many sick people there are and take that information to the chief, the chief should then take it to the D.O. and the D.O. to his boss, so that we can find ways of helping those who are at home.

This notion was emphasized in a memorandum by members of the government, sent to the Committee of Experts on the Constitutional Review in response to the 2009 Draft Constitutions' proposals to scrap the PA.⁸⁶ There was also some awareness

⁸⁵ See the Ministry of State for Provincial Administration and Internal Security website, at <http://www.provincialadministration.go.ke/detail.php?op=3002>, accessed 12/03/10.

⁸⁶ The government, criticising the proposals in the Harmonized Draft Constitution of Kenya, 2009, portrayed the PA as the umbilical cord which links the executive power of the State to the grassroots. The Head of Public Service, Francis Muthaura, noted that the PA "plays a pivotal role in the running government affairs especially at the grass root levels, hence the need to continue having it in place." Permanent Secretary, Francis Kimemia, argued that the PA played a unique reconciliatory role during moments of Kenya's political turmoil, including the post-election violence in 2007/8. They nevertheless

among some PLWHAs of the importance of these local administrative offices: for instance, although she did not think they were assisting her, suggesting a nepotistic slant in the exercise of their duties, interviewee 8 nevertheless thought that:

The chief should know how many people in my home area have [the disease], how many are sick, and how are they supposed to be supported, through these NGOs... so you see the chiefs are very important but they are careless. They are the ones supposed to be talking to the D.O.s about how many people are sick and need to be attended to.

Many PLWHAs recognized the proximity of these officials to themselves and other people on the ground, and arguably the colonial exercise of implanting a consciousness about this new entity, the State, in everyday social and political life at the grassroots was successful.⁸⁷ These authorities have managed to adopt or maintain the traditional propinquity of customary authorities to the community, as responses to the question of where LAOs could and should assist with the health needs of PLWHAs revealed. For instance, interviewee 18 remarked that, "They should [help] because they are the ones who are closest to us." Interviewee 37 agreed: "Yes, because they are the ones who live with people in the villages and they know who has a problem." So, too, did interviewee 48, who thought, "They should [help] because they are the people who mingle with us in our daily activities." For interviewee 48, "They are the people nearest to me and they can help from above."

This seeding of consciousness about the State and membership national public becomes ever more important given the ethnic-based systems of authority that compete with the modern State for the allegiance of the citizen-subject, as will be seen presently. Yet the LAOs' privileged reach is simultaneously hamstrung by the negative attributes that people have come to associate with the State, negating its legitimacy; these, too, were articulated by several respondents, who generally

identified flaws in the system: "dictatorial, corrupt and illiterate officers from the Assistant Chiefs to Provincial Commissioners." (*The Daily Nation*, 'Government Strongly Defends Provincial Administration,' 15th December 2009)

⁸⁷ Indeed, a number PLWHAs demonstrated a willingness to engage with LAOs and seek assistance from them on a range of social and economic issues, although the results appeared invariably unsatisfactory. For instance, interviewee 36 decried the lack of initiative she saw in LAOs and wondered how they would be able to assist her when they had been inconsequential insofar as her other needs (lack of school fees and rent) were concerned. Interviewee 40, another who was weary of "a lot of corruption in this country," had a case pending at the local chief, a school-fees waiver request for an orphan (her nephew) under her care. She noted she was awaiting the outcome of this before she made up her mind about LAOs.

perceived LAOs as unwilling or unable to assist with their health needs despite the clear role they could play. Interviewee 15 said point-blank: “I don’t see this happening,” an opinion repeated elsewhere.⁸⁸ For some the issue was one of insufficient resourcing by the remote central State. Interviewee 3 declared: “In our country Kenya, presently, those are the harder people in the society [to engage]. Surely, they don’t even have the resources to talk about all these things.” This was echoed by interviewee 22 who said that LAOs “can’t help if there is nothing they are receiving so that they can give back to people.” This enhances a perception of the State as unconcerned and unresponsive to local concerns, drawing subjects ever closer into the primordial realm of Ekeh’s analysis; this discussion is taken up shortly and revisited in Chapter 8.⁸⁹ But others suggested that LAOs were plagued by a residual colonial-era problem which had resulted from the arbitrary, sometimes unsupervised exercise of State authority in the customary sphere: corruption. For instance, interviewee 39 insisted: “Those are people who if given money they’ll just eat... Maybe they should [help], that’s if they allocate the funds to help those with HIV instead of pocketing it for their own needs.” For interviewee 42, those unconnected to power had little access to State help:

Not in Kenya! I don’t think [they can help]. But you know how our country has been. People are not caring. Those fellows only take care of themselves. And even if you give aid to those poor people, it will not reach us. Never. They look after themselves. Say, even if these drugs were offered, if they went through the chief, he might try to sell them and get something for himself. So you see, they don’t mind the welfare of those who are not able to reach those drugs... [T]hey are the people who are supposed to be in the frontline to assist. But I don’t think they do it.

Interviewee 48 concurred:

No, no, no, no! I have never had trust in those people. You’ve seen that the money has just gone to the constituency (this with ref to an announcement that government would channel its AIDS support funds through parliamentary constituencies.) I am from Embakassi where David Mwenje is our MP. Things are stand-still. I even went to a meeting there sometime and told them I wished the donors would even come and

⁸⁸ “So far, no [they do not help], especially where I come from [in] Nyanza District (Western Kenya). Out of experience, I know they don’t. They think that they have their own burdens and don’t want to listen to other people’s.” (Interviewee 17)

⁸⁹ In an effort to devolve to individual constituencies the coordination of various AIDS-related activities, in December 2003 the president launched Constituency AIDS Control Committees. These were meant to provide a focal point for multi-stakeholder actions at local level. (See State House Kenya, *Speech by His Excellency Hon. Mwai Kibaki... on the Occasion of the Launching of the Constituency AIDS Control Committees and the Pamoja Communication Campaign Strategy at the KICC*, 1st December 2003, at <http://www.statehousekenya.go.ke/speeches/kibaki/dec03/2003011201.htm>, accessed 02/03/10). However, as highlighted in Chapter 4, these have been plagued by reports of financial mismanagement and corruption by State officials.

take the money back to their countries other than giving it to Kenyans who know what is going on and cannot help their people.

Indeed, local authorities or the Ministry for Local Government have often been consistently cited as one of the worst offenders in Transparency International Kenya's index of the country's most corrupt organizations; a 2008 survey placed the PA in sixth position.⁹⁰ It revealed that 76 % of respondents seeking assistance from the organization encountered a bribery demand⁹¹; 5% paid up⁹², without which there was a 42% chance, the second-highest among the organizations, of being denied service or incurring a penalty, whether or not it was deserved.⁹³ Each respondent who interacted with the PA reportedly paid an average of three bribes to the organization⁹⁴, with the average bribe valued at Ksh.816⁹⁵, approximately GBP 6.30 per exchange rates at the time the surveys were conducted⁹⁶, a considerable sum considering that over half of respondents declared a monthly household income of less than Ksh.10,000⁹⁷, approximately GBP 77.90.

One respondent, interviewee 16, related the challenges of trying to get involved in local meetings about PLWHAs' welfare.

I had gone to the D.O. about a month ago. They keep telling they're having meetings.... So I ask if I can attend and they say 'no' and because they have the money, they just want to 'eat' the money. So I am wondering how they can sit there and discuss PLWHAs and they are [HIV-] negative and don't know how we feel or what we want. Yet we want to participate. They tell me to leave my contact details with them but you just hit a wall.

Others raised concerns about confidentiality, specific to PLWHAs. For instance, interviewee 30 said:

[LAOs] are people who help only in spreading the word that so-and-so is ill. And you will not get help from them. I went back home recently and heard that a few things had been brought for HIV patients: blankets, food and so on, especially those who

⁹⁰ Transparency International Kenya, *The Kenya Bribery Index 2008*, 2008, at <http://www.tikenya.org/documents/KenyaBriberyIndex08.pdf>, accessed 10/10/09, at 16. The survey involved a random sample of 2,400 respondents from all of Kenya's 8 provinces, with a 56%-46% rural/urban and male/female distribution. (at 5)

⁹¹ *ibid*, at 17

⁹² *ibid*, at 19

⁹³ *ibid*, at 20

⁹⁴ *ibid*, at 22

⁹⁵ *ibid*, at 24

⁹⁶ See Forex in Kenya, at http://www.forexinkenya.com/FOREX_GBP.aspx, accessed 10/10/09)

⁹⁷ Transparency International Kenya (n 90), at 6. In fact, 19 % declared monthly household incomes of between Ksh. 10,000 and 24,999, 28% Ksh. 5,000-9,999 and 23% of less than Ksh. 4,999.

have been left with orphans. Their names were registered. But I do not want to register with them in my District because I believe they will just use that information and spread it around.

Interviewee 19 agreed: You know sometimes you keep silent, you don't want to expose yourself to people. Now, if you tell the chiefs, you will be exposed, won't you? You know if you have these things [the disease], they take it badly." For interviewee 11, some officials were unconcerned about individual needs: "I don't think they care much and they give appointments they don't keep...And then on top of that he goes and spreads the rumours in the whole village." These gave a sinister tone to the State's proximity to the individual, a situation which LAOs' access at local level facilitated. This presents a dilemma for PLWHAs who may want to seek help if it were indeed available but fear exposure. As interviewee 41 said, "I can't say [whether they can help] because I have never asked or disclosed my status to them."

A few, however, thought that LAOs were ideally-placed to address myths about HIV/AIDS, which fuel stigma against PLWHAs, precisely because of their nearness and access to individuals on the ground, suggesting chiefs' *barazas* or forums as an ideal setting. Interviewee 38 felt that LAOs should be involved in "talking about AIDS. In fact, during their *barazas* they should tell people, 'even if you've seen a lady, you should think twice.'" However, she was doubtful whether they can offer to most the kind of help that most really needed, that of the material variety: "Because many are sick, your burden is your burden," she concluded. Interviewee 14 voiced similar opinions: "They should [help] at community level because they can sensitize the people around, they can help those who are ignorant access help and because there are so many people who don't know what to do with themselves, may be they can be helped at that level." This may fall within a core PA function, disseminating and interpreting government policy, at which interviewee 16 suggested they were already failing. She said:

[They can help by] making awareness campaigns, because I don't think they have raised enough awareness campaigns about HIV/AIDS..., mostly young people.... With all this money in circulation, why are they buying big cars and growing fat, yet we are only getting thinner and thinner and dying? We should just put that money where it's supposed to be. If it's about buying ARVs, we should buy ARVs, if it's food supplements, the same. If it's cheap drugs from India, they should give them to us.

And even interviewee 11, despite her fears about confidentiality, noted above, felt “they should help- they can even be gathering people in their locality and talk about the issue.”

Interviewee 6, who had, underlined the status of LAOs at community-level, but identifying a familiar rural-urban difference in attitudes, was sceptical about whether they had the sufficient sensitivity and information to deal the epidemic’s complexities. He explained:

I was at home up-country and it was very interesting. The rumour had already gone round the village that I was suffering from AIDS. ... But even after my closest friend died of AIDS, no one could stand at the funeral and say this man died of AIDS. It is the chief, who should speak out about this, if the villagers find it difficult. ... People must learn to accept the disease... I went back and told the sub-chief I wanted to register a community-based organization in my own village in Vihiga (western Kenya). He had heard about the disease but he was shocked. He said that he’d heard that this disease affects people mentally and so I must be mentally ill! I told him there was nothing wrong with me and I only went because in that short period that I was at home, imagine about 5 people, my age-mates, died. 2 ladies, 3 men- just like a joke. But even now when you go and speak to the father and ask him ‘what killed your son?’ He cannot tell you that it’s the virus. You need maybe a chief or even a church elder to tell people otherwise they won’t believe. And may be the sooner we accept it, the sooner we can get help, like counselling- chiefs can counsel- they are good men. You know when they come and pay you a visit in your house, you know you feel great. They can come and comfort those who are sick and boost morale. And also because you know they are leaders, they don’t just come like that- they’ll have a gift, may be a little money or food. It is a boost.

In a similar vein, others, like interviewee 12 felt that LAOs lacked the necessary compassion and understanding: “You know issues like this... if you take them to people like chiefs, let me tell you when people hear you have this disease, they spite you, even if you used to get along very well, you see suddenly they want nothing to do with you.”

Interviewee 6 may have perhaps encountered some of the illiterate officials whom even the government acknowledges exist⁹⁸, and for which one respondent blamed

⁹⁸ See *The Daily Nation*, ‘Government Strongly Defends Provincial Administration,’ (n 86). Other respondents had similar criticisms: interviewee 47, for instance, said of some LAOs: “They are stupid people who can’t do anything! Yes [they should help] but I don’t think know about it. ... [T]hese chiefs and DOs ... only know how to eat *nyama choma* [roast meat]!” Interviewee 29 said: “Well, yes [they can help] but you see when people are not educated on this issue they cannot be helpful to you at all.... Interviewee 10 agreed: “No. I don’t think they can help me. Just as I have said when you tell people you have this illness, they don’t even want to associate with you.... May be this chief is

the recruitment process.⁹⁹ Comments regarding unsuitable, if educated, government officials recall one of Ekeh's central arguments about the legitimization of the postcolonial African State. He contends that education acquired currency in the colonial era as a ticket to, and symbol of, a European life of luxury. The expectations of the emergent educated African bourgeois class were no longer confined to the manual labour intended for the 'natives', a notion encouraged by the colonizers. After independence, many Africans continued to expect that an education entitled them to rule and validated their claims to the socio-economic benefits of the postcolonial State.¹⁰⁰ Notwithstanding, the African bourgeoisie of the colonial era, which comprised the ruling elite in post-independent Kenya and elsewhere on the continent, still had a legitimacy deficit.¹⁰¹ Two main fissures ran through the postcolonial political terrain it inherited: one was the ethnic division within the bourgeoisie class itself, also stoked by the colonial powers; the other was the unhealed rift with the customary authorities.¹⁰² This influenced perceptions about State's legitimacy in the eyes of ordinary Kenyans, and their notions about whether they can make claims of entitlements from it, or if it would deliver on its obligations.

One respondent interestingly suggested that only the intercession of the remote- but more powerful- central State can compel those at local level to act, for despite their proximity to him LAOs make no effort to recognize his need or offer assistance, a notion reminiscent of the colonial-era perception of the local State as selective in the execution of its duties:

A person like the chief or D.O. cannot help me. Only the government can help me.... [LAOs] should be compelled to help because the D.O. is the one who is closest to people. So if the government can force these ones to give help to a person who is HIV-positive then they can do something. But I myself cannot just come out and go to the D.O. and ask him to help me in this or that way- he can't. (Interviewee 23)

Arguably, for him the proximity of local government also removes the anonymity that the individual might otherwise enjoy, making the PLWHA wary of discriminatory

someone who when you look at him, his education standard is lower than yours. So you say it is best to keep it to yourself."

⁹⁹ He argued, "They should [help] but in the current system the way the chiefs are employed, they are people who can't help you. They look after themselves and do not worry about others.... (Interviewee 13)

¹⁰⁰ Ekeh (n 7) at 96 and 100, and 104-5.

¹⁰¹ *ibid* 103

¹⁰² *ibid* 104

action. Similarly, other individuals who lack political or economic (often the same thing in Kenya) or social connections may also perceive themselves as vulnerable to selective State inaction, or, worse, negative State attention. By the same token, however, the closer gaze of the State via its local agents benefits those it would select for patronage, expediting their ascent and mainlining them to the even greater prizes at the centre of government.

What the responses above highlight are the lingering effects of the practice of Statecraft at the grassroots, particularly of its more dubious aspects, and its influence in moulding contemporary perceptions about the role of the wider State, its effectiveness in meeting its obligations to the individual and, allied to this, its legitimacy. Yet the same questionable practices during the colonial era also allowed enterprising and opportunistic elements to establish themselves, heralding new power relations in the customary sphere and catalyzing the dissolution of many aspects of the traditional systems. This process, through which the African petite bourgeoisie class was created, was important in two ways: the first was political: it was central to the anti-colonial movement of the post-war years. In fact, Ekeh views the African independence struggle as a contest between this class and their fellow European bourgeois counterparts about the legitimacy to rule.¹⁰³ Berman exposes the predictable outcome of the paradox at the heart of the colonial endeavour, the active production of (relatively) 'civilized' Africans who nevertheless could only enjoy the limited rights of the customary. For despite encouraging peasant commodity production in the effort to nurture an even broader network of African collaborators, it would have been impossible for the PA to allow the fullest opportunities for African accumulation of wealth through agricultural production while requiring these same people to ensure satisfactory production levels for European estate owners.¹⁰⁴

The second was socio-economic and was transformative in a number of crucial ways: the growth of the African petite bourgeoisie had been driven primarily by the introduction of wage labour in the colonial economy. It was an opportunity for those in lower positions in the traditional hierarchies to bypass the rigid rules and processes

¹⁰³ Ekeh (n 7) 103

¹⁰⁴ Berman (n 6), 201

by which wealth, and therefore social advancement was acquired. Unsurprisingly, it was largely “young, unmarried propertyless men” who sought wage labour in the early part of the colonial era.¹⁰⁵ Internal migration became prevalent in the colonial era as men shifted to urban centres and cash crop farms in search of better incomes to cover the tax costs that were a feature of the new capitalist economy.¹⁰⁶ Their newfound wealth allowed them to dislodge older generations, long the gate-keepers to such institutions as marriage, which, as seen before, were central to prestige and social mobility.¹⁰⁷

Linked to this was the gradual but critical admission of women into the wage economy, which gave them access, albeit limited, to a society beyond the highly controlled one of the traditional in which their identity, as discussed previously, was welded to that of their fathers or husbands. This gave some women a measure of social and economic autonomy, offering some freedom from cultural constraints. Opportunities in the growing urban centres also removed them from the immediate gaze and scrutiny of traditional power. They could thus begin to re-imagine their identities as women, their relationships with, and duties to the collective¹⁰⁸, explore links with communities beyond the kinship unit and begin to articulate certain demands as individuals against the colonial and postcolonial States. But the system of patriarchy persisted, merely extending to the new sphere and the new economy, and the exclusion of women in the formal economies and politics is another enduring characteristic of the postcolony.¹⁰⁹

Colonial policies and practices also accelerated and entrenched the separation between the private sphere of home and family and the public one of work. As Tamale notes, “[w]here domestic work had coexisted with commercial work in pre-colonial satellite households, a new form of domesticity, existing outside production,

¹⁰⁵ *ibid* 60

¹⁰⁶ Nzioki, Akinyi, ‘The Effects of Land Tenure on Women’s Access and Control of Land in Kenya,’ in Abdullahi A. An-Na’im (ed.), *Cultural Transformation and Human Rights in Africa*, (London: Zed Books Ltd, 2002) at 236

¹⁰⁷ Mamdani (n 2), 118

¹⁰⁸ Mamdani (n 2), 119

¹⁰⁹ See Nzomo (n 22), 78-9

took over.”¹¹⁰ Ultimately, therefore, women’s capacity to become a key component of this new class and further exploit the labour opportunities that held the key to social, economic and political transformation, was- and remains- severely curtailed.

Significantly, too, with customary institutions severely undermined and the colonial cash economy absorbing individuals from mixed social and economic levels, it became easier for such persons to shake off the various kinship duties that defined these ties. Mamdani remarks on the more individualized notion of rights now adopted by relatively successful peasants.¹¹¹ The economic and legal atomization of society often occurred simultaneously, as Martin Chanock’s study of Malawi and Zambia reveals.¹¹² This is a significant development in the construction of individual subjectivity during colonial and postcolonial eras, and is part of the process of separating individual identity from that of the collective. Its impact on notions of entitlement can arguably be discerned in PLWHAs’ consciousness about the onerous financial pressures their illness placed on their families and friends, as is evident in coming chapters. Many felt that they, rather than any institutional actors, were primarily responsible for fulfilling their own health needs. It suggests that one of the outcomes of individualization has been the propagation of ideas about the individual’s responsibility for her own welfare and less reliability on traditional mechanisms of assistance or cooperation, even as the human rights enterprise urges her to defer these matters to the institution of the State.

This is not the only contradiction facing the individual in the postcolony.

IV. The Bifurcated State

The end of colonialism ostensibly bestowed the rights of citizenship upon all black Africans. However, in Mamdani’s bifurcate State paradigm, which is the framework and platform for discussions here, the post-independent African State is as

¹¹⁰ Tamale, Sylvia, ‘Gender Trauma in Africa: Enhancing Women’s Links to Resources,’ *Journal of African Law*, Vol. 48, No.1 (2004), pp. 50-61, at 52

¹¹¹ Mamdani (n 2), at 120

¹¹² See Chanock, Martin, *Law, Custom and Social Order: The Colonial Experience in Malawi and Zambia* (Cambridge: Cambridge University Press, 1985) at 36

fragmented as the colonial one despite its deracialization, a process which took place in earnest at the close of colonial rule in Kenya with processes such as the restructuring of agrarian systems and laws.¹¹³ At the heart of this fracture is the legal colonial hangover of pluralism. Legal pluralism means the operation of “tiered and interactive normative systems... within a system either within or without the formal state legal system.”¹¹⁴ There are two species of legal pluralism: juristic or diffuse. In the former, the State’s official legal system, though predominant, recognizes other types of systems, such as customary laws, and attempts to lay down the values they will apply; in the latter, the State neither originates nor controls the rules or processes by which a group may control the social behaviour of its members.¹¹⁵

In Kenya, where customary courts were rebranded African courts, as with many African countries without a unified legal system, initial narrowly-defined efforts focused on amalgamating the courts system rather than the substantive law.¹¹⁶ Today there are no such customary courts and decision-making rather problematically takes place across a range of levels, from family to clan to village.¹¹⁷ The constitutions of the three East African countries presently regard customary laws on an equal footing with modern laws¹¹⁸, and although they apply only to civil matters, these encompass crucial areas: marriage, divorce and succession. These have significant consequences for the pattern of HIV infection and the attainment of health, as well as the socio-economic situation, particularly of women. On the issue of succession, for instance, Kameri-Mbote notes that a system of legal pluralism operates in Kenya that combines both juristic and diffuse pluralism.

But the precise content of customary law remains elusive. The task of restating the law in written form did not mean its codification.¹¹⁹ This left much of its interpretation to local officials and tended to flesh out procedural rather than

¹¹³ See Okoth-Ogendo (n 75), at 155.

¹¹⁴ Kameri-Mbote (n 10), *op.cit.*, at 5

¹¹⁵ *ibid*

¹¹⁶ Mamdani (n 2), at 130

¹¹⁷ Kameri-Mbote (n 10), at 4

¹¹⁸ *ibid*, at 1

¹¹⁹ Mamdani (n 2), at 131

substantive aspects.¹²⁰ Indeed, disparities often exist between customary law as defined by courts and as it operates on the ground; in the absence of these institutions' intervention it is the latter interpretation that governs daily life.¹²¹ And despite the benefits of flexibility in the law the potential dangers of ambiguous or unknowable laws are clear, not least the lack of clear guidance for those subjected to its norms. For the law is susceptible to manipulation from the gatekeepers of its knowledge, a status that serves to galvanize their power. Further, customary legal systems may entrench inequalities, for, as in the colonial era, "the "hallmark of African customary law is the dominance of older male members over property and lives of women and their juniors."¹²² However, it must not be assumed that civil law is always to be preferred over its traditional counterpart. As explained in the next chapter, the application of customary rather than modern statutory laws sometimes results in more equitable outcomes for some marginalized groups: customary systems have been more willing to enforce traditional obligations such as women's inheritance rights.¹²³

But crucially for the discussion on rights, legal plurality challenges the fundamental notion of equality before the law.¹²⁴ Modern constitutions confer rights, and thus citizenship, to those in the civil sphere. Meanwhile, where the traditional edifices of social regulation remain- in the customary realm- subjects must contend with the impulse of traditional legal systems to enforce custom rather than secure rights.¹²⁵ Thus is power reproduced and reinforced within this sphere. After independence and only until very recently the typical Kenyan remained a subject, benefiting from but unable to exercise the political rights of citizenship.¹²⁶

¹²⁰ Sec. 27(a)(iii) of 2009 Harmonized Draft Constitution of Kenya proposed that the State, as part of its mandate to respect culture, "research into and documentation of the cultures of Kenya, including national history and customary law." (CECR, *Harmonized Draft Constitution of Kenya*, 17th November, 2009 (n 84), at 21). However, this provision does not appear to have survived the constitutional process and is not contained in the new Constitution.

¹²¹ Kameri-Mbote (n 10), at 1

¹²² *ibid*, at 4

¹²³ *ibid*, at 1

¹²⁴ Mamdani (n 2), at 130

¹²⁵ *ibid*, at 110

¹²⁶ Ndegwa, Stephen, 'Citizenship Amid Economic and Political Change in Kenya', *Africa Today*, Vol. 45, No. 3/4 (1998), pp 351-368, at 353-4

Modern constitutions and legal systems often recognize and attempt to address the normative conflicts that sometimes arise between civil and customary laws, especially where customs may be repugnant to human rights principles. For instance, the new Constitution includes the provision in Art. 2(4) that “[a]ny law, including customary law, that is inconsistent with this Constitution is void to the extent of the inconsistency and any act or omission in contravention of this Constitution is invalid.”¹²⁷ Yet customary laws and, it is argued throughout this research, their moral framework, are often deeply entrenched: Kameri-Mbote, pointing out the false presumption of redundancy of custom in matters of succession and inheritance, notes occasions when customary legal norms have prevailed over statutory laws.¹²⁸ There is evidence from Kenyan marriage and divorce case law that Africans do not consider themselves as disentangled from traditional laws even when they have undertaken marriages under modern statutory laws.¹²⁹

This is the essence of the rupture in Mamdani’s postcolonial State: the simultaneous and sometimes conflicting exercise of power by the central State and residual traditional institutions within the same social, legal and political space. But the postcolonial divide differs in two important ways from its predecessor: firstly, where the colonial-era civil and customary spheres were rigidly, insurmountably, demarcated by race, the new fault line is primarily rural/urban. The structures and symbols of power of the central State are based in urban centres while those of traditional authorities are invariably found in rural areas. Citizens and subjects are therefore nowhere as confined to their spheres as before and they may indeed consciously seek or assert membership in both realms to access social, economic, political or emotional goods. Membership to one or the other realm is more fluid and

¹²⁷ Republic of Kenya (n 84). This approach is similar to that of the South African Constitution, for example, whose Equality Clause in Chapter 2 outlaws discrimination “on any one or more grounds including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language, and birth,” and provides no avenue for derogation in the name of custom. Zimbabwe’s Constitution, in contrast, “specifically exempts customary, family, and personal law from the fundamental rights and freedoms guaranteed by its Declaration of Rights.” (Oliver Phillips, ‘(Dis)Continuities of Custom in Zimbabwe and South Africa: The Implications for Gendered and Sexual Rights,’ *Health and Human Rights: An International Journal*, Vol. 7, No.2 (2004), pp. 82-113, at 91 and 92)

¹²⁸ Kameri-Mbote (n 10), at 1 and 6

¹²⁹ Kameri-Mbote, Patricia, ‘The Law of Succession in Kenya: Gender Perspectives in Property Management and Control,’ (Nairobi: Women and Law in East Africa, 1995), on *International Environmental Law Research Centre (IELRC) website at <http://www.ielrc.org/content/b9501.pdf>*, accessed 12/03/10, at 10

while criteria such as economic mobility and formal education and skills may apply and regulate entry and movement between the spheres to a certain extent, such membership is not the unattainable, receding horizon it was in the colonial period.¹³⁰ What this suggests is not so much a dichotomy between citizen and subject, but more likely a dual-identity: citizen-subject. Ndegwa notes that this duality has been a feature of the manner in which citizenship developed in Kenya.¹³¹ It may be discerned in responses by PLWHAs who referred to returning to the rural areas of their birth as ‘going back home’ even if they might live primarily in urban areas. One, a Nairobiian, it will be recalled, referred to “my own village in Vihiga [Western Kenya].”¹³² His fellow Nairobiian spoke of “those [PLWHAs] who are at home, in the rural areas.... There, people just take Panadol and sit there.”¹³³ Another from Kisii town, said “I was able to go back to work, where I asked someone there, who knew my family back home, to tell my family that I wasn’t feeling well.”¹³⁴ As Ndegwa puts it:

...[P]eople experience a convergence of demands from both of their citizenships, rather than some people experiencing a republican form, others the liberal form. Thus, individuals experience liberal citizenship demands at the national level which they may or may not find consistent with (or advantageous to) civic-republican demands within ethnic communities.¹³⁵

Secondly, and linked to this, the colonial State enforced a physical separation of the realms as both a means and end to the desired social and political partition. This is almost impossible in the postcolonial environment for the reasons given above. And while the rural/urban split continues to be a guide as to the location of the frontiers demarcating the spheres, more nuanced elements are involved which are no less real for their intangibility. Interviewees’ responses often suggested an innate awareness of their location, intimating at the normative, psychological and ideational beacons that mark the barriers and reflect differing notions about identity and values. Interviewee 38’s opinions about Panadol ‘treatments’, above, are a case in point; interviewee 5, too, spoke of the rural/urban disparities in attitudes about AIDS:

¹³⁰ See Ekeh’s argument on the value placed on a Western education, earlier. (Ekeh (n 7), at 96 and 100). See also Jean-François Bayart, who stresses the role that education had played since the colonial era in producing social stratification (Bayart (n 7), at 75).

¹³¹ Ndegwa (n 126), at 353

¹³² Interviewee 6, on pg 175, above

¹³³ Interviewee 38

¹³⁴ Interviewee 30

¹³⁵ Ndegwa, Stephen N., ‘Citizenship and Ethnicity: An Examination of Two Transition Moments in Kenyan Politics,’ *American Political Science Review* (1997), Vol. 91, No.3, pp. 599-617, at 603

But in the country, people have a big problem. I can tell you that for those people accepting has been hard for them. They don't know what is going on, apart from that when you have this disease it's a bad disease and it's going to kill you.

Other interviewees spoke of the rural areas as conducive to misconceptions and superstitions about the epidemic. Interviewee 18, for instance, said, "Firstly, this rubbish in the villages is one of the things that is responsible for spreading diseases. If you're already sick, your illness doubled by this rubbish." Interviewee 8 noted similar misinformation in the rural areas:

At home [rural areas] people have this disease but they don't know. They are even afraid of going to the VCTs. So even if you tell someone you have it, they'll run away from you. They'll start rumour mongering. But here in town people are free. You see if you come here in the clinic people are free. Someone can talk to you- they are very free. But at home people are still malingering.

Interviewee 25 advocated education here, saying, "We should be taught about preventive measures because many are getting infected in the villages because of ignorance or lack of good information."

Respondents applied this inherent knowledge of the differences between the spheres in choices about whether, where and when to disclose information about their seropositivity, showing an acute awareness about how such information might be received and its possible effect on their social status in either sphere. To do this they had to be sensitive to differences in the prevailing moral frames of reference in either realm and be able to shift between them when necessary. In this sense, individuals demonstrated a capacity to cultivate multiple identities to aid the navigation of these two spaces.¹³⁶ This is not uncommon and, as will be seen in the last chapter, a multiplicity of sometimes conflicting values can be held within the same person, rendering simultaneous membership of both spheres possible. PLWHAs' responses in this regard point towards the catalytic role of non-State actors in changing attitudes about HIV/AIDS and shaping and reconstructing PLWHAs' subjectivities, expounded on in the latter chapters of this research. The postcolonial citizen-subject who can attain the tools to navigate between the civic and customary spaces, who can

¹³⁶ See Ndegwa, 'Citizenship and Ethnicity: An Examination of Two Transition Moments in Kenyan Politics,' (n 135), at 603

understand and respect- or appear to respect- the norms and prevalent power dynamics and hierarchies in each sphere and adapt accordingly can access the valuable benefits of membership- citizenship- in that respective sphere. Ndegwa compellingly argues that in Kenya today ethnic citizenship, with the hallmarks of “identity, authority and legitimacy for members of an ethnic group,” exists and deserves to be viewed alongside national citizenship.¹³⁷ But perhaps part of the reason it has not been more integrated into the wider analysis about rights and entitlements is that those who shape the debate, the African middle- and educated-classes, have historically dismissed the pull of ethnic citizenship, ignoring the role this membership has in their own lives.¹³⁸

The above highlights the tensions at play in PLWHAs’ responses about healthcare entitlements throughout, for these issues are essentially about their perceived relationships with the State, their families and the wider community. It adds layers of complexity to any discussions about rights because the State is not the sole- perhaps not even the primary- entity in which an individual seeks and/or claims citizenship and so asserts entitlement claims against. Yet human rights theories and covenants yolk the two in a relationship of rights and duties. Only recently with the growth of powerful extra-State actors in the economic and development sphere has a debate begun about their role in the human rights dynamic. As has been noted, while many PLWHAs do indeed identify government as duty-bound to provide for health needs, with several appearing to base their entitlement claims on their membership of the national community- their Kenyan citizenship- many more cite their husbands, families, NGOs and faith-based organizations as (the) duty-holders.

The postcolonial State in Kenya, and those in the ruling classes in particular, have failed to embrace large swathes of the traditionally marginalized in the numerous power struggles that have characterized national politics and starved the entire system of rights. Emergent forms of hegemony have followed traditional matrices of exclusion, which were amplified under colonialism: for example, ethnicity and

¹³⁷ *ibid*, at 601

¹³⁸ *ibid*, at 608

gender.¹³⁹ Women, for instance (though they should not be treated as a monolithic entity¹⁴⁰) have been keen to participate in national political processes and historically form the majority of voters at national elections; yet they are often relegated to the role of pawns in male-dominated political games.¹⁴¹ And because they comprise the largest number of PLWHAs in Kenya, it is unsurprising that their exclusion from, or limited integration in, the national public should lead them to seek membership-citizenship- in alternative non-State associations. Such inequalities have been further magnified by the unprecedented political, economic and military resources available to dominant forces to secure their positions.¹⁴²

Where then does colonialism leave the institution of the nation-State and the notion of a national consciousness? Mutua has argued that the notion of a national identity in Kenya and other African countries was only temporarily and superficially evoked by the independence movement, and that the creation of consciousness has had to take place concurrently with the creation of the nation itself.¹⁴³ Postcolonial nation-building opened up a potent arena for the manufacture of history and validation of power, with the creation of symbols of nationhood, golden calves for an embryonic national community, reflecting the struggles for political power and resources.¹⁴⁴ Members of more dominant ethnic groups may be more predisposed to identifying with, and investing in, such a community. Ndegwa notes that it is less threatening for bigger ethnic groups to transfer their allegiance to the national State because they are at least guaranteed participation in the political community, that is, the enjoyment of their citizenship rights.¹⁴⁵ In Kenya, those whose position could be bolstered by advocating for national unity (the ruling political party) did so, while the

¹³⁹ Bayart (n 7), at 107

¹⁴⁰ Maria Nzomo cites 1992 as “the year of gender solidarity when women put their differences aside and unified across class, ethnic, religious, rural, and urban divides to draft a common gender agenda for democratic change and female empowerment.” (Nzomo (n 22), at 87)

¹⁴¹ *ibid*, at 89. She outlines the onerous burden borne by women, for example, a result of the western-instigated Structural Adjustment Programmes (SAPs) of the 1990s, declaring that the patriarchal system can be traced from household to global level (at 82). She notes that policies of economic liberalization were avidly pursued despite evidence that their effects were more harmful than positive. (at 79)

¹⁴² Bayart (n 7), at 111

¹⁴³ Mutua (n 4), at 86

¹⁴⁴ See, for instance, the politics of commemorating national heroes in Zimbabwe, Werbner, Richard, ‘Smoke From the Barrel of A Gun: Postwars of the Dead, Memory and Reinscription in Zimbabwe,’ in Werbner Richard (ed.), *Memory and the Postcolony* (London; New York: Zed Books, 1998)

¹⁴⁵ Ndegwa, ‘Citizenship and Ethnicity: An Examination of Two Transition Moments in Kenyan Politics,’ (n 135), at 606

others promoted alternative associations- the ethnic group- as the key site for the enjoyment of citizenship. The latter extended and embedded their preferences in their policies about access to land- on which, it will be recalled, citizenship was traditionally based- which they sought to restrict only to those with membership to specific ethnic groups within each region.¹⁴⁶

And yet it is on this construct of a nation-State, however fragile, with its hybrid African and European fingerprints¹⁴⁷, that Mamdani asserts the rights of the citizen are based; by contrast the subject in the customary sphere must draw her rights from the tribe.¹⁴⁸ But Ndegwa contends that contrary to the surfeit of rights envisioned by Mamdani, Kenya's civil sphere enjoyed only limited rights after independence.¹⁴⁹ As for the subject in the ethnic realm her privileges depend on the fulfilment of her obligations to this socio-economic unit which, as the coming chapters exemplify, may significantly impact on her livelihood- and health. Her failure to participate actively in this primordial community and to conform to its norms may result in the withdrawal of its privileges. Indeed, such is its pull- and negative impact on public life, as some PLWHAs complained- that its members may censure those in their number who in the performance of their duties in the civil sphere appear to exercise impartiality to others outside the group, negating what advantage this would have given their own members.¹⁵⁰

One may also consider how Kenya's human rights movement has, since the 1990s, mined a new space for participation and citizenship that may directly challenge the authority of the State even though each entrenches the other in its functions. In this new space, human rights norms become the adhesive around which members cohere, allowing them to re-imagine the individual-State relationship and notions of duties and entitlements. The attraction of the idea of universal human rights is obvious especially to marginalized groups like PLWHAs: if rights adhere to all peoples regardless of gender, ethnicity, socio-economic status, etc, then ostensibly these shared norms equalize membership and unite these disparate elements. They may

¹⁴⁶ *ibid*, at 608

¹⁴⁷ Bayart (n 7), at 33

¹⁴⁸ Mamdani (n 2), at 292

¹⁴⁹ Ndegwa, 'Citizenship Amid Economic and Political Change in Kenya' (n 126), at 353-4

¹⁵⁰ Ekeh (n 7), at 110

also transcend the spheres, embracing the discontented of the civil realm and the constrained of the ethnic.

And yet the reality of rights is rather different from the rhetoric. The challenges of actualizing rights and the disillusionment that this engenders is an issue raised by some PLWHAs. The State's failure to deliver on the promises of rights only feeds perceptions about its illegitimacy. The result may be a retreat from the national public into the customary or primordial one, particularly in times of hardships such as the AIDS epidemic. These clearly identify a role for the individual as part of a community and still hold out the promise of certain rights in exchange for the fulfilment of certain obligations. And, most importantly, their foundations are more established than those of the emergent communities of the nation-State or human rights.

What of the individual? Even in the postcolony, her subjectivity and frame of reference is still considerably informed by institutions and norms with roots in the pre-colonial past of her forebears. However, colonialism has significantly altered their structure and content and the context in which she engages with them. She exists between the individualism of the new social, economic, legal and political environment that is the legacy of colonialism, and the resilient collective identity that is privileged by the customary. She experiences the pull of its authority and that of the relatively new institution of the State. All of these factors affect her perceptions about her health entitlements. The addition of the acronym 'PLWHA' to her identity further skews this, adding a unique complexion to her notion of selfhood and rights, as the next few chapters now illuminate.

Chapter 5: Needs and Requirements I: Nutrition and Resources

With the preceding chapters having mapped the dynamic social, economic, cultural and political context within which PLWHAs' subjectivities and notions of entitlement are produced, Chapter 5 begins the process of examining how they are reflected in interviewees' responses about their self-identified health needs.

The first of the empirical chapters, it focuses on two key requirements, nutrition and income. These are addressed concurrently here as most respondents identified lack of money as the main barrier to accessing adequate nutrition. These two requirements are linked in another fundamental way: in Kenya's agriculture-based economy, access to land may not only guarantee food security¹ but also a cash income. Thus, it often determines patterns of wealth and therefore patterns of risk to HIV infection, and the capacity to meet healthcare and other socio-economic needs. Paul Hunt underlines this nexus noting that, "[g]ood health is central to creating and sustaining the capabilities that poor people need to escape from poverty."²

This chapter therefore investigates the underlying challenges PLWHAs face in meeting the aforementioned needs, as well as how and to whom they assign responsibility for meeting them. It argues that PLWHAs' desire for economic autonomy, revealed in interviews for this research, highlights altered perceptions about the reliability of the ancient kinship and other social networks addressed in Chapter 3 and their matrices of privileges and obligations. The impact of land tenure systems on women in particular is analyzed in detail, as women's access to Kenya's chief mode of

¹ Food insecurity is said to exist when: "...people lack secure access to sufficient amounts of safe and nutritious food for normal growth and development and an active and healthy life. It may be caused by the unavailability of food, insufficient purchasing power, inappropriate distribution, or inadequate use of food at the household level. Food insecurity, poor conditions of health and sanitation, and inappropriate care and feeding practices are the major causes of poor nutritional status. Food insecurity may be chronic, seasonal or transitory." (Food Insecurity and Vulnerability Information and Mapping System (FIVIMS), 'Knowledge and Learning,' 2010, at http://www.fivims.org/index.php?option=com_content&task=blogcategory&id=23&Itemid=39, accessed 27/12/10.)

² Hunt, Paul, 'The UN Special Rapporteur on the Right to Health,' *Health and Human Rights: An International Journal*, Vol.7, No. 1 (2003) pp. 1-27, at 6

production is largely dependent on their relationships with men, limiting their autonomy and space for agency.

Examining nutrition and resources thus proves an effective lens through which to review how the themes addressed in previous chapters shape PLWHAs' conceptions about entitlements and rights. A crucial aspect to emerge from the interviews featured in this chapter is how AIDS, and PLWHAs' perceptions of public attitudes about AIDS, effects a sense of dislocation for many sufferers. As is argued here, this appears to cause many to reassess their place in the wider socio-economic configuration and recalibrate their notions of entitlement to socio-economic goods such as healthcare.

I. Food and HIV/AIDS

Nearly all those interviewed for this research listed a good diet as one of their key requirements. Indeed, as mentioned in Chapter 1, the Bill of Rights in Kenya's new constitution reinforces the importance food to the survival of all Kenyans by formally elevating it to a right owed by the Kenyan State to all Kenyans.³ Many interviewees' responses reflected a widespread absorption of the message that proper nutrition was an imperative complement to their ART regimen⁴, with several elaborating on the specific dietary requirements. For instance, interviewee 15 spoke of "Eating properly, that is, eating fruits and vegetables and fish", while interviewee 45 mentioned "a high-protein diet." Interviewee 43 said she required "A good balanced meal with 3 types of fruit with 3 varieties of colours. ... I know there are those who oppose the use of ARVs and want to use only the fruits and good diet but if your CD 4 count is low, the drugs help a lot. They are still learning more about the nutritional

³ Art 43(1)(c) declares that it is every person's right "to be free from hunger, and to have adequate food of acceptable quality." (Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010*, 2010, Kenya Law Reports (www.kenyalaw.org), accessed 10/12/13, (Published by the National Council for Law Reporting, with the Authority of the Attorney General) at 31).

⁴ The World Food Programme (WFP) underlines this point, noting on its website: "Good nutrition is vital for the health and survival of all people, but it is particularly important for people with HIV and AIDS. HIV and associated diseases weaken the immune system and increase the body's need for energy. Food can provide the first line of defence in warding off the detrimental effects of HIV and AIDS and help people recover from illness." (WFP, 'HIV and Nutrition,' 2007, at http://www.wfp.org/food_aid/food_for_hiv/nutrition.asp?section=12&sub_section=2, at accessed 19/04/07)

benefits and they tell us as they find out.”⁵ This information was sourced directly from health officials: for example, interviewee 8 said that she had learnt a lot on the issue from the counselling offered at the hospital: “You know through counselling, they have taught us how to take care of ourselves, which food is nutritious.... Now I know how to take care of myself, what foods to eat, to weigh myself, which I never used to take seriously.” It also came from posters and other media in health institutions such as those where the interviews were conducted. Respondents commonly used phrases such as “eating well” or “a balanced diet.” One, interviewee 37, spoke of the need for “[m]edicines, and a good balanced diet is very important otherwise you cannot build up your CD4 count.” Lack of food has been cited as the most likely factor behind the non-adherence of ARV therapy.⁶ To one interviewee not yet on ARVs food was the most important requirement: “Food first!”, she declared.⁷ Another, already receiving ARVs, noted an ironic side-effect of the drugs:

Well, I try to get the drugs, food and the money, but the one main problem is the money because you have to divide [it] between all your other needs. It’s funny because these drugs give you such a huge appetite! So you have to eat- you might even feel like stealing when you don’t have the money to buy food! (Interviewee 40)⁸

Tony Barnett and Alan Whiteside observe that HIV-infected adults and children face energy requirements of 10% above normal to sustain physical activity and growth.⁹ The WHO emphasizes the importance of a good diet in managing HIV/AIDS, illustrating the circular relationship between the illness and diet:

People with HIV who are also suffering from hunger and/or nutritional deficits are more likely to fall ill with opportunistic infections and less likely to be able to recover

⁵ Indeed, the WHO makes clear that there is no evidence to support the view that a good diet alone, in the absence of drugs, would halt the progress of HIV into AIDS. (UNAIDS, ‘Fact Sheet,’ 2005, at [http://data.unaids.org/Publications/Fact-Sheets03/who fs %20aids treatment nutrition 30mar05 en.htm](http://data.unaids.org/Publications/Fact-Sheets03/who_fs_%20aids_treatment_nutrition_30mar05_en.htm), accessed 15/04/07). The WFP makes the same point: “Good nutrition is not a substitute for life-extending drug therapies. But nutritious food, in combination with safe water, good hygiene and care, can help people with HIV stay healthier longer, adhere to drug therapies and lead a better quality of life.” (WFP, ‘HIV and Nutrition,’ (n 4))

⁶ The WFP quotes a study by Marston, B., and de Cock, K. M. (‘Multivitamins, Nutrition, and Anti-retroviral Therapy for HIV Disease in Africa,’ *New England Journal of Medicine*, Vol. 351, No. 1 (2004), pp. 78-80), as evidence of this. (WFP, ‘HIV and Nutrition,’ (n 4))

⁷ Interviewee 38

⁸ The WHO says: “HIV progressively damages the immune system, which can make a person susceptible to a range of opportunistic infections and lead to conditions such as weight loss, fever and diarrhoea. These HIV-related conditions can lower food intake by reducing appetite and interfering with the body’s ability to absorb food. HIV also alters metabolism which can often lead to increased energy and nutrient requirements for people with HIV infection.” (UNAIDS, ‘Fact Sheet,’(n 5))

⁹ Barnett ,Tony and Whiteside, Alan, *AIDS in the Twenty-First Century: Disease and Globalization* (Basingstoke; New York: Palgrave Macmillan, 2006) at 239

from them. In addition, people who are sick with HIV-related illnesses are also less able to work normally, to earn income or to produce food, which can lead to nutritional deficits both for themselves and for their dependants.¹⁰

However, despite respondents' awareness of the need for a good diet, many felt their current nutritional intake fell below recommended standards with the cost involved restricting access. Interviewee 35 put it plainly: "[I require] good food, but even if I am aware I must take food, if there is none then there is nothing I can do about it." Examples of typical responses included: "I am getting food but not to the standard required because I am short of money." (Interviewee 21); "I try to get food but it isn't always a balanced diet." (Interviewee 4). One respondent, having listed his needs as "drugs and food", continued: "...[A]ll these things require money. But I have no job- the illness took me out of my job. So these needs of food and so on, I don't yet know how I'll get them but I have started being treated." (Interviewee 23). Interviewee 30 said: "I need a good diet- fruits like mangoes and pineapples- and since I started taking the ARVs, I have had a very good appetite so it is actually possible for me to eat well. It's just that I don't often get the food, that is, I don't get the money to buy the food. ...The cost is immense- daily, it can come to Ksh 500 [approximately GBP £3.35], if you count all those things. But you have to limit it [your expenditure] so that even tomorrow, you may also have something." The problem appears to have worsened in the years since the interviews were conducted because of increases in the price of staples such as maize¹¹ as well as food shortages caused by the recent severe

¹⁰ UNAIDS, 'Fact Sheet,' (n 5)

¹¹ A 2010 survey of 1,200 Kenyan adults reported that cheaper food was the main New Year's priority for 19% of interviewees, second only to a new constitution, which topped the wish list for 22% of interviewees. (Reported in *The Daily Nation*, 'New Law, Cheaper Food and Jobs, Top of 2010 List: Survey,' 2nd January 2010). The WFP says that 3.8 million Kenyans, about a tenth of the entire population, are currently dependent on food aid after the long rains failed in 2009. The organization adds that maize prices in September 2009 were up to 130% above normal. (There were no figures available from the Kenya National Bureau of Statistics (KNBS) for maize prices for September 2009 but the Consumer Price Index (CPI) puts the price for a 2kg bag of maize grains in December 2009 at Ksh. 35.69. There are statistical difficulties when trying to get a complete picture of how this compares to wages during this period as, once again, there were no up-to-date statistics for the wage structure in Kenya. The most recent figures available online from the KNBS are from 2007 and give the average monthly wages for a range of blue-collar jobs in urban centres such as Nairobi, where all my interviews took place, as between Ksh. 6,447 and 8,171. (KNBS, 'Gazetted Monthly Basic Minimum Wages in Urban Areas (Excluding Housing Allowance)', 2007, at <http://www.knbs.or.ke/index.html?SQMSESSID=101561fb04e4511cde553e35a3da421e>, accessed 01/02/10). Other figures from the KNBS give the projected real average earnings for 2005 as Ksh.182,742 p.a., that is Ksh. 15,228 per month. (KNBS, 'Kenya: Facts and Figures, 2006,' (n 11) 2006, at <http://www.knbs.or.ke/downloads/pdf/Kenyafacts2006.pdf?SQMSESSID=101561fb04e4511cde553e35a3da421e>, accessed 21/02/10). See a summary at WFP, 'Kenya Country Report,' <http://www.wfp.org/countries/kenya>, accessed 01/02/10.

drought. The WFP summarizes the barriers to achieving food security in Kenya as “poverty, high demographic growth, arid and semi-arid lands in the north and east, droughts and HIV/AIDS.”¹² According to the organization, an estimated 31% of Kenyans are undernourished.¹³ Moreover, there are often pre-existing problems of malnutrition among the poor.¹⁴

Under these circumstances, the interviewees provided in their responses the range of strategies they employed to meet their nutritional needs, including assistance from family and other social ties, discussed in more detail shortly. PLWHAs also mentioned the part played by the numerous community-based organizations (CBOs, more of which in coming chapters) with which some had come into contact. WOFAK, for example, provided some members with food. Interviewee 1 said: “At the moment, I volunteer in WOFAK that is where at least when I cook for the orphans I get food.” In a follow-up question, when another WOFAK member (interviewee 6) was asked whether he was able to get his other stated needs- food and shelter- he replied: “Well, WOFAK is doing wonderful things. WOFAK has programme that gives people some food- they may not give you the whole thing, but if they give to supplement on the little that you have in your house, it is good. Who gives you food in this country every week? Nobody! Even your own parents when you go (upcountry) they tell you ‘it is finished- you have to buy some now.’ But I really appreciate the work of WOFAK because a friend of mine also told me she goes there sometime they give her 2 packets of *unga* (flour) and one packet of sugar.” But one respondent argued that the organization providing her free ARVs should feed her, too, as it previously had done.¹⁵

¹² See WFP, ‘Kenya Country Report,’ (n 11)

¹³ At *ibid*. The WFP defines undernourishment as “the status of people whose food intake does not include enough calories (energy) to meet minimum physiological needs [and] is a measure of a country's ability to gain access to food.” (WFP, ‘Glossary’, 2010, <http://www.wfp.org/hunger/glossary>, accessed 08/02/10).

¹⁴ Barnett and Whiteside (n 9), at 239

¹⁵ She said: “I get the medicine from MSF and they too used to give us food too. But they no longer do so. I don’t quite understand why but it really used to help me a lot. Especially when I was ill, my social worker would bring food, or even cook for me. They would bring the food to our homes for us to cook but if you were weak they would make it for you. But from December 2003, they stopped and I have suffered a lot as a result. Now I just beg, for Ksh10 [approximately GBP 0.07] here, Ksh. 5 there.” (Interviewee 36). A shortage in funding had reportedly led to the halt.

This view was echoed elsewhere, with interviewee 37 suggesting an even broader range of demands.¹⁶

Such responses reflect the pre-eminence of campaigns for greater access to ARVs. Indeed, some, like the “3 by 5” initiative, launched by the WHO and UNAIDS with the aspiration of providing ART to 3million PLWHAs in developing countries by the end of 2005, did not appear to factor into their campaign proper nutrition.¹⁷ While the number of Kenyans accessing ART has risen impressively (over 336,000 in 2009, or over 70% of adults in need, more of which in Chapter 6), only 30,000 of these received nutritional support.¹⁸ This reflects a narrow definition of the real health requirements of HIV/AIDS, as the WFP and others acknowledge. A Kenyan PLWHA is quoted by the WFP in a statement that is almost identical to the one made by interviewee 37 above: "If you give us ARVs, please give us food, just food."¹⁹

One respondent for this research even considered ART without a proper diet pointless:

I get both of them [my requirements] but with difficulty,” he said. “PLWHAs may not have the balanced diet because of poverty. You can give them the drugs but they cannot get the food they need. If you don’t take the balanced diet you’re just wasting the drugs. You may not even survive. So those 2 things must go together. So I’ve come to realize that not only drugs can help you. (Interviewee 45)

From this one might surmise that among some PLWHAs increased availability of and access to ART from State and non-State actors has engendered a sense of entitlement to food, its obvious complement. One may speculate about whether the respondents above would have voiced similar demands if the ART was itself not freely provided or subsidized. Is this the proverbial inch given, mile taken? Does guaranteed provision of one requirement automatically lead to the expectation of more, and is this necessarily a bad thing? It is argued here and at greater length in the coming chapters that as State and extra-State health providers have increased their activities in

¹⁶ “I think it is the duty of those who provide medicine for me, MSF, to provide even the food and everything for me because I am not able to.”

¹⁷ For more on the “3 by 5” initiative, see WHO, ‘The 3 by 5 Initiative’, 2007, at <https://www.who.int/3by5/en/>, accessed 19/04/07

¹⁸ National AIDS Control Council (NACC), *UNGASS 2010: United Nations General Assembly Special Session (UNGASS) on HIV and AIDS 2010: Country Report- Kenya*, http://data.unaids.org/pub/Report/2010/kenya_2010_country_progress_report_en.pdf, accessed 10/04/10, at 16

¹⁹ WFP, ‘HIV and Nutrition,’ (n 4)

catering to poverty-stricken PLWHAs there have been campaigns from activists for more to be done. It is through such processes that a sense of entitlement appears to have evolved among some PLWHAs. But caution must be applied not to interpret these acts as purely charitable or the claims made particularly upon wealthy donors and NGOs as without basis, as indeed some interviewees reviewed in Chapter 7 did. PLWHAs' demands must be analyzed in the context of the legal or moral obligations of such entities and the asymmetrical global and local power relations between the key actors in the ART/AIDS debate.

There will be a broader discussion of ARVs and campaigns for access to drugs in the next two chapters. For now, it is important to address the crucial link between HIV/AIDS and food production and to demonstrate how the latter factor affects and is affected by the epidemic. Alex De Waal and Alan Whiteside, writing in 2003, suggested in their New Variant Famine hypothesis that HIV/AIDS was to blame for the wave of famines facing southern Africa, and considered the odds for recovery poor.²⁰ They identified four new factors related to the epidemic, which exacerbate pre-existing problems like drought, poverty, financial mismanagement and the increasing wealth gap between rich and poor. In addition to the malnutrition-HIV/AIDS link noted earlier, their catalogue included "household level labour shortages... attributable to adult morbidity and mortality, [as well as] the rise in numbers of dependants; loss of assets and skills [resulting] from increased adult mortality; [and large] burden of care ... for sick adults and children orphaned by AIDS...."²¹

The illness mostly affects adults at their most productive.²² This essentially removes from the food-production equation the very people charged with ensuring food security and proper nutrition. The consequences are devastating for agro-based economies, primarily the incapacitation of actual and potential agricultural sector workers. The country is particularly susceptible to low-productivity caused by AIDS-related illnesses due to the minimal levels of mechanization within the production process. Earlier estimates of deaths within the sector put the figure at 7 million since

²⁰ de Waal, Alex and Whiteside, Alan, 'New variant famine: AIDS and food crisis in southern Africa,' *The Lancet*, Vol. 362, No. 9391 (2003), pp. 1234-1237

²¹ *ibid*, at 1234. See also Barnett and Whiteside (n 9), at 245-6.

²² See Rugalema, Gabriel, 'HIV/AIDS and Adult Mortality in Rural Tanzania,' *East African Geographical Review*, Vol. 20, No. 2 (1998), pp. 25-38, at 26

1985 in 25 of the most hard-hit countries in Africa, Kenya being one.²³ Here, a report estimated that 3.9 million agricultural labourers may have been lost to HIV/AIDS between 1985 and 2000, further suggesting a loss of 16.8 million more between 2000 and 2020.²⁴ Though these figures would most likely now require a considerable downward revision- itself a separate, contentious issue, addressed in Chapter 6- all sectors have undeniably been significantly affected by the epidemic.²⁵ As stated earlier, the cost of morbidity and mortality involves not only loss of labour but loss of expertise in the sector. At one point, Kenya's Ministry of Agriculture, for instance, estimated that 58% of deaths of its staff are AIDS-related; a gap in expertise has also been noted among the ever-increasing AIDS orphan-headed agricultural households, of whom only 7% were said to possess sufficient know-how for agricultural production.²⁶

Rural areas, in which the vast majority of Kenyans- over three-quarters- live, are worst affected.²⁷ In a view echoed by several interviewees, Barnett and Whiteside observe that the often subtle effects of the epidemic on rural life remain largely unaddressed. They highlight, for instance, the long-term loss of farmland following deaths from AIDS; disputes over property rights and inheritance; and the deterioration of rural infrastructure due to loss of manpower and skills.²⁸ For this

²³ Food and Agriculture Organization, (FAO) 'AIDS: A Threat to Rural Africa: Fact Sheet', 2007, at <http://www.fao.org/FOCUS/E/aids/aids6-e.htm>, accessed 19/09/07.

²⁴ FAO, *HIV/AIDS, Agriculture and Food Security in Mainland and Small Island Countries of Africa*, report of the Twenty-Second Regional Conference for Africa, Cairo, Egypt, 4-8 February 2002, at <http://www.fao.org/DOCREP/MEETING/004/Y6059E.HTM>, accessed 17/09/07

²⁵ See UNAIDS, 'Results of Recent Population-based Surveys,' 6 July 2007, at http://www.unaids.org/en/MediaCentre/PressMaterials/FeatureStory/20070705_population_based_surveys.asp, accessed 21/09/07. The most recent HIV prevalence surveys, from which various projections are generated, are now population-based rather founded on the blood tests of pregnant women visiting pre-natal health care centres. This new survey model is considered a more accurate reflection of the incidence of HIV/AIDS, and has seen the HIV prevalence rates in most countries reduced dramatically. In Kenya, for example, the HIV prevalence figures for 2001, published in the Report on the Global Epidemic in 2002 was 15%. A 2003 population-based survey put the figure at less than half of this, 6.7%. (UNAIDS, 'Comparative Statistics,' 2007, at http://data.unaids.org/pub/InformationNote/2007/070705_comparativestats_hhsurvey_en.pdf, accessed 10/02/10)

²⁶ Both from FAO, 'AIDS: A Threat to Rural Africa: Fact Sheet', (n 23)

²⁷ The United Nations Population Fund (UNFPA) State of the World Population Report for 2009 estimates that 22% of Kenyans are urban dwellers, which amounts to 78% rural dwellers. (UNFPA, *State of World Population, 2009: Facing a Changing World: Women, Population and Climate*, 2009, at http://www.unfpa.org/webdav/site/global/shared/documents/publications/2009/state_of_world_population_2009.pdf, accessed 05/02/10)

²⁸ Barnett and Whiteside (n 9), from 244. See also UNAIDS, 'A Review of Household and Community Responses to the HIV/AIDS Epidemic in the Rural Areas of sub-Saharan Africa,' UNAIDS, *A Review of*

reason, there will also be a detailed analysis later in the chapter of the role of the system of land tenure in influencing levels of food production and determining the pattern of beneficiaries from this resource.

At a household level, illness or death of adults, particularly of a mother, considerably diminishes the nutritional capacity, especially in least well-off households.²⁹ And significant numbers of mature women are removed from the equation because disproportionate numbers of them are infected at a younger age.³⁰ There are well-documented long-term implications for undernourished children, including “perennial underachievement, [with] children of underachievers... also likely to be underachievers.”³¹ Families may also lose their breadwinners, who may be unable to work on the farms they depend upon for subsistence or a cash income. Seropositive farm labourers who rely on their wages not only to purchase food but other necessities such as shelter, healthcare and so on, find themselves unable to pay for these basic needs. There are further effects: an ill HIV-positive adult from an agriculture-reliant family means that others within the family unit, who are often the sole or primary source of care, must look after the sufferer or orphaned children, drawing them away from their farm tasks.³² The net result is a reduced income at a time when it is especially needed³³; and even death, too, often further depletes the household’s resources.³⁴ Poverty, exacerbating and exacerbated by ill-health and

Household and Community Responses to the HIV/AIDS Epidemic in the Rural Areas of Africa, UNAIDS Best Practice Collection, 2009, at http://data.unaids.org/Publications/IRC-pub01/JC390-Household_en.pdf, accessed 15/07/09, at 13)

²⁹ There is evidence of this from Tanzania and Uganda: “Research in Tanzania showed that per capita food consumption decreased 15 percent in the poorest households when an adult died. A study carried out in Uganda showed that food insecurity and malnutrition were foremost among the immediate problems faced by female-headed AIDS-affected households.” (FAO, *HIV/AIDS, Agriculture and Food Security in Mainland and Small Island Countries of Africa*, (n 24))

³⁰ de Waal and Whiteside (n 20), at 1235

³¹ Rugalema, Gabriel, ‘Coping or Struggling? A Journey into the Impact of HIV/AIDS in Southern Africa,’ *Review of African Political Economy*, Vol. 27, No. 86 (2000), pp. 537-545, at 542

³² See Barnett and Whiteside for a summary of the effects that the illness or death of an individual has on her household and the wider community, which include the loss not only of a source of income earner or care giver but also as an educator within the family, the loss of her leadership, service in, and support to the community of which she is a member. (Barnett and Whiteside (n 9), at 199). See also de Waal and Whiteside (n 20), at 1236; Rugalema, ‘Coping or Struggling? A Journey into the Impact of HIV/AIDS in Southern Africa,’ (n 31), at 539.

³³ See also FAO, *HIV/AIDS, Agriculture and Food Security in Mainland and Small Island Countries of Africa*, (n 24)

³⁴ As Whiteside writes, quoting a 1997 World Bank study of Kagera in Zimbabwe, death is an expensive business, which, unlike aspects health expenses which the State may subsidize, falls completely on households: “In Kagera households medical expenditures were higher when AIDS was the cause of

hunger, may become entrenched and prove intractable in the long run.³⁵ There were signs of that “hunger-poverty trap” in the interview samples seen earlier. PLWHAs make various attempts to try and cope at family and community levels with the stresses on nutrition and income. Many households look to relatives for help. For instance, interviewee 27 revealed that, “My sister [helps me] especially with the diet. The medication I buy myself but if I don’t have money she helps me.” Similarly, interviewee 27 said that, “If I was at work, it should be me paying for my expenses. But because I’m not, I depend on my family.” For interviewee 26, “When I got sick I lost my job. Then I had to go back and live with my parents who paid for my education. So they are the ones catering for my bills and for my food but they have very heavy burdens...” Interviewee 6 speculated on how extended families might be integrated into helping PLWHAs meet their dietary needs: “Now, I may also tell you about extended families- that is where they come in. You know, it’s very difficult for someone to give you Ksh 1,000 (approximately £7.70) but they can do shopping for you worth Ksh 2,000 (approximately £15.40). So my sister can get me some things to eat, and so can my brother. So about food, for me it’s ok.”

While some PLWHAs, as earlier quotes illustrate, try to address the diminished capacity to meet their nutritional requirements by cutting back on some meals or reducing their intake, others seek less expensive sources of nutrition or substitute their usual diet with locally found foods.³⁶ Interviewee 16 remarked: “It all comes down to money because without money I cannot buy my nutrition. For example, I have now been forced to become a vegetarian. Fruits and vegetables are becoming cheaper now but I still need money to buy them.” Support groups for PLWHAs also try to inform their clients on sources of affordable, nutritional food. One respondent, interviewee 29, had been trained and now volunteered as a community-based worker

death. But ‘strikingly for all groups except men with AIDS, medical expenses were overshadowed by funeral expenses. On average, households spent nearly 50 percent more on funerals than they did for medical care.’ (Whiteside, Alan, ‘Poverty and HIV/AIDS in Africa,’ *Third World Quarterly*, Vol. 23, No 2 (2002), pp 313–332, at 322)

³⁵ The FAO reiterates Barnett and Whiteside’s earlier-noted views, calling hunger a barrier to “the health and productivity of individuals and their efforts to escape poverty. It acts as a brake on the potential economic and social development of whole societies. It is no coincidence that more rapid advances have been made in poverty reduction as opposed to hunger alleviation.” (FAO, ‘The State of Food Insecurity in the World, 2006,’ <http://www.fao.org/docrep/fao/009/a0750e/a0750e01.pdf>, accessed 19/04/07)

³⁶ UNAIDS, ‘A Review of Household and Community Responses to the HIV/AIDS Epidemic in the Rural Areas of sub-Saharan Africa,’ (n 28), at 19.

for a reproductive health organization. When asked whether she felt that the needs of PLWHAs were being adequately met she replied:

...[S]ome are in slums and they have nothing even to eat. For example, we get help from organizations such as Pathfinders who show us cheap ways to get a balanced diet. They tell us about how you can make meals from vegetables, how you can find fish cheaply. So you see, we learn. We learn that even if you must eat some meat as part of your diet, it doesn't have to cost too much.

The impact of HIV/AIDS on food security at the basic household level has serious repercussions when replicated at the national level. As has been noted, "[t]he epidemic undermines three of the main determinants of economic growth: physical, human and social capital, and thus has a major impact on development."³⁷ Although this should underline the importance of monitoring the epidemic's effects on rural, agri-based economies like Kenya's, a joint FAO/UNAIDS study argued that this specific impact of the illness was often overlooked as recently as turn of the millennium.³⁸

And just as the decline in incomes from agriculture is influenced by the HIV/AIDS epidemic, it becomes a catalyst for visible social and economic shifts that have serious repercussions for the spread of HIV. One of these, rural-to-urban migration, may predate the epidemic but it has been accelerated by the deterioration of agricultural earnings.³⁹ Better employment prospects for the formally educated and highly skilled as well as a thriving informal sector for those with minimal or no education drive the move.⁴⁰ Most of the migrants are young; thus, a significant population of poverty-stricken elderly is left behind in the rural areas, with neither the children on whom they would traditionally rely nor the donors to whom their plight is not often

³⁷ FAO, *HIV/AIDS, Agriculture and Food Security in Mainland and Small Island Countries of Africa*, (n 24)

³⁸ FAO/UNAIDS, *Sustainable Agricultural/Rural Development and Vulnerability to the AIDS Epidemic*, UNAIDS Best Practice Collection, December, 1999, at http://pdf.dec.org/pdf_docs/PNACK239.pdf, accessed 21/09/07, at 8

³⁹ Kalipeni, Ezekiel, *et al*, 'Mapping the AIDS Pandemic in Eastern and Southern Africa: A Critical Overview,' in Kalipeni, Ezekiel; Craddock, Susan; Oppong, Joseph. R.; and Ghosh, Jayati (eds.), *HIV and AIDS in Africa: Beyond Epidemiology* (Oxford: Blackwell Publishing, 2004) at 60. In their article Kalipeni, *et al*, include statistics from the World Bank from 1999, which put the decline of the agricultural contribution to Kenya's GDP since 1980 to 29%, down from 32%. As noted, this figure, according to the World Bank, is now 25%.

⁴⁰ The 1998/99 Integrated Labour Force Survey (ILFS) found that "[o]f the three sectors of the economy, small-scale farming and pastoralist activities engaged 42.1 per cent of workers. Informal sector and formal or modern sector absorbed 31.6 per cent and 26.3 per cent of the total workforce." (KNBS, 'Kenya: Facts and Figures, 2006,' (n 11)). More recent employment figures from KNBS on "modern establishments" in both urban and rural areas show the informal sector to Kenya's biggest employer, with 7,475,600 employees in 2007 out of a total 9,450,300. (KNBS, 'Gazetted Monthly Basic Minimum Wages in Urban Areas (Excluding Housing Allowance)', (n 11))

considered 'sexy'.⁴¹ Many of the migrants are also men, resulting in an increase in rural female-headed households.⁴² The evidence indicates that despite the remittances they often receive to bolster their finances these *de facto* female-headed households are invariably poorer than their male-led counterparts.⁴³ This has notable repercussions for HIV/AIDS because many of those who are ill return to their impoverished rural communities to live out the remainder of their lives, placing on them the burden of care with its crippling food, medical, funeral and other expenses.⁴⁴ This is aggravated by the tendency of many single urban migrants to start new families while there, not only resulting in less remittances but also an eventual loss through morbidity and mortality for two or even more families.⁴⁵ And crucially for the spread of HIV, this migration often sees a change in sexual practices, with even married individuals engaging in sexual behaviours that their new freedom and circumstances now facilitate.⁴⁶ The previously-quoted FAO/UNAIDS study, although warning that this is not an automatic consequence of rural-urban migration (with Dakar, Senegal presented as a case in point) nevertheless noted:

Migration is usually accompanied by a disruption of family life (separation from family and sociocultural norms, isolation and loneliness, and a sense of anonymity that offers more sexual freedom), which partly promotes the demand for and supply of sexual services, and more generally, makes migrants more vulnerable to adopting high risk sexual behaviour. Migration does not only render the migrants

⁴¹ Barnett and Whiteside (n 9), at 230

⁴² Wa Githinji, Mwangi, *Ten Millionaires and Ten Million Beggars: A Study of Income Distribution and Development in Kenya* (Aldershot : Ashgate Publishing Ltd, 2000) at 53. Here, the idea of headship is taken to mean "a combination of authority and well as economic contribution. However, it has been noted that the application of this concept is complicated especially because it is often self-asserted by survey respondents and could be driven by considerable subjectivity and biases that are not well understood. For example, there is often a lack of symmetry, in that female headship tends to be identified where there are no adult males present, whereas male heads generally co-reside with adult women and/or other males. Divorced, separated, widowed or never-married women may hold *de jure* (legal) headship of a household. But, *de facto* headships arise in situations where men are absent from the household for at least 50 percent of the time, but where they may continue to participate in household decision-making." (CBS, *et al*, *Geographic Dimension of Well-Being in Kenya: Who and Where are the Poor? A Constituency Level Profile Volume II*, 2006, at <http://www.knbs.or.ke/surveys/poverty/pdf/KenyaPovAtlasIfinal2cl.pdf>, accessed 12/01/10, at 53

⁴³ wa Githinji, (n 42), at 53

⁴⁴ FAO/UNAIDS, *Sustainable Agricultural/Rural Development and Vulnerability to the AIDS Epidemic*, (n 38)

⁴⁵ wa Githinji, (n 42), at 53

⁴⁶ Whiteside writes about why a truck driver, for instance, away from home for long periods, may vary his sexual behaviour: "He might have sex with a commercial sex worker because he is bored, he feels his job is dangerous and he deserves some compensation, he is frequently away from his wife and family, he experiences peer pressure from his fellow drivers to engage in this activity and he has the necessary money." (Whiteside (n 34), at 317)

vulnerable to HIV/AIDS but their families as well, as households that resort to migration do so because of dire need.⁴⁷

Indeed, interviewee 8 for this research hinted that the sexual indiscretions of her husband, who was then working in the city, had been responsible for her HIV infection. She felt that as her husband he had a duty to provide for her health needs. With an additional follow-up question deemed necessary to tease out some of her answers, she went on to detail how he was failing in this task:

Interviewer: Why do you say he is irresponsible, if I may ask?

Interviewee: By the time I was sick he ran away and left me hanging. So the in-laws took over. He left me to die. He has money, he works, yet he left. He didn't even ask where to take me to hospital so I was down. So these people took me to the hospital. At least now I'm happy- I'm alive.

Interviewer: Why [do you think it your husband's duty to provide for your needs]?

Interviewee: Because we're together. When I came from my home I was not having that disease. I gave birth the first time and the kid was ok- it did not have that disease. We got it because this is someone who is a drunkard, out of carelessness.

Her response suggests a sense of self and a basis of claims to health entitlements in common with interviewee 19 in Chapter 3; both were given in a context where women were traditionally dependent on their male relatives for their material wellbeing, a fact which remains true for many due to the persistently inequitable distribution of resources, as will be seen shortly.

Interviewee 8's relationship to her husband may have been the cause of her deadly illness but it was also the licence on which she claimed assistance from him and her affinal kin. She exhibited unease about the extent of her claims on the latter, an opinion most likely influenced by her perceptions of the onerous nature of the requirements of her illness. She said,

If you have a husband like I do, for someone to take you on as a responsibility is very hard. It's just because of sympathy, a goodly heart, that they have taken the responsibility to get me to where I am now. Because even right now my husband doesn't want me to be with him, he is still here in Nairobi but I came all the way from home [for my clinic appointment] and I am going straight back because I don't want any interference. You know if you have this disease you want to be settled in your mind. You don't want quarrels and everything.

⁴⁷ FAO/UNAIDS, *Sustainable Agricultural/Rural Development and Vulnerability to the AIDS Epidemic*, (n 38), at 8. See also Kalipeni, *et al*, (n 39), at 60, in reference to South African miners.

As has already been established, a married woman was traditionally deemed to 'belong' to her husband's family upon marriage, automatically obliging them to meet most of her needs. This would negate the kind of reluctance the respondent demonstrated. Her attitude may thus reflect shifting notions about the nature of kinship and other traditional social bonds, much altered in the colonial and postcolonial era but which have become even more strained for families encountering resource-demanding problems such as HIV/AIDS.⁴⁸

Further, one might argue that the interviewee's response reflects a construction of a notion of entitlement based on her identity as a PLWHA: for it is questionable whether she would have been similarly reluctant to seek her in-laws' help if her illness was similarly resource-demanding but *other* than HIV/AIDS. Her view appears to be that their offer of assistance was no longer based on their traditional obligations as in-laws or relatives but on "sympathy, a goodly heart"; she appears to perceive this as a charitable act on their part rendering it as easy to withdraw as it is to offer. It may thus be argued that the interviewee has recalibrated her ideas of what she was entitled to from them and their obligations towards her because her requirements were specifically AIDS-related; in other words because she was a PLWHA. Arguably she thought her claim less deserving or a dereliction of her in-laws' familial or social duties more understandable- maybe even justifiable- because she was afflicted not just by a resource-consuming illness but also an often shameful, stigmatizing one.

And yet it is an inconvenient time for many PLWHAs to have their certainties about the reliability or durability of age-old kinship duties shaken, for the HIV/AIDS crisis has made these networks absolutely crucial to the sustenance of many. But the epidemic exerts countless pressures on these same bonds, and "prime-age adult mortality", for instance, particularly accelerates their dissolution.⁴⁹ The death of an adult female is an especially effective catalyst for the decimation and destabilization of the core family unit.⁵⁰ There are additional pressures due to the demands of caring for

⁴⁸ Barnett and Whiteside (n 9), at 247

⁴⁹ See Rugalema, 'HIV/AIDS and Adult Mortality in Rural Tanzania,' (n 22), at 27

⁵⁰ Barnett and Whiteside (n 9), at 247. See also Rugalema, 'Coping or Struggling? A Journey into the Impact of HIV/AIDS in Southern Africa,' (n 31), at 540. Also Whiteside (n 34), who quotes a study of

HIV/AIDS-stricken children and the orphans of deceased PLWHAs.⁵¹ All these concerns played on many PLWHAs' minds as they considered what assistance they were entitled to claim from their kinship and other social networks.⁵² One respondent, interviewee 16, underlined her dependency on her immediate family for her material and emotional needs, but she was also clear-eyed about its toll on them and expressed concerns about whether such generosity could be sustained:

We need a lot of love and this, even from our own family members, is sometimes difficult to come by because they don't want to understand. They feel that you put yourself in these boots and it's up to you to know how you're going to survive. Others might feel that if you were not in this mess, we wouldn't be this broke. For example, I have gotten sick 3 times where I have had to be admitted and my family spent KSh500,000 (approx. GB£3,355) altogether. And it's not so easy. I think that's why some people go all secretive and they just die without telling anyone [that they are ill] because they feel they are going to be a burden.

Another, interviewee 11, was similar uneasy about her reliance on her parents:

I used to earn Ksh. 10,000 (approximately GB£ 67) a month. I have rent to pay, food to buy, transport costs and then add to that hospital and medical bills and plus proper food. Now this becomes a problem- I may not afford, unless I come and stay with my parents or my brother, which is not possible because now he has gotten married. And so has my sister. So I go back to my parents, who can't turn me out. They are educated and Christians, they didn't reprimand me because I have the virus. They knew I didn't get it rightfully. I was just raped and I explained to them and they knew all about it.

215 households in Manicaland, Zimbabwe, from 2000, where "[s]ixty five percent of households where the deceased adult female used to live before her death were reported to be no longer in existence in both the urban and rural sites.' This lends weight to the supposition that often the worst impact is invisible because it is among those who are not counted." (at 321)

⁵¹ Figures from UNAIDS, 'Kenya', 2010, at

<http://www.unaids.org/en/CountryResponses/Countries/kenya.asp>, accessed 10/02/10.

⁵² One respondent, interviewee 16, underlined her dependency on her immediate family for her material and emotional needs, but she was also clear-eyed about its toll on them and expressed concerns about whether such generosity could be sustained: "We need a lot of love and this, even from our own family members, is sometimes difficult to come by because they don't want to understand. They feel that you put yourself in these boots and it's up to you to know how you're going to survive. Others might feel that if you were not in this mess, we wouldn't be this broke. For example, I have gotten sick 3 times where I have had to be admitted and my family spent KSh500,000 (approx. GB£3,355) altogether. And it's not so easy. I think that's why some people go all secretive and they just die without telling anyone [that they are ill] because they feel they are going to be a burden." (Interview 16). Another, interviewee 11, was similar uneasy about her reliance on her parents: "I used to earn Ksh. 10,000 (approximately GB£ 67) a month. I have rent to pay, food to buy, transport costs and then add to that hospital and medical bills and plus proper food. Now this becomes a problem- I may not afford, unless I come and stay with my parents or my brother, which is not possible because now he has gotten married. And so has my sister. So I go back to my parents, who can't turn me out. They are educated and Christians, they didn't reprimand me because I have the virus. They knew I didn't get it rightfully. I was just raped and I explained to them and they knew all about it." (Interviewee 11)

Interviewee 11's response here offers interesting insights into the subjectivity of a PLWHA and has also been discussed in Chapter 2; she echoed the concerns of interviewee 8, earlier, on the financial pressures that her illness was placing on her family. But her comments also suggested that she believed it was partly due to the tragic means by which she became infected that she continued to receive her parents' sympathy and assistance. By stating that she had not become infected "rightfully", a word which she herself used in her English-conducted interview, she appeared to be endorsing the position that there are those who are blameworthy and so less entitled to assistance. This reflects popular perceptions seemingly shared, at least to some extent, by the respondent herself, which associate HIV infection with deliberate risky behaviour and sexual licentiousness. It is linked to ideas about stigma and sexuality, especially female sexual autonomy. It contributes to the discussion here by suggesting how a PLWHA's subjectivity is constructed, how as a PLWHA she measures her sense of her own value to her family, community, country, her self-worth, her dignity, and consequently what she is entitled to and from whom. Many of these discussions will be revisited in coming chapters.

II. Income and HIV/AIDS

Many PLWHAs explicitly mentioned income or employment as separate health needs, underlining the fact that meeting the myriad health demands of HIV/AIDS relies on access to economic resources, and highlighting Barnett and Whiteside's point that "as with their chance of being infected, the impact of the disease will depend on their circumstances and the resources they can command."⁵³ Their contention was repeated in various interviews: Interviewee 30 stated that "[t]he main problem is money because it limits all the others." For interviewee 43, "Money is the big problem because it governs all others. I get my drugs free from MSF but the lack of money influences all the other things." Interviewee 29 recognized that "[s]ometimes you can get [all your health needs] without problems but sometimes you may not have the money. So it all comes down to money, which also influences whether you'll have peace of mind or not, which is important."

⁵³ Barnett and Whiteside (n 9), at 198

Before further examining this issue, it must be mentioned that interviewees were not asked to disclose details about their incomes, for reasons already noted in Chapter 2 (in note 17, pg 87). The analysis of income in this section of the thesis, however, is able to rely on interviewees' responses which allude to their financial well-being and which arguably provide richer information based on a respondents' personal analyses of a range of issues which pertain to their income and expenditure, but which also incorporates an evaluation their satisfaction or otherwise with the subsequent imbalance, and the ramifications this has on their ability to fulfil their health needs and realize their nominal rights to health.

Respondents spoke of the assorted strategies for securing money to meet their healthcare needs, including help from family and friends (as seen earlier) or others.⁵⁴ Some like interviewee 29, cited above, tried to use their expertise as PLWHAs for money: "Even the work that I do to get some money is voluntary, done with outreach programmes- I go and talk to people and hope to get something small out of it. But there's no guarantee I will get anything- sometimes I don't. I also do some home-based care so I can learn how to look after myself as well as others."

Many of the responses highlighted one thing: the desire for self-sufficiency. Interviewee 37, for instance, appeared distressed about having to seek help when she might otherwise have been able to provide for herself. She noted, "With the food, I have never gone to the MSF to plead for help. When I was better, I used to work and provide these things for myself. But now, I can't even work with on a small business." Interviewee 3, though he mentioned food and medicine as among his health needs, ranked a job, which may guarantee self-sufficiency, above these, firmly stating: "First of all I need employment, that's the way I can get money.... If the government provides me with employment, indirectly they have provided me with all these other needs. So that will cover most of the things."

The role of the government in facilitating individual self-sufficiency also resonated with Interviewee 48, who was prepared to take responsibility for all her other

⁵⁴ For instance, interviewee 17 said, "I get both the food and ARVs but I struggle to get them because I don't have job and really depend on donations."

healthcare needs if the government could fulfil the main duty she accorded it: securing her employment: “[I]f the government gave me a job to do I would easily provide for my own needs without bothering other people. Because if you look at me, I’m strong, I’m not sick. I can work, I can do the same as other people. I don’t keep falling sick often, partly because of the medication I’m taking.”

The circular link between health needs and the need for financial autonomy was succinctly captured by a number of respondents. “[W]hen you have these two things [food and medicine], survival is much easier,” said interviewee 40, for instance. “For example, when I have eaten well and taken my medicine, I am normally able to work on my sewing business and I am able to support myself.” As interviewee 44 briefly put it: “If I had a job and I was healthy, I would be able to provide for myself.”

Yet unemployment remains endemic in Kenya, with some figures putting it at 40%.⁵⁵ In a survey, quoted earlier, 11% of respondents named employment as their most important priority for 2010.⁵⁶ But some respondents like interviewee 11 drew attention to further PLWHA-specific problems: the complications of managing their illness made consistent presence at work difficult; employers were insensitive to, or

⁵⁵ Employment statistics are tricky to decipher, a fact not improved by lack of access to recent statistics from the Kenyan government, hence the use of this figure from the Central Intelligence Agency (CIA) World Factbook on Kenya, which gives this figure as the estimated rate of unemployment for both 2001 and 2008. (CIA, ‘World Factbook,’ at <https://www.cia.gov/library/publications/the-world-factbook/geos/ke.html>, accessed 10/01/10). But just how the compilers of this report define unemployment is unclear, as it may not necessarily mean that a person is not involved in some form of economic activity. The 1998/99 Integrated Labour Force Survey (ILFS), for example, notes: “The results show that there were 15.9 million persons aged 15-64 (the working population) of which 77.4 per cent reported to be economically active. Most of the active population was youth between 24-34 years of age. About 14.6 percent of the economically active were unemployed. Some 3.6 million persons reported to be economically inactive, representing 22.6 per cent of the population aged 15-64 years. Majority of the inactive population was full time students (47.3 per cent). Only 2.0 per cent of the inactive population reported they were out of the labour force because they were retired.” It then gives the figures for employed persons aged between 15-64 at 10.5 million, and thus employment rates of 85.4%: “The working population was largely made up of unpaid family workers (39.6 per cent), mostly working in the rural areas and paid employees, largely concentrated in urban areas (33.4 per cent). Self-employed persons constituted 23.8 per cent of the employed. Of the three sectors of the economy, small-scale farming and pastoralist activities engaged 42.1 per cent of workers. Informal sector and formal or modern sector absorbed 31.6 per cent and 26.3 per cent of the total workforce.” (KNBS, ‘Kenya: Facts and Figures, 2006,’ (n 11)) The KNBS gives the provisional figure for total number of employed in 2007 as 9,450,3000; this is less than the figures from 1998/9 given in the ILFS study above. (KNBS, ‘Employment Statistics,’ at <http://www.knbs.or.ke/>, accessed 10/02/10).

⁵⁶ Reported in *The Daily Nation*, ‘New Law, Cheaper Food and Jobs, Top of 2010 List: Survey,’ (n 11). A report in the same paper from 2005 shows Kenyans’ gloomy outlook on job opportunities in the country despite promises by the then-new NARC government, with 60% expecting unemployment to increase that year. (*The Daily Nation*, ‘Most Kenyans “See Little Hope” for Employment,’ 2nd June 2005)

impatient with, their health needs; and, even though the government has now enacted legislation explicitly prohibiting discrimination on the basis of HIV status⁵⁷, employers discriminated against them in the job market. The legislation itself may be open to unfavourable interpretation for PWHAs, as it prohibits discrimination of PLWHAs from employment or promotion, unless an employer can prove that “the requirements of the employment in question are that a person be in a particular state of health or medical or clinical condition.” It is not inconceivable that this exception in Sec. 31(2) might be liberally interpreted, so that it may exclude employers who, deliberately or otherwise, misjudge or underrate a PLWHA’s capacity to fulfil the functions of her job, perhaps because they do not apprehend the impact of the illness on a specific individual and the various socio-economic factors- such as access to ART, proper nutrition, emotional support, etc- that determine good health. Moreover, with stigmatization of PLWHAs still present in society, legislation alone, though important, is insufficient to halt discrimination or hostility against PLWHAs in the workplace. The stress that a PLWHA might undergo due to fear or anxiety about having her status revealed, as will be seen in Chapter 6 when psychosocial needs of PWHAs are addressed, may be enough to force her to leave her job voluntarily with the disastrous consequences for her economic security that this chapter illustrates.⁵⁸

For instance, Interviewee 11 was critical of her employers’ attitude: “Well, had I been working, I would have supported myself and I thought my employer would have been reasonable and may be waited for me to come up again [for her health to improve] and go back to class and earn my money. But now I take the whole burden back to my parents.” Interviewee 2 called for similar understanding from potential employers:

[W]ork ... is difficult to get, especially people like us, because, you go to work today [but] tomorrow you’re down... So organizations like maybe [WOFAK] can take us. Because they understand us a lot. But these others of individual people... it is very difficult to take people like us- they can’t stomach that today you’re there, tomorrow you’re not.

⁵⁷ Sec. 31 (‘Discrimination in the workplace’) of the 2006 HIV and AIDS Prevention and Control Act (Kenya Law Reports, ‘Laws of Kenya’, at www.kenyalaw.org, accessed 12/10/10

⁵⁸ See also National AIDS Control Council (NACC), *Public Sector Workplace Policy on HIV and AIDS*, 2005, The Office of the President, Directorate of Personnel Management, at http://www.nacc.or.ke/2007/images/downloads/hiv_aids_policy_at_work_place.pdf, accessed 03/03/09, which declares as a policy objective “establishing structures and promoting programmes to ensure non-discrimination and non-stigmatisation of the infected and affected.” (at xi)

Similarly, interviewee 2 cited the consequences of such lack of understanding: “[T]he problem is always money, which starts with lack of a job. You know when you get this illness, you are removed from your job, which is the biggest problem.”⁵⁹ She added that the government (“because they are the ones governing the country”) should take responsibility: firstly, for the provision of drugs and, secondly, for the creation of jobs for PLWHAs “because not everybody who is living with HIV/AIDS cannot work, some of us are capable of working.” These views about the government’s role in job creation are further echoed by interviewee 38, who opines that the government can replicate its U-turn on ARVs and provide jobs, too, saying, “Yes, [the government] can help: for example, we have drugs that were not previously available. Maybe they can also give jobs to those affected, so that from there we can get money to buy food and medicine.”

The inability to find employment and (re)gain financial independence appeared to be a cause for shame or embarrassment for some respondents. One, interviewee 2, cited above, was bitter at the perceived squandering of her expertise, having said earlier in her interview that she suspected she lost her job because of discrimination: “...[A]bove all, I’d be glad if I had gotten a place to work because I trained as a secretary, and my career- it is like I am just wasting it.” Her response reflects the sense of value and self-worth that many draw from work and the capacity to acquire a skill and, through it, gain employment. Not only does this contribute to a PLWHA’s economic security it also boosts an image of herself as a vital, useful member of her household and community.⁶⁰ Her ability to contribute to her own needs and requirements through paid work enhances her sense of individual responsibility, which is so crucial to the concept of human dignity.⁶¹

⁵⁹ For efforts to eradicate the routine practice by employers to carry out pre-employment HIV screening, ostensibly for the purposes of medical insurance (incidentally, insurers are now also prohibited from discriminating on the basis of HIV status) see *The East African*, ‘Kenya Plans to Ban Aids Tests by Employers,’ 27th August 2001. But the report also notes some counterproductive results of PLWHA rights activism, which is also a sign of just how far attitudes, if not actions, have changed: “[i]n Uganda, relatively high public awareness of the rights and a strong HIV lobby has forced some employers to subject their employees to mandatory tests.”

⁶⁰ See Schweitzer, Ana-Maria; Mizwa, Michael B.; and Ross, Michael W., ‘Psychosocial Aspects of HIV/AIDS: Adults,’ *HIV Curriculum*, Baylor International Pediatric AIDS Initiative (updated 28/01/10), at <http://bayloraids.org/curriculum/files/25.pdf>, accessed 01/03/10; at 335

⁶¹ Schachter, Oscar, ‘Human Dignity as a Normative Concept,’ *The American Journal of International Law*, Vol.77, No.4 (1983), pp 848-854, at 850

Work, therefore, and the ability to find it, keep it, and gain from it, can play an important role in shaping a PLWHA's subjectivity and in reaffirming her humanness, and could allow her to re-imagine her relationship to entities such as the State and reassess her entitlements. A number of respondents did indeed appear to base their notions of entitlement to healthcare from the government on the taxes levied on them as paid employees, with some hinting at claims to healthcare entitlements based on a relationship between the (employed) citizen and the State not unlike that between a customer and a service provider. But this raises questions about how individual and State responsibilities are to be delineated if the emphasis is on self-sufficiency, which, after all, cannot be achieved by all.⁶²

Yet the socio-cultural environment still makes it hard particularly for women to be integrated within the employment market and to vie with men on an equal footing, largely because of their competing domestic obligations.⁶³ Worse, this contribution is itself underrated, as Tamale points out:

The fact that women's lives are defined by the ideology of domesticity, that their unwaged productive and reproductive labour in the domestic arena is unacknowledged, undervalued and invisible in economics statistics, largely explains their resource-less status and points to some radical ways of tackling the problem.⁶⁴

Work is also inevitably directed towards narrow goals for many women: for instance, where it might be a gateway to self-empowerment for women, such aims are often subordinated to their efforts to cater to family needs like healthcare and nutrition.⁶⁵ Nzomo notes that even where women demonstrate entrepreneurship, such as

⁶² Nyamu-Musembi and Cornwall offer the following critique of one of (the NGO) CARE's projects in Kenya, which to help or 'empower' horticultural farmers market their products without the unreliable assistance of government officials, by encouraging them to join a private enterprise instead: "The approach... suggests that ultimately the process of asserting and realising the farmers' rights translates into a 'right to opt out' of public services. In such circumstances where will the impetus for improvement in public services come from? ... [D]oes that take the pressure off the government to improve public services? Who will be left to speak up with those who have no choice but to depend on the government services?... What implications does an income strategy have for the broader social and political environment for claiming and realisation of rights?" (Nyamu-Musembi, Celestine, and Cornwall, Andrea, 'What is the 'Rights-Based Approach' All About? Perspectives from International Development Agencies,' *IDS Working Paper 234* (Institute of Development Studies (IDS): Brighton, Sussex, November, 2004), at 41)

⁶³ Nzomo, Maria, 'The Political Economy of the African Crisis: Gender Impacts and Responses,' *International Journal*, Vol. 51, No.1 (1995-1996), pp. 78-102, at 82

⁶⁴ Tamale, Sylvia, 'Gender Trauma in Africa: Enhancing Women's Links to Resources,' *Journal of African Law*, Vol. 48, No.1 (2004), pp. 50-61, at 51

⁶⁵ Nzomo (n 63), at 83

interviewee 43 who was involved in a “[community-based] organization called Osilgi VCT, where we do some self-help work selling handicrafts,” the purpose of their efforts is often restricted to the family’s survival needs rather than “women’s strategic gender needs”.⁶⁶

Women’s economic conditions in particular deteriorated in 1990s’ Kenya under the Structural Adjustment Programme (SAP)-inspired economic policies, just as the HIV/AIDS infection rates were peaking.⁶⁷ Nzomo remarks on the fight by destitute urban women to preserve their source of livelihood:

Poor urban women have defied government directives and threats against informal income-generating activities in non-designated urban areas. The hide-and-seek game between women hawkers and law enforcement agents has increased, and despite AIDS, female prostitution is on the increase; women beggars with their children and even elderly women are a common sight, especially in Nairobi.⁶⁸

The issue of female prostitution, a significant driver in Kenya’s HIV/AIDS epidemic, is especially noteworthy.⁶⁹ Reduced employment opportunities mean that many female urban migrants have turned to offering sex in exchange for money or vital goods or services; the riskier the services offered the higher the fees.⁷⁰ On the shores of Lake Victoria in Western Kenya, informal affiliations have evolved based on such exchanges: the “jaboya” relationships which involve male fishermen and the women dependent on them for their catch, boost local HIV infection rates. One fisherman interviewed for *IRIN/PlusNews* said he had many girlfriends, one of whom stated that her economic circumstances prevented her from leaving the relationship although she had a steady boyfriend. As for condoms, which neither respondent admitted

⁶⁶ *ibid*, at 82-3

⁶⁷ *ibid*, at 81-2

⁶⁸ *ibid*, at 91

⁶⁹ An estimated 14% new HIV infections in Kenya are linked to sex work, that is, infections “among sex worker, their clients, or other sex partners.”(UNAIDS, *Global Report: UNAIDS Report on the Global AIDS Epidemic, 2010*, 2010, at http://www.unaids.org/documents/20101123_GlobalReport_em.pdf, accessed 12/12/10, at 30). See also UNAIDS/WHO, *Sub-Saharan Africa: AIDS Epidemic Update Regional Summary*, 2008, at http://data.unaids.org/pub/Report/2008/jc1526_epibriefs_ssafrica_en.pdf, accessed 10/10/09, at 15-16, for more on the role of the commercial sex industry in driving Kenya’s epidemic.

⁷⁰ See Schwandt, Michael, *et al*, ‘Anal and dry sex in commercial sex work, and relation to risk for sexually transmitted infection and HIV in Meru, Kenya’, *Sexually Transmitted Infections*, 21st June 2006, at <http://sti.bmj.com/cgi/rapidpdf/sti.2006.019794v1>, accessed 21/05/08, at 7 (This issue is addressed in the wider context of myths about African sexuality in the next chapter.)

using regularly, she said: "I know condoms are good, and I would want to use them if I had the power, but the power belongs to somebody else, not me."⁷¹

Carolyn Baylies, *et al*, write of the commodification of sex in an urban neighbourhood in Zambia, where their interviews reveal that "the exchange of sexual favours is not just a 'survival strategy' but routinised as an accessory to other commercial transactions... ." ⁷² Those women- and the many men, for this is perhaps even more applicable to them- who turn to commercial sex work as an income-earner of last resort may have a strong sense of guilt about this 'choice' because of the combination of moral or cultural norms that dictate sexual relations in society (Chapter 3). The stigma associated with commercial sex work or even the suspicion of it, coupled with that attached to HIV/AIDS, has a powerful effect on PLWHAs, as interviewees throughout this research reveal. These perceptions undoubtedly mould sex-workers' subjectivities and appear also to shape their ideas about their entitlements to assistance from their families, communities, religious organizations, the State, NGOs and other actors that play a role in providing PLWHAs' health needs. It is likely that they may be less compelled to seek help not just because of possible feelings of shame or embarrassment but because they may not think they deserve or are entitled to any assistance: they may believe that they have violated a strict moral or cultural code, one that they, too, share.

All the above confirm the objections raised by Rugalema and others about the analysis of 'coping strategies' sometimes employed in studies into the effects of HIV/AIDS on households. The coping concept, which suggests that households and communities have plans (strategies) to enable them recover from the consequences of the epidemic and resume or even better their previous living standards, is questionable, even cynical.⁷³ Rugalema suggests that households react to needs as

⁷¹ *IRIN PlusNews* 'Ooko and Pamela- Snapshot of a Jaboya Relationship,' February 9th 2010, at <http://www.plusnews.org/Report.aspx?ReportId=88042> , accessed 12/02/10.

⁷² Baylies, Carolyn, *et al*, 'AIDS in Kanyama: Contested Sexual Practice and the Gendered Dynamics of Community Interventions,' in Baylies, Carolyn, and Bujra, Janet, *AIDS, Sexuality and Gender in Africa: Collective Strategies and Struggles in Tanzania and Zambia* (London: Routledge, 2000) at 100

⁷³ Rugalema, 'Coping or Struggling? A Journey into the Impact of HIV/AIDS in Southern Africa,' (n 31). Rugalema attributes the rise of the coping strategies framework to studies around famine and doubts its suitability to the HIV/AIDS epidemic. He gives 'coping' its everyday meaning: "...to overcome a difficult situation so that, for example, after a disaster or other major setback, a household is able to

they reveal themselves, disposing of their much-needed assets as the requirements of illness or death demand.⁷⁴ At the core of this concept is the market system (and the presumption of an individual, household or community's ease of access to, and engagement with, it), rather than dependence on the State, and has its ideological roots in neo-liberal, free-market thinking.⁷⁵ Paradoxically, so do theories of individual human rights; but while the coping concept envisions limited State involvement in providing basic needs for the poor, individual human rights theories entrench the State as the main partner in the human rights dynamic, clearly demarcating its obligations not only to protect the individual but, as countless human rights instruments now recognize, to provide socio-economic needs such as healthcare. The market's disenfranchisement and impoverishment of the poor⁷⁶ is also revealed more starkly by the current financial crisis.⁷⁷ But as an exploration into access to Kenya's most valuable resource now shows, significant facets of this disenfranchisement predate both the financial downturn and the HIV/AIDS epidemic.

III. Land: Inequality of Access

Access to resources, pivotal to bearing the costs of long-term, debilitating health concerns like AIDS, also influences the pattern of HIV infection. The interviewees' responses on their nutritional and financial needs especially brought into sharp focus the issue of poverty, which is the difference between socio-economic rights as rhetoric and reality. And with land being Kenya's primary resource, it is perhaps unsurprising that poverty issues featured highly in the responses given the representation among the interviewees of two key demographics with restricted access to it. The first is that of informal settlement dwellers, of the whom there were

regain its former living standard, or even surpass it." (at 538) See also Barnett and Whiteside (n 9), at 350-352.

⁷⁴ Rugalema 'Coping or Struggling? A Journey into the Impact of HIV/AIDS in Southern Africa,' (n 31), at 541

⁷⁵ *ibid*, at 539

⁷⁶ *ibid*, at 540; Barnett and Whiteside (n 9), at 351

⁷⁷ See the economic update from the World Bank of the effects on Kenya of the ongoing financial crisis, and the slow recovery at: World Bank, 'Kenya Still Standing Despite Four Major Shocks,' 17th December 2009, at

<http://web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/AFRICAEXT/KENYAEXTN/0,,contentMDK:22421627~pagePK:1497618~piPK:217854~theSitePK:356509,00.html>, accessed 10/02/10. See also *The Daily Nation*, 'Why the State's Economic Stimulus Plan Must Work,' 1st January 2010

a self-declared number from the Nairobi's Kibera.⁷⁸ In 2009, the Ministry of Land noted that “[t]he essence of ‘informal’ or ‘spontaneous’ or ‘squatter’ settlements is the absence of security of tenure and planning [which presents] a challenge for land planning and development.”⁷⁹ The second demographic with restricted access to land is women⁸⁰, who comprised most of the respondents. Residents of informal settlements are particularly marginalised, and destitution and food insecurity overlap here with the greatest devastation.⁸¹

Women's dependence on relationships with men for access to land will be recalled from Chapter 3. This accentuates the importance of marriage, divorce and inheritance rights.⁸² Although by State law daughters can inherit land from their fathers today, in practice women's access continues to rely on their association with men, depriving many of the benefits enjoyed by their male counterparts.⁸³ These limited rights equate to limited citizenship and lack of access to, or control over, resources remains “the single most important cause of gender inequality on the continent.”⁸⁴ Citizenship entails the recognition of their right to access assets as individuals unmediated by men and to participate similarly in public life, and will be explored in more detail in coming chapters.

The previous chapter previewed the consequences of the new colonial system of land tenure, which promoted individual titling and ownership. The advantages of the

⁷⁸ A 2001 UN-HABITAT estimate, the most recent on offer, puts the slum-urban ratio in Kenya at 71%. (UN-Habitat, ‘Kenya’, 2007, at <http://www.unhabitat.org/categories.asp?catid=206>, accessed 20/09/07)

⁷⁹ Republic of Kenya, Ministry of Lands, *Sessional Paper No. 3 of 2009 on National Land Policy* (Nairobi: Government Printer, August 2009), 49.

⁸⁰ *ibid*, at 7

⁸¹ WFP, 2007b, ‘Kenya’, at http://www.wfp.org/country_brief/indexcountry.asp?country=404, accessed 18/04/07

⁸² See Karanja, P. W., ‘Women's Land Ownership Rights in Kenya,’ *Third World Legal Studies* (1991), pp. 109-136, at 109

⁸³ “[T]he Law of Succession Act gives daughters the same rights as sons to inherit their parents' property. Once a disposition in favour of a daughter is made, it cannot be voided by reason only that it was made to a daughter who will eventually have access to land through marriage. This, however, does not guarantee her full enjoyment of the land or protect her from being dispossessed by her brothers, especially where the land has not been registered in her name. The Act also does not require the equitable distribution of a parent's assets amongst his or her children and particularly, it does not obligate a father to provide for a daughter. The practice therefore is that fathers continue the customary practice of transferring land to their sons on the assumption that a daughter will marry and gain access to land through her status as a wife.” (*ibid*, at 131)

⁸⁴ Tamale (n 64), at 51

process were promoted on the basis that it had “great advantages in giving the individual a sense of security in possession”; resolving the “present unsatisfactory fragmented usage of units of an economic size”; and unshackling culturally-constrained Africans by providing them with new avenues for socio-economic “mobility and private initiative.”⁸⁵ Okoth-Ogendo argues, however, that behind these publicized motives lay darker ones as the colonial government struggled in the mid-1950s to hold back the mounting pressure for political, social and economic reform: for the “[i]ndividualisation of tenure was also.... a political instrument which could be used to blunt African demands for land redistribution.”⁸⁶ Nevertheless, the land titling juggernaut progressed, and its effects soon became visible: social dislocation and the dissipation of community networks, and evidence, too, for the first time, of the depth of the landlessness problem among Africans.⁸⁷

Decades later, the latter outcome has continued and worsened as the process of individual titling has been sustained in the post-independence era. For one interviewee for this research, landlessness meant that a valuable possible source of income and sustenance was beyond her reach: “[I]f I was given a place to build some rooms and told I can rent them out and collect the rent at the end of every month—that’s what I would do. Or if I was given a plot to farm, I could help my children.” (Interviewee 37)

Akinyi Nzioki estimated that two million people- approximately 400,000 families- were landless in 2002, noting a year-on-year increase of 1.5%.⁸⁸ Individual land titling may account for part of this acceleration and further aggravate the positions of traditionally marginalized groups like women; Jean Davison, for instance, has argued that women under the land-titling regime farm significantly smaller parcels of land

⁸⁵ Okoth-Ogendo, H.W.O., *Tenants of the Crown: Evolution of Agrarian Law and Institutions in Kenya* (Nairobi: Acts Press, 1991), at 70

⁸⁶ *ibid*, at 71.

⁸⁷ *ibid*, at 75-6.

⁸⁸ Nzioki, Akinyi, ‘The Effects of Land Tenure on Women’s Access and Control of Land in Kenya,’ in An-Na’im, Abdullahi A. (ed.), *Cultural Transformation and Human Rights in Africa*, (London: Zed Books Ltd, 2002) at 239. It must be noted that Nzioki actually lists the estimated figure of landless as “two billion people.” However, this appears to be a typing error as such a figure would be clearly absurd in reference to a country whose current population, following the preliminary results of the population census of late 2009, is estimated at 38.7 million. (Reported in *The Daily Nation*, ‘Kenyan Population Up to 38.7m: Draft Report,’ 22nd January 2010)

than their mothers before them.⁸⁹ Nzioki, moreover, quotes a study by Parker Shipton which indicates that the promise of ready cash from land sales convinces many poverty-stricken new title-holders to sell their assets.⁹⁰ Yet Gray and Kevane note government efforts in a 1990 administrative directive to ameliorate the new titling regime's inherent discrimination against women, which sought to limit men's rights to selling land without their wives or children's consent.⁹¹ Additionally, Thomas Pinckney and Peter Kimuyu, in their 1990s study of the agriculturally viable Murang'a District, also pointed out a shortage of land-secured credit and government policies designed to obstruct land sales that may trigger family disputes.⁹² Their statistics, they argued, offered no tangible evidence that purchase and sale of land enabled by the individualizing of titles was responsible for such inequality.⁹³

Yet there are often discrepancies between policy on paper, however well-meaning, and practice. Furthermore, while Pinckney and Kimuyu's studies are insightful on a quantifiable activity in one specific region of Kenya at a specific time and the impact upon it- or otherwise- of land-titling, their analysis is arguably narrow: it does not contextualize the process of individualization of tenure or address its wider effects, particularly on traditionally disadvantaged groups like women. In this regard, there are a couple of noteworthy points, relevant to earlier discussions about deteriorating household food security, lack of economic autonomy for women and the accelerated urban migration⁹⁴, all with consequences for the HIV/AIDS epidemic.⁹⁵ Firstly, the land titling process, which consisted of three stages- adjudication, consolidation and

⁸⁹ Davison, Jean, 'Who Owns What? Land Registration and Tensions in Gender Relations of Production in Kenya,' in Jean Davison (ed.), *Agriculture, Women and Land: The African Experience* (Boulder: Westview Press, 1988), quoted in Gray, Leslie and Kevane, Michael, 'Diminished Access, Diverted Exclusion: Women and Land Tenure in Sub-Saharan Africa,' *African Studies Review*, Vol. 42, No. 2. (1999), pp. 15-39, at 24

⁹⁰ Nzioki (n 88), at 239

⁹¹ This directive, they add, permits "the first child as the representative of all the children and allowing female children to have a say in stopping land sales." (Gray and Kevane (n 89), at 26)

⁹² Pinckney, Thomas C. and Kimuyu, Peter K., 'Land Tenure Reform in East Africa: Good, Bad or Unimportant?' *Journal of African Economies*, Vol. 3, No. 1 (1994), pp. 1-28, at 10

⁹³ In fact, Pinckney and Kimuyu suggest that between 1977 and 1991 in Murang'a, the area in central Kenya where one of their investigations was conducted, there was actually a slight decrease in land inequality. (ibid, at 21-22)

⁹⁴ The Ministry of Lands quotes the 1999 Population Census as indicating an, "overall growth rate of Kenya's urban population [of] 6% implying a very rapid rural-urban migration pattern." (Republic of Kenya, *Sessional Paper No. 3 of 2009 on National Land Policy* (n 79), at 5.)

⁹⁵ See ibid, at 50, in which the Ministry of Lands "recognizes...as cross-cutting issues requiring special intervention: poverty, HIV and AIDS, youth and gender issues, and corruption."

registration- was almost entirely dominated by men.⁹⁶ This, as Nzioki observes, meant that women's interests were largely unrepresented.⁹⁷ Secondly, to facilitate the conversion of multi-layered, intersecting traditional rights into individually-held ones, families resorted to selecting one member in whom to invest these new ownership rights, almost always the male head of the household, either the husband or eldest son.⁹⁸ So tenure is overwhelmingly male, leaving women with no source of collateral for loans through which they might invest in the improvement of crop production⁹⁹ or seek to improve their economic positions.¹⁰⁰ Gray and Kevane note Shipton's 1988 investigation of tenure reform in Western Kenya's Nyanza Province, which found that seven years after its completion only 7% of the land parcels had women registered as sole or joint owners.¹⁰¹ The vast proportion of title-holders is male although individualization of title has benefitted some wealthier women who acquired land for themselves and could thus transfer it as they wish.¹⁰² And the production of modern property rights through individualization of title must be seen as synonymous with the production of power, be it socio-economic or political.

As Kameri-Mbote stresses, this has further entrenched the notion of land-ownership as the sole domain of male family members and given them unprecedented rights in the land to the exclusion of certain family members. She highlights the lack of awareness among family members of the extensive privileges now held by those they had nominated for ownership rights, and the assumed expectation that customary rights of usage and access would automatically remain protected: but the Registered Land Act (1963) does not acknowledge women's customary rights of use.¹⁰³ Consequently, they are dependent on the title-holder's goodwill.¹⁰⁴

⁹⁶ Angelique Haugerud notes writes: "The initial phase of defining and adjudicating clan and individual rights to particular parcels of land involved both clan elders and appointed officials such as assistant chiefs and chiefs." (Haugerud, Angelique, 'Land Tenure and Agrarian Change in Kenya,' *Africa: Journal of the International African Institute*, Vol. 59, No. 1 (1989), pp. 61-90, at 63)

⁹⁷ Nzioki (n 88), at 237.

⁹⁸ Karanja, P. W. (n 82), at 122

⁹⁹ *ibid*

¹⁰⁰ Haugerud (n 96), at 81

¹⁰¹ Gray and Kevane (n 89), at 24

¹⁰² *ibid*, at 29. Also Kameri-Mbote, Patricia, 'Gender Dimension of Law, Colonialism and Inheritance in East Africa: Kenyan Women's Experiences', *International Environmental Law Research Centre (IELRC) Working Paper 2001-1*, at 14, at <http://www.ielrc.org/content/w0101.pdf>, accessed 12/10/05.

¹⁰³ She observes: "According to the registration statute, a right of occupation at customary law would only be protected if noted on the register which many families did not bother to do for they saw no possibility of a piece of paper vesting any more rights in the family representative than he would have

Three things emerge: one, although registration of title can and did address some problems relating to security of tenure, outcomes were mixed.¹⁰⁵ It has proved difficult to adapt the new system of tenure to a context of all-inclusive, intersecting land rights, a process which, to reiterate Shipton as quoted by Nzioki, “can never be free of disagreement, deceit, and difficult compromise, and... can sometimes tear families apart.”¹⁰⁶ In some cases, various classes of women- the unmarried, divorced or separated- lost the cultivation rights they enjoyed in their fathers, brothers or sons’ land under customary law.¹⁰⁷ And yet there is a confluence in the objectives of the State and custom: recalling the discussion in Chapter 3 about the interconnecting themes of land and patriarchy, the State, appears to have assumed an even harder line than custom, and has arguably used its legislative machinery and processes to embed its disapproval of women whose attempts to elevate their social status are considered counter-normative. That the titling system should enhance the more sinister aspect of land as a divisive asset rather than the real and symbolic commodity on which familial and community bonds are based is worrying, especially in light of the significance of these links during crises like the AIDS epidemic.

Secondly, Kimeri-Mbote brings under scrutiny Kenya’s post-independent legal plurality¹⁰⁸, which has its roots in the colonial era, where settler land was governed by English law and ‘African’ land was subject to African law, a legal dualism which though formal did not guarantee African property rights from incursions by the colonial State

had at custom. Cases of such family representatives seeking to evict the other family members from the family land escalated. Africans still continued to look upon registered land as family land and perceived the person registered as a trustee of the members of the family.” (Kimeri-Mbote (n 102), at 7)

¹⁰⁴ Ikdahl, I.; Hellum, A.; Kaarhus, R.; Benjaminsen, T.A.; and Kimeri-Mbote, P. ‘Human Rights, Formalisation and Women’s Land Rights in Southern and Eastern Africa,’ *Studies in Women’s Law*, No. 57 (July 2005), at 91. See *Kenya Law Reports*, ‘Registered Land Act, Laws of Kenya,’ Chapter 300, at http://www.kenyalaw.org/kenyalaw/klr_app/frames.php (accessed 10/02/10)

¹⁰⁵ Frank Place and S. E. Migot-Adholla point out the mixed outcomes of the implementation of the Swynnerton Plan: the “registration program increased tenure security in Kisii (district) [but] it was found to decrease tenure security in the form of new disputes in Mbeere.” (Place, Frank and Migot-Adholla, S. E., ‘The Economic Effects of Land Registration on Smallholder Farms in Kenya: Evidence from Nyeri and Kakamega Districts,’ *Land Economics*, Vol. 74, No. 3 (1998), pp. 360-373, at 360)

¹⁰⁶ Nzioki (n 88), at 237-8. She also notes the difficulty that many farmers encounter trying to deal with new rules about recording land transactions.

¹⁰⁷ Haugerud (n 96), at 66

¹⁰⁸ See also Kimeri-Mbote, Patricia, ‘The Land Has Its Owners: Gender Issues in Land Tenure Under Customary Law in Kenya,’ *IELRC Working Paper, 2005-9*, International Environmental Law Research Centre (IELRC), at <http://www.ielrc.org/content/w0509.pdf>, accessed 20/12/09

as it set about furthering its project.¹⁰⁹ Despite the primacy of the State's legal framework (which the new Constitution would maintain to the extent of any discrepancy¹¹⁰), a customary regime co-exists within and alongside it. But such integration is not seamless and clear. Customary notions of land ownership have influenced and been influenced in their practice by the system of individual titling, with some observers arguing that their apparent defects stem from being left to informally adapt to the altered environment.¹¹¹ The resulting confusion returns to Mamdani's thesis of the unresolved bifurcated State and the blurred postcolonial line that separates the spheres governed by civil and customary law. Place and Migot-Adholla observe that possession of a land title certificate rarely indicates the rights a farmer claims to the land, with some title-holders declaring they have no rights to sell while others with no such title nevertheless asserting such rights.¹¹² It is noteworthy that many family members appear to continue to exercise their customary land rights even after the land has been registered under individual male household heads.¹¹³ Interestingly, some have even forgone the acquisition of title altogether either because they perceive the costs of the process as outweighing the benefits¹¹⁴, or to minimize conflict and tensions.¹¹⁵

This legal forum-shopping is perhaps the inevitable result of plurality and maybe the best outcome under the circumstances. Arguably, it allows litigants to choose which regime defines and addresses their conflict better and offers more favourable chances of reaching mutually acceptable outcomes. Indeed, the new Constitution asserts as an overarching principle of government land policy the "encouragement of communities to settle land disputes through recognized local community initiatives consistent with this Constitution."¹¹⁶ This means that such initiatives must not have outcomes abhorrent to those principles which the government would be obligated to pursue in its land policy; these are enunciated in Chapter Five, Art. 60(1) and include:

¹⁰⁹ Okoth-Ogendo (n 85), at 18-19.

¹¹⁰ Republic of Kenya, *Laws of Kenya: The Constitution of Kenya* (n 3), Art. 2(4).

¹¹¹ Ik Dahl, *et al* (n 104), at 85

¹¹² Place and Migot-Adholla (n 105), at 371

¹¹³ Nzioki (n 88), at 238. Also, Pickney and Kimuyu (n 92), at 23

¹¹⁴ Place and Migot-Adholla (n 105), at 371

¹¹⁵ Pickney and Kimuyu (n 92), at 24. Place and Migot-Adholla point out that "[s]uch disputes are perhaps inevitable under any tenure regime given the high population pressure coupled with few opportunities outside of agriculture." (Place and Migot-Adholla (n 105), at 371)

¹¹⁶ Republic of Kenya *Laws of Kenya: The Constitution of Kenya, 2010* (n 3), Art. 60(1)(g)

ensuring “(a) equitable access to land”¹¹⁷; [and] “(b) security of land rights.”¹¹⁸ Crucially, as seen in Chapter 3, it proscribes gender discrimination in State, customary or other policies associated with land or property in land.¹¹⁹ How these community/customary authorities would share their tasks with the National Land Commission (which the Constitution proposes to establish (Art. 67 (1)) and other relevant government agencies is unclear, although the National Land Policy of 2009 asserts a desire to streamline land disputes institutions and mechanisms.¹²⁰ To the majority of Kenyans, the former are likely to be the fastest and most accessible means of settling disputes; and yet they come with the baggage of structures and norms that entrench male power. However, both dispute resolution systems, in fact, can be rightfully accused of being male-dominated, as much of Kenyan public life is, and women’s participation will continue to be curtailed either way.¹²¹

The new Constitution’s recognition of the need for gender equity in land distribution is, of course, significant: it would provide a legal basis for challenging State failure to redress gender inequality and enshrining these ideas in a national constitution rather than piecemeal legislation carries greater weight. However, realizing these policies presents a massive challenge: Nzomo and Kamari-Mbote, while lauding the efforts of an earlier, similar draft constitution in addressing gender equality and equity issues¹²², crucially observe that the law does not exist in a vacuum and the existing

¹¹⁷ The second part of this principle- “and associated resources”- formerly contained in the Harmonized Draft of 2009 (see Chapter Seven: Art. 77(2) (a), Committee of Experts on Constitutional Review (CECR), *Harmonized Draft Constitution of Kenya*, 17th November, 2009, on the website of The Local Democracy, Peace and Human Security, University of the Western Cape, at <http://www.ldphs.org.za/resources/local-government-database/by-instrument/constitution>, accessed 12/03/10), has not survived into the new Constitution, and given the role of land as the primary mode of production, appears to place significant limits on the scope of this requirement.

¹¹⁸ Again, this principle has been truncated from the earlier version to be found in Art. 77(2)(b) of the 2009 Harmonized Draft; this read, “security of land rights for all land holders, users and occupiers in good faith.” The section retained provides greater room for interpretation; in particular, the omission of the requirement of good faith does not, prima facie, preclude the claims where land rights were acquired in bad faith, as is so often the case in Kenya. (ibid)

¹¹⁹ All from Chapter V, ‘Land and Environment’, Art. 60(1). (Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010* (n 3))

¹²⁰ Republic of Kenya, *Sessional Paper No. 3 of 2009 on National Land Policy* (n 79), at x

¹²¹ Nzomo, Maria and Kamari-Mbote, Patricia, ‘Gender Issues in the Draft Bill of the Constitution of Kenya: an Analysis (Contribution for the Constitution Review Commission of Kenya),’ *IELRC Working Paper 2003-1*, at <http://www.ielrc.org/content/w0301.pdf>, accessed 21/11/09, at 2

¹²² The new Constitution retains many aspects of the 2009 Harmonized Draft Constitution, which in turn replicated the 2005 Draft Constitution (Wako Draft) with regards to the relevant sections here on land and property and human rights. The Wako Draft failed to be adopted after a national referendum

social, economic and political environment hinder *de facto* change.¹²³ So, too, the new Constitution and its gender-related programme: its commitment to a human rights-based approach must be accompanied by efforts to eliminate the numerous obstacles on the ground.¹²⁴

The friction between State and customary law feeds into discussions about responses to the modern State's attempts to bring the population within its centralized domain, away from the customary. While the State and its power still often appears remote, particularly at the domestic level, the customary realm and its norms continue to loom large. The promulgation of the human rights enterprise at the grassroots significantly depends on the acceptance of State authority. If significant numbers still defer to customary authorities and norms, especially in the domestic arena where many human rights violations begin- discrimination, violence against women, lack of access to healthcare, among others- then rights advocates must seriously consider the fundamental impediment that this entails for the inculcation of their paradigm of rights and its notions of entitlement. They must address the limited success of the postcolonial State in exerting its authority in key aspects of social, economic and cultural life and its failure to cultivate the moral authority that might earn it greater prominence in the collective imagination of its citizen-subjects.

Thirdly, Kameri-Mbote's observations about the unforeseen consequences of individualized land tenure underscore the difficulty in attempting to graft one idea, with its own internal logic and dynamics of rights and obligations, onto another where these terms entail altogether different things. There is an interesting paradox here, for example: the modern human rights enterprise, with the individual as its focal point, advocates precisely the kind of individualization of rights that absolute land titles bestow and which are intended to provide a bulwark against State or corporate encroachment. Yet here that same individualization of rights, propagated as it is within an already highly unequal context, further embeds the disparity. Men naturally benefit the most from a system of tenure which permits the establishment

in November 2005, although the main sticking points related to competing ideas about governance and the apportioning of executive power.

¹²³ Nzomo and Kameri-Mbote (n 121), at 14

¹²⁴ For a detailed analysis of a human rights-based approach to addressing inequalities of women's access to land see Ik Dahl, *et al* (n 104)

of absolute individual claims to the land, unfettered by the obligations of custom.¹²⁵ In effect, they acquire a new set of rights backed by the State machinery. It is, as Gray and Kevane put it,

...the right to go before the formal apparatus of the state and trump informal claims to land. Under formal titling women are dually condemned; land is no longer available through customary channels and women are severely restricted in their financial and social ability to gain land through government or market routes.¹²⁶

Successive systems of land tenure have continuously abandoned women to the unpredictable and unsecured goodwill of their male kin and can be rightfully said to have helped establish a conducive environment for the country's HIV/AIDS epidemic. Widows are especially vulnerable.¹²⁷ Some, Karanja writes, were not considered heirs on their husbands' death and therefore risked losing their rights to land¹²⁸; others, formerly custodians of the family land on behalf of their male children, saw it sold without their permission. Widows without male children were at even greater risk as the land would often revert to their husband's relatives.¹²⁹ Interviewee 5, who articulated at length her fears of losing her land should her husband, also a PLWHA, predecease her, felt that local government officials could intervene to educate opportunists, particularly in the rural areas:

...You see, they are saying funny things especially in the countryside. You find that when you're infected and your brother is there and he knows you're infected, and this man is married, he has kids and they start planning how they will sell your *shamba* (piece of land). And these are things that the Chief and the DO can put a stop to and tell them, 'My friend, even if your brother is weak, it doesn't mean that you have you have to take all his land because your brother is dying.' But you find that when such things are happening, the women, we're the ones who suffer most. You end up now going back home (your place of birth) because you don't even have a small *shamba* to cultivate. So that means that your husband has died and you don't own anything...They should help because this problem starts from the grassroots. You're told that 'from today, no vegetables in this *shamba* for you. If you're found here taking vegetables, you will see stars (be beaten)!' That is after your husband has died. And if you go to that *shamba* and get even one green maize, you will even be beaten. So you find life in that homestead very difficult and you decide to leave.

¹²⁵ Kameri-Mbote makes a similar observation. (Kameri-Mbote (n 109), at 14

¹²⁶ Gray and Kevane (n 89), at 24

¹²⁷ Republic of Kenya, *Sessional Paper No. 3 of 2009 on National Land Policy* (n 79), at 51

¹²⁸ Karanja, P. W. (n 82), at 127. She writes: "Customary laws of inheritance, which are still highly respected even in areas under land reform, preclude a daughter's right to inherit land. A widow under customary tenure could not pass land to her daughters and her land passed to her husband's male relatives. Under current land legislation, a widow whose children are female may be effectively unable to pass on land to her daughters, not because legislation precludes it but because it would be considered socially unacceptable. To pass such land to daughters would threaten the territorial integrity of the clan upon marriage, which though not legally wrong, would, however, still be considered socially unacceptable." (at 128)

¹²⁹ *ibid.* See also Gray and Kevane (n 89), at 25

But Karanja also points to some of the socio-cultural reasons why women and widows do not proactively seek to secure their land rights when opportunities arise to do so: these range from lack of awareness about these rights which meant, for instance, that widows seldom transferred land rights to themselves after their husbands' deaths, "and indeed do regard themselves as trustees for their male children until those same male children grow up and kick them out!"¹³⁰ Additionally, women who might be able to buy land sometimes abandoned the effort if it might threaten the husband's status in the home and result in marital discord.¹³¹

A point must be made, too, about the move towards cash crop production, one of the underlying reasons for land tenure reform in the colonial period in the first place. This shift increased the economic value of land, intensifying the erosion of women's rights to land and further concentrating its economic benefits in male hands.¹³² Ironically, moreover, the agricultural labour burden onto women increased contemporaneously, effectively devaluing their contribution to the mode of production.¹³³ The effects of increasing cash crop production are far-reaching: the transferral of household income from women to men affects the quality and quantity of household nutrition, normally a woman's domain.¹³⁴ Further, it accentuates farmers' dependency on the unpredictable cash-crop market and therefore potentially affects their food and healthcare budgets, while also reducing the amount of land available for food production, which may also contribute to a wider rise in food prices, thus further aggravating food insecurity.¹³⁵

¹³⁰ Karanja, P. W. (n 82), at 132. Karanja quotes a study by Florence Butegwa in 1986 in Nairobi and Busia, in which nearly 60% of the 400 women interviewed thought they had no right to own property in their own names.

¹³¹ *ibid*

¹³² Karanja, P. W. (n 82), at 123 and 117. See also Gray and Kevane (n 89), at 33. See also Nzioki (n 88)

¹³³ *ibid*, at 232

¹³⁴ Falconer, J. and Arnold, J.E.M., *Household Food Security and Forestry: An Analysis of Socio-Economic Issues*, FAO (1991), at <http://www.fao.org/docrep/006/t6125e/T6125E01.htm>, accessed 27/09/07. The 2009 KDHS report indicates that 83% of married women respondents made the decision on what food to cook independently. (Kenya National Bureau of Statistics (KNBS), *et al*, *Kenya Demographic and Health Survey (KDHS) 2008-09*, KNBS, June 2010, at <http://www.measuredhs.com/pubs/pdf/FR229/FR229.pdf>, accessed 13/12/10)

¹³⁵ One discussion of this is to be found in Falconer and Arnold, *op.cit.*, whose report details the socio-economic effects of deforestation for the purposes of agriculture.

The advent of land titling, thus, in consolidating parcels of land under mainly male title-holders, replicates the worst aspects of customary systems of tenure. It is this crucial point that Pinckney and Kimuyu's findings do not capture; mere statistics on sales and purchases of land cannot tell the whole- or even, perhaps, significant part of- the story of land inequality. Replacing previously-held obligations to guarantee access with mere goodwill wrenches a crucial lever of power from the hands of women. Gray and Kevane also highlight the grave consequences for women, still reliant on their relationships with men to access land, in the face of population growth and corresponding land scarcity. They point to a development in Kisii, Western Kenya, which they say is not unique to this country, where a new category of landless women arose for whom bridal wealth was not paid due to shortage of land but who nevertheless entered into informal relationships with men or eloped with them. Such marriages had no legal status until the men agreed to pay the brideprice, which might happen over a long period of time, leaving the women vulnerable; as yet unintegrated into the patrilineal system of tenure which provided them and their offspring with access to land, they could arbitrarily be evicted from the home.¹³⁶ The figures given for eloping women worryingly increased from 26% in the 1960s to 87% in the 1980s.¹³⁷ Such dependency exacerbates the inequality of women's resources and their stake within the wider system of power. Arguably, only the increase in other forms of property other than land such as cash can be said to most aid women's economic empowerment. But, as noted above, in a mainly agriculture-based economy like Kenya's even this is inevitably closely allied to land and, for the majority of rural-dwelling women in particular, access to land remains fundamental to income and livelihood.

IV. Women, Resources and HIV/AIDS

It is hard to overemphasize the interconnectedness of the themes of ownership and control of resources, gender disparity and HIV/AIDS. Despite Nzioki's worthwhile caution not to treat women as a monolith¹³⁸, they nevertheless traditionally relied on

¹³⁶ Gray and Kevane (n 89), at 20-1

¹³⁷ *ibid*, at 21

¹³⁸ She accounts for differences in status and rank, comparing, for example, the greater allocation for a traditional chief, and therefore for a chief's wife, as opposed to an ordinary member of the community, and hence his wife; a disparity, too, between the first wife and her co-wives. (Nzioki (n 88), at 232)

their association with men to access resources, making marriage- and remaining in marriage- crucial to their economic security, even when the conditions are unfavourable and may even increase the risks of HIV infection.¹³⁹ For instance, the preliminary report of the 2008-9 Kenya Demographic and Health Surveys (KDHS) revealed that nearly 40% of married, divorced or separated female interviewees aged 15-49 years reported physical or sexual abuse by husbands, although this was down 5% from the 2003 study.¹⁴⁰ (There was a correlation, too, between socio-economic background and the prevalence of physical violence.¹⁴¹) 15% of married women had been sexually abused, 2 percentage points up from 2003. The report further shows that among interviewees who reported having had sex in the previous 12 months, twice as many men (38% to 18% women) were likely to engage in higher-risk sex, defined as sex with non-marital, non-cohabiting partners.¹⁴²

The link between marriage and access to resources is of immense significance to the spread of HIV/AIDS. Many female respondents interviewed for this research cited their husbands' sexual infidelity as the source of their infection. Some of these responses have already been reviewed. Interviewee 30, for instance, noted in Chapter 2, detailed the friction wrought by the discovery of the infection and exemplified the tragic dependency of a wife upon her husband for hers and her children's material survival and the sometimes grave consequences of pursuing the social respectability associated with marriage. It is noteworthy that the respondent was employed as a post-office messenger at the time of the interview, and that she made references to having held a job or jobs at various other points. Nevertheless, she also made references to the household's financial difficulties saying, for instance 'We had nothing' and 'I had no money to make any milky tea or even make food for the children...' So despite periodic employment, it would seem that she hardly earned enough to cater for hers and her children's needs, which, alongside the social

¹³⁹ In Kenya, an estimated 44% of "people newly infected through heterosexual HIV transmission are infected within marriage or cohabitation." (UNAIDS, *Global Report: UNAIDS Report on the Global AIDS Epidemic, 2010* (n 69), at 30)

¹⁴⁰ Office of the Prime Minister, *Official Launch of 2008/2009 Kenya Demographic and Health Survey Preliminary Report*, November 5 2009, available on the website of Ministry of State for Planning, National Development and Vision Twenty Thirty, at http://www.planning.go.ke/index.php?option=com_docman&task=cat_view&gid=55&Itemid=75, at 2

¹⁴¹ Poorer and less educated women were more likely to suffer violence. (KNBS, *et al, Kenya Demographic and Health Survey (KDHS) 2008-09* (n 134), at 247-8)

¹⁴² Office of the Prime Minister (n 140), at 2

pressure for a woman to remain within a marriage, may explain the interviewee's reasons for maintaining the union as long as possible.

The interview also exemplified the suspicions, rumours and accusations about HIV/AIDS which pit family members against one another and weaken some of the very kinship bonds that such families might increasingly rely on in times of financial and emotional needs. Parts of her response are worth recalling here:

I used to be married. I lived with my husband but I could tell he was not trustworthy. I spoke to his parents. His mother insulted me. She said that I had insulted her and her son. When it comes to my sisters-in-law, I got the same kind of treatment. ... He would give his money away, waste it on other women. Later, I noticed he was getting ill. Every time I suggested we should go to hospital, he would abuse me and say it was not necessary...[My sisters-in-law] would beat me up but [my husband] would say to them, 'Leave this one alone. We will end up together in the same way we started together.' I think he had already told them....

Later in the interview, she picks up the story again, shifting to a period after the events above, when she was no longer living with her husband and with the help of her brothers had found a new place to live with her children. She has also, sadly, tested positive for HIV:

I can swear that from the moment I got married, I have never been with anyone else other than my husband. When I think about it I am so bitter, so bitter. Even in my area my family, my brothers, they support me because they know I am not the kind of person who moves around with men. Some people may laugh at you and asking how else then you got the disease... You see a man taking someone's young daughter, the next time you see her she is in hospital and she is ill. You ask, what is wrong with such a person?But my problem is that I was married by a man who likes to drink alcohol- he is here and there. No matter how much you tell him about this illness, he will not listen to you, until he gets ill then he will believe. (Interview 30)

This interview raises many issues that will continue to be analysed here and elsewhere. For now, it highlights the high price many women are still paying for remaining within marriages with sexually unfaithful partners. Grey and Kevane note that anything from divorce to a lack of male offspring might cost them their right to access land.¹⁴³ This raises the further question about HIV prevention strategies that may be employed by women who remain in these unions so as to continue to access resources for themselves and any children but who suspect their husbands of sexual infidelity. This may involve refusing to have sex or using prophylactics such as

¹⁴³ Gray and Kevane (n 89), at 18

condoms. More will be said on preventative methods when access to information and advice is discussed in coming chapters. It is now important to touch briefly on sexual habits and attitudes. The arena of sexual interactions encompasses gender power relations and it is here that women's social, economic, and cultural status and HIV/AIDS collide. Women who are dependent on husbands or partners for their wellbeing must balance two issues: the kind of sex they are prepared to have, why, when and with whom, and the risk of infection as well as the socio-economic benefits that may come with the relationship.

The preliminary report of the 2008-9 Kenya Demographic and Health Surveys (KDHS)¹⁴⁴ revealed, among other things, that among respondents who had sex with two or more partners in the past 12 months (in relation to which there was an urban-rural differential¹⁴⁵), only 32% of women and 37% of men said they had used a condom during last sexual intercourse. Among respondents who had sexual intercourse in the previous 12 months with a person who was neither their spouse nor a cohabiting partner, 35% of women and 62% of men reported using a condom at last sexual intercourse with that person.¹⁴⁶ Meanwhile, the detailed breakdown of a number of attitudinal indicators from the 2003 survey crucial to HIV/AIDS also revealed important, and perhaps inevitable, differentials between urban and rural populations. To start with, it noted that acceptance of women's sexual autonomy was "rather high" in Kenya, with over 50% of women and 56% of men responding that a series of hypothetical situations were all justifiable grounds for a woman's refusal to have sex with her husband.¹⁴⁷ These included knowledge that a husband had a sexually transmitted illness (STI) and knowledge that he had sex with other women. As to the first of these scenarios, amongst the female respondents, 92.1% of the urbanites as opposed to 85.4% of their rural counterparts thought a wife was justified

¹⁴⁴ The evidence in this part of the thesis is drawn from the two most recent KDHS reports from 2003 and 2008-9. Where available, reference is made to findings in most recent study and comparisons made with those on the same or similar questions in the earlier report. But on some questions there were no identical or similar data available in the latest report and the KDHS 2003 is therefore relied upon.

¹⁴⁵ Among women the urban/rural differential was 2.2% to 0.8%; among men it was 10.5% to 8.9%. (KNBS, *et al*, *Kenya Demographic and Health Survey (KDHS) 2008-09* (n 134), at 188-9)

¹⁴⁶ Office of the Prime Minister (n 140), at 2

¹⁴⁷ Central Bureau of Statistics (CBS), *et al*, *Kenya Demographic and Health Survey (KDHS) 2003*, Central Bureau of Statistics, *et al*, July 2004, <http://www.measuredhs.com/pubs/pdf/FR151/FR151-KE03.pdf>, accessed 19/09/07.

in refusing sex; on the second scenario the urban/rural differential was 85.1% to 76.7%.¹⁴⁸ There was a smaller differential amongst male respondents: 94.3% of urbanite respondents and 92.3% of rural dwellers thought a woman justified in refusing to have sex with an STI-carrying husband; 80.8% of the urbanites and 76.6% of the rural dwellers felt the same if the wife had knowledge of her husband's sexual infidelity with other women.¹⁴⁹

What is interesting, however, are what male respondents consider justified reactions to such wifely rebuffs. In the 2008-9 survey, 5% of urbanites and 10.7% of rural dwellers considered withholding money from the wife a valid reaction, both considerably fewer than in 2003¹⁵⁰; the urban/rural disparity was 3.3% to 5.2% among those who thought use of force to obtain sex justifiable under those circumstances, and 7.4% to 9.9% who favoured sex with another woman as a response.¹⁵¹ The 2008-9 KDHS report also indicated that a substantial number of women, too, particularly older and rural-dwelling, believed that a husband was justified in using physical violence on a wife who refused to have sex with him.¹⁵² When it came to attitudes towards condom use, an encouraging 81% of men and 75% of women aged 15-49 years, the most critically affected age-group in Kenya's HIV epidemic, believed that condoms could help prevent HIV; the urban/rural differential was 81.4% to 72.4%.¹⁵³ The 2003 survey recorded only a slightly lower percentage of men with knowledge of the preventive value of condoms (78%); however, it also showed that more than a quarter of them felt that a woman had no right to tell a man to wear a condom, with comparatively more urbanites so opining.¹⁵⁴

¹⁴⁸ *ibid*, at 48. Of the female respondents, there were 2,056 urban-dwelling and 6,139 rural dwellers.

¹⁴⁹ *ibid*, at 49. Of the male respondents, 907 were from urban areas and 2671 were rural dwellers.

¹⁵⁰ KNBS, *et al*, *Kenya Demographic and Health Survey (KDHS) 2008-09* (n 134), at 240. These figures were down from 2003: in the KDHS report of that year the figures were 10.3% of urbanites and 14% of rural dwellers. (CBS, *et al*, *Kenya Demographic and Health Survey (KDHS) 2003* (n 147), at 50)

¹⁵¹ KNBS, *et al*, *Kenya Demographic and Health Survey (KDHS) 2008-09* (n 134), at 240. In 2003, the urban/rural disparity was 5.7% to 10.2% among men who found use of force justifiable under those circumstances. Further, 11.5% to 10.9% in favour of a response of having sex with another woman (CBS, *et al*, *Kenya Demographic and Health Survey (KDHS) 2003* (n 147), at 50)

¹⁵² Respondents were grouped into a series of age ranges from 15-19 years to 45-49 years; the numbers endorsing such violence increase with every age category, ranging from 17.8% among 15 to 19 year-old, to 30.6% among 45 to 49 year-olds. The urban-rural differential was more than double with 11.9% urbanites to 26.5% rural-dwellers. (KNBS, *et al*, *Kenya Demographic and Health Survey (KDHS) 2008-09* (n 134), at 237)

¹⁵³ *ibid*, at 175

¹⁵⁴ When broken down, the figure was 29.8% amongst urban-dwelling men in comparison to 22.4% amongst rural-dwellers (CBS, *et al* *Kenya Demographic and Health Survey (KDHS) 2003* (n 147), at 204)

The above statistics raise a number of issues: firstly, while attitudinal statistics are a helpful in gauging how opinions may alter over time, they come with health warnings: they may not reflect respondents' actual behaviour. Secondly, the sometimes considerable urban/rural differentials are telling: for there may be perhaps a more nuanced explanation here than the fact, for instance, that there is greater availability of HIV prevention information in urban than rural areas, a fact borne out by several interviewees. It suggests that the argument made in Chapter 3 applies here, that these discrepancies can also be accounted for by looking at the different normative systems and authorities at play in these different spheres. This explanation is sustainable even if allowances are made for the fact that Kenyans today move fluidly between the physical and conceptual space of the urban and the rural. The cultural norms that so influence rural attitudes to sex and gender relations emanate from power structures based in these heartlands and it is here that they exert their greatest authority. As such, opinions here are understandably more likely to reflect the social and cultural conservatism that defines this domain.

Thirdly, the KDHS figures reemphasize the potentially deadly dependence which the durable link between a woman's access to resources and marriage often creates. The data confirms the hollowness of the old mantras urging faithfulness, condom use or rejection of unprotected sex within marriage. A significant number of men, who tend to decide whether condoms are used during sexual intercourse, do not consider it as a woman's right to unilaterally demand their use and the figures for condom use reported by the study are woefully low for a country with Kenya's HIV infection rates. Yet other respondents in the survey would find no justification in a wife's refusal of sex even if the husband has an STI, and among the apparently justified reactions to such rejection are discontinuation of the recalcitrant wife's source of money and the use of force. All this underlines the importance of strategies for HIV prevention that enhance women's individual economic autonomy. But there are bright spots in the data, too, not least in that younger women appear to hold a sense of entitlement to sexual autonomy without the risk of physical violence. This positive generational change suggests that negative attitudes about justified violence against women may be on the wane and reinforces a key argument in this research about the mutability

of subjectivities and attitudes on which individual notions of entitlements and rights are founded.

Analyzing the PLWHAs' requirements of nutrition and resources, therefore, may help illuminate a number of the broader themes tackled in this research: the evolution of notions of entitlement, citizenship and the relationships between the individual, the community and the State. It also allows us to locate land, the common denominator that binds these two requirements, in the HIV/AIDS debate. The tension between State and customary approaches to land tenure exemplifies a fundamental friction between the anticipated rewards of membership to the community of the nation-State versus those offered by membership to the community of the ethnic: the individual human rights that the State guarantees the citizen versus the privileges of kinship that the customary offers its subjects. Should the prevalent norms of the latter be allowed to limit the citizenship rights of the former? To which domain should the PLWHA pledge her allegiance to extract the most privileges: the State, which appears so remote from the individual at the point when she sits down to a plate of food, and yet assures her that she is entitled to certain basic needs?¹⁵⁵ Or the customary, whose age-old social networks may have combined to provide that plate of food but which decrees that her ownership rights to the piece of land on which she might grow it herself are limited because she may be a woman, of low social standing, and so on?

Land also appears to be implicated in the construction of subjectivity and the moulding of broader ideas about entitlements. The customary norms and processes by which it was- and still often is- acquired entrenches those norms. By virtue of its permanence and immovability, it becomes a potent symbol of the rootedness of custom and a conduit for the traditional ideas about the privileges and duties it entails. Some of these notions- obligations to guarantee certain land rights to kinship members, for instance- are beneficial. But the gender inequality and inequity that underlies them actively excludes a swathe of the population from enjoying the full rights of citizenship. Moreover, land, symbolically and practically, binds the interests

¹⁵⁵ The new Constitution of Kenya makes it the right of every Kenya "to be free from hunger and to adequate food of acceptable quality." (Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010* (n 3), Art. 43(1)(c))

of every individual that is dependent on it in ever-widening networks, from the smallest household level, to the clan, the community, the ethnic group and the nation at large. It is a manifestation of the connectedness of these networks and a repository for their shared history. Few things, then, repudiate the notion of man as an autonomous entity more successfully than land, whose productivity not only necessitates community and cooperation but whose rituals of succession and inheritance emphasize the idea of the individual only as part of a dynamic, regenerating whole. Any association with land and its resulting processes is bound to impress this fact on the individual and contribute significantly to her sense of self, her subjectivity. This is a far cry from the concept of the unfettered individual at the heart of the human rights enterprise, with rights that may be claimed against both the State and her fellows. All of these ideas will be revisited in the coming chapters.

Chapter 6: Needs and Requirements II: Psychosocial and Medical Needs

This chapter, which focuses on PLWHAs' medical and psychosocial needs, continues the empirical analysis of their main self-identified health requirements. The discussion involves a number of interconnected strands: the first explores the confluence between the psychosocial aspects of AIDS and some of the principle debates addressed by this research. Of particular importance is the effect of AIDS-related stigma. As the chapter shows, several interviewees for this research reported urban-rural differences in attitudes towards AIDS and PLWHAs. Yet PLWHAs, who often locate themselves in both domains, as seen in Chapter 4, must internalize and adapt to the conflicting value systems that their dual memberships and identities entail.

Another strand in this chapter reinforces the thesis on the dislocation of subjectivities and morphed notions of entitlement that may be wrought by HIV infection, this time expounding on the role played by the mainly sexual *mode* of infection. It draws on a number of interviewees' comments, that (alleged) violation of prevalent sexual norms may rightly disentitle individuals, including some fellow PLWHAs, from making claims against those with whom they share social and moral spaces.

Yet as the second part of this chapter illustrates social bonds remain pivotal in the realization of PLWHAs' health rights, often stepping in to fulfil the State's obligations. In a strand which buttresses arguments raised in Chapter 5 about the costs of realizing healthcare, a spotlight is thrown on the hidden expenses still associated with accessing anti-retroviral treatment (ART) despite its improved availability and accessibility.

This leads to another of this chapter's main strands: the contribution, underscored by PLWHAs' responses, of NGOs (the most visible embodiment of civil society organizations (CSOs)) and donor agencies in advocacy for, and provision of, cheaper or free ART. The interposition of CSOs in the State-citizen relationship and its

ramifications on the rights debate, a discussion addressed in more detail in Chapter 7, is already visible here. The clear role of NGOs in particular in offering PLWHAs alternative and positive narratives by which to (re)define their lived experiences, and a new vocabulary and paradigm in human rights by which to (re)conceive their identities and entitlements from the State, is of fundamental importance to this research.

I. Psychosocial Needs

Many interviewees underlined the fact that HIV affects the person at more than just the physical level: it encompasses a number of critical psychosocial elements already considered in earlier chapters. Studies have shown that problems surrounding mental health are more common among PLWHAs than the general public; yet this aspect of the epidemic and the support needs of PLWHAs remain little-investigated, particularly in poor countries where HIV infection rates are highest.¹ Moreover, these issues may have epidemiological consequences: research suggests that “psychological, psychosocial and psychiatric factors play a significant role in how well people comply with antiretroviral treatment (ART)...” with depressed subjects, for instance, showing poor adherence to treatment.²

Several respondents explicitly mentioned the need to remain stress-free as part of their key health requirements. For instance, interviewee 29 said she need a “Good diet, a good place to live, to ensure that the children are doing well, with their studies, and to live well without problems.” “I need a balanced diet, said interviewee 47, “and to take my medicine, avoid alcohol and live positive! I should avoid stress and just be happy.” Meanwhile, interviewee 14 “...[tried]to avoid stressful situations;

¹ Kelly, Kevin; Freeman, Melvyn; Nkomo, Nkululeko; and Ntlatlaba, Pumla, *The Vicious Circularity of Mental Health Effects of HIV/AIDS: Symptom and Cause of Poor Responses to the Epidemic*, Centre for AIDS Development Research and Evaluation (CADRE), 11th July 2007, <http://www.cadre.org.za/files/Mental%20Health%20Kelly%20et%20al.pdf>, accessed 02/03/10; at 3-4. This study was conducted in South Africa. See also Collins, Pamela Y.; Holman, Alea R.; Freeman, Melvyn C.; and Patel, Vikram, ‘Relevance of Mental Health to HIV/AIDS Care: What are the Mental Health Consequences of HIV?’ *AIDS*, Vol. 20, No. 12 (2006): pp. 1571-1582, at http://www.medscape.com/viewarticle/542467_16, at Section 16, accessed 02/01/10.

² Kelly, *et al* (n 1), at 10. And although it is not a focus of discussions in this thesis, underlying psychological problems are said to increase a person’s risk to HIV infection. (See Schweitzer, Ana-Maria; Mizwa, Michael B.; and Ross, Michael W., ‘Psychosocial Aspects of HIV/AIDS: Adults,’ *HIV Curriculum*, Baylor International Pediatric AIDS Initiative (updated 28/01/10), at <http://bayloraids.org/curriculum/files/25.pdf>, accessed 01/03/10; at 334)

I take my ARVS; I attend to any medical problems- I go to hospital; [I try] to be happy.” Interviewee 49 noted: “So as to improve my immune system in need to eat well, not to get stressed and take drugs.”; while Interviewee 44 was aware “I also need not to be stressed, which happens a lot with this illness.” Interviewee 42 also worried also that pressures wrought by her illness might affect those closest to her: “I am not satisfied because I stress my mother, too. Won’t that affect her health too, which will also be an additional cost? And she doesn’t even make that much money.” She and interviewee 45 appeared to view health holistically, adopting in their definitions of healthcare aspects of mental as well the physical well-being.³

Yet stress remains a common complaint among many PLWHAs, who have to cope with a number of situations, including the bereavement of spouses and children also as result of AIDS.⁴ Another primary stressor, mentioned by several interviewees and a recurring theme throughout this research, was the difficulty or inability to meet their health needs, as well as other basic requirements for themselves and their families: “We have a certain ill person who never leaves the bed, doesn’t know what he’ll eat or drink.... [I]t would be better that that person only have to worry about what they’ll eat and where they’ll sleep. If they have to worry also about where to get money for the drugs, that is too much.” (Interviewee 29). Other respondents highlighted similar issues: “If I can walk in and out of hospital knowing I [have medical insurance] cover, I know that I can live a less stressful life and have more money in my pocket.” (Interviewee 47); “Well, I’m not working so paying my house rent is a problem, getting a balanced diet is a problem; I need to be at peace, I should be able to manage my stress but I can’t because I’m not working, that is a problem- it’s stress in itself.” (Interviewee 1); “There’s a lot of stress. I am straining a lot because nobody wants to take the responsibility. You know apart from HIV/AIDS, you have other responsibilities- children, who are in school- that’s my responsibility. If I could be assisted then it would be better.” (Interviewee 25); “Shelter, even right now I have to

³ “It means getting the drugs to prolong your life- they may not cure you but they extend your life so you’re able to take care of your children. You live longer and you’re not stressed.” (Interviewee 42) “[Healthcare] means that I must get medication and also have a relaxed mind because I have realized that if you’re worrying or disturbed, then even if you’re taking medication, it will not work.” (Interviewee 45)

⁴ See Sikkema, K. J. , Kalichman, S. C. , Hoffmann, R. , Koob, J. J. , Kelly, J. A. and Heckman, T. G., 'Coping Strategies and Emotional Wellbeing Among HIV-Infected Men and Women Experiencing AIDS-Related Bereavement', *AIDS Care*, Vol.12, No. 5 (2000), pp. 613- 624

look for a house and shift because I can't afford to pay rent there any longer. So it has been stressing me a lot." (Interviewee 5); "...[I]n the case of medication, it's so expensive, you have to stress yourself because you can deny yourself something which you want like clothing or something like that so that you can get the money." (Interviewee 27); "... I am short of money.... Like now, I am not working, so getting money, paying rent and whatnot is a problem to me. So if I can get ways of manoeuvring this, it can even reduce worry, because the child is still young, the mother is just there and I am the bread-winner." (Interviewee 21).

The circularity between higher incidences of mental health problems among PLWHAs and unemployment or poverty have been suggested, and, similarly, those with children are more likely to suffer due to the burden of care and concern for their dependants' future welfare.⁵ While finding solutions that altogether eliminate or alleviate the socio-economic problems is ultimately the only real solution, Schweitzer, *et al*, outline ways in which professionals might help a PLWHA cope psychologically with the challenges these issues pose.⁶

In addition, there was the psychological distress that resulted from the actual diagnosis itself, an experience that most PLWHAs aware of their status will likely have experienced, and which is captured below by interviewee 16. Her response not only highlights the inadequacy of counselling services for PLWHAs but is a poignant reminder that for the many young people in her situation diagnosis often represents the curtailment of long-term dreams⁷:

...I need counselling. We need to be counselled because it's very easy to go crazy with this illness. For example, I was told when I was 22. There I was- I haven't even finished my education, gotten married, have no children- it's so stressful. And I didn't even know where to start.

A PLWHA often undergoes significant psychological readjustment upon HIV diagnosis: this frequently involves an initial period of denial about the disease and its consequences, but may develop into secondary illnesses such as depression or other mental disorders due to failure to access treatment, stigma and the fear of

⁵ Kelly, *et al* (n 1), at 4-5

⁶ Schweitzer, *et al* (n 2), at 341

⁷ Kelly, *et al* (n 1), at 8

ostracism.⁸ There may be a fundamental transformation in her notion of self and self-worth, which may derail personal ambitions and expectations.⁹ Interviewee 6 described this eloquently in his response relating to his efforts to earn a living:

I'm trying to pick up because you see the work I was doing needed a lot of presentation and immediately I realized I suffered from this disease, it had finished me completely. Even when I came out I came out a very shrunk man. I lost all my personality; I could feel very inferior when I went to talk to a client. It affected me almost in all ways. So I had to lose all the clients I had. There are some who know my status, others I never bothered to tell- I just disappeared. So it is something I'm trying to pick up. I was trying to see if I can get some funds and I wanted to come out a new man. Even in dressing! I'll go back into business soon- that's what I believe! So about my income I cannot tell you that I am someone who can be employed. I can't work under somebody- I am used to managing myself and being self-employed.

His sentiments are germane to this research: they provide just one example of how a PLWHA's sense of self may become altered, and how this in turn may shape her ideas about her entitlements and rights. As Schweitzer, *et al*, assert, "[r]edefining identity through the condition of HIV can be a big challenge because it can come in deep contradiction with life goals and plans."¹⁰

Whereas interviewee 6's senses of identity and peace of mind appeared intimately linked to his profession, the connection for others lay with their spirituality or religious faith. This is not uncommon for sufferers of an illness that is often fatal, and spiritual relief may be just as vital to mental wellbeing as the more broadly recognized psychological and social aids.¹¹ Interviewee 8 asserted:

I think [PLWHAs] should have a peaceful and Godly mind. In the house you should be together. You have to accept this disease because you have it and you can live with it for the time that you can. Because, I have a child and I have to bring up to the stage where when you have to leave him, he is able to take care of himself.

⁸ Schweitzer, *et al* (n 2), at 339

⁹ *ibid*, at 337-8. See also DeRoche Peter, and Citron, Kenneth, 'Psychotherapy,' in Citron, Kenneth; Brouillette, Marie-Josée; and Beckett, Alexandra (eds.), *HIV and Psychiatry: A Training and Resource Manual* (Cambridge: Cambridge University Press, 2005), at 166-7

¹⁰ Schweitzer, *et al* (n 2), at 335

¹¹ *ibid*, at 347. Interviewee 8 said: "I think [PLWHAs] should have a peaceful and Godly mind. In the house you should be together. You have to accept this disease because you have it and you can live with it for the time that you can. Because, I have a child and I have to bring up to the stage where when you have to leave him, he is able to take care of himself."; "...I also have to have moral support, and the acceptance plays a big role; there's also spiritual nourishment and shelter." (Interviewee 48); "First and foremost, I am a God-fearing person. I always focus on my God first. Secondly, I worry about my kids coz I'm a widow, being a widow, I don't earn good salary, I'm just on a pension. (Interviewee 2)

Interviewee 48 "...[had] to have moral support, and the acceptance plays a big role; there's also spiritual nourishment..." Interviewee 2 declared herself "first and foremost ... a God-fearing person. I always focus on my God first. Secondly, I worry about my kids coz I'm a widow, being a widow, I don't earn good salary, I'm just on a pension."

Moreover, religion norms often form a significant part of the moral framework and language by which PLWHAs define their relationships with, obligations to and entitlements from others. Unsurprisingly, hence, some respondents, like interviewee 8 quoted next, perceived a duty for faith organizations in providing assistance for this aspect of their health needs, an especially invaluable function where the kind of supports usually endorsed by the dominant biomedical paradigm are scarce:

Even church leaders. They should pray for people, give them hope. With God, everything is possible. I know. I didn't even have drugs, I was just left there, sick, with no food. Someone has run away from you, you have a child, you're sleeping hungry, waking up hungry, you have no money. But I know through God, everything is possible for me- that's why I'm alive now.

Such organizations enjoy implicit public trust in many parts of the world. For instance, respondents like interviewee 2 felt that the proximity of religious leaders to people in the community gave them the kind of access that should enable them to fulfil this important function "...[because] in a church, that's where you get many people. So church leaders can be able to know the needy amongst them." They are suitably positioned to undertake the spiritual counselling and educative roles within the community which have become a proven gateway to the treatment and care of PLWHAs.¹² Yet religious notions on sin and punishment have also often helped endorse and perpetuate rather than dispel the stigma and discrimination suffered by PLWHAs, encouraging the perception of AIDS as a penalty for counter-normative behaviour, a viewpoint which some PLWHAs may internalize.¹³ This feeds into the

¹² See for instance a UNAIDS case study on the intervention of a group of Buddhist monks in Thailand, which reported as one of its outcomes that, "[s]ince local people are accustomed to telling monks their difficulties, monks become a conduit for supporting many HIV-positive people who have not disclosed their status to others. Once disclosed to the monks, if they wish such people they can be referred to support groups and assistance programmes." (UNAIDS, *HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes*, 2005, at http://data.unaids.org/publications/irc-pub06/JC999-HumRightsViol_en.pdf, accessed 21/03/10; at 24)

¹³ Helen Epstein writes, for instance, of the early response of the globally-influential, U.S.-based evangelical movement, which discouraged funding for AIDS because of pervasive negative attitudes

well-documented denial among some religious communities.¹⁴ Such apparent intolerance may alienate some PLWHAs, leading to disengagement with, and isolation from, what could be vital sources of psychosocial support.¹⁵

But there are other avenues for psychosocial relief: for instance, voluntary counselling and testing centres (VCTs) may offer some basic counselling.¹⁶ However, counselling as a dedicated profession is still a relative novelty in sub-Saharan Africa, as Rachier, *et al*, observed as recently as 2004. They noted several recommendations from a conference by the Kenya Association of Professional Counsellors (KAPC) for scaling up access to, and improving the nature and quality of, services available for PLWHAs.¹⁷ The KAPC suggested even wider goals for the counselling process, proposing, for example, that counsellors address issues pertaining to gender inequality as part of their advice to female PLWHAs, helping them and their male counterparts to “explore the circumstances of their lives and to consider

about the homosexual men who were among the earliest visible PLWHAs. (Epstein, Helen, *The Invisible Cure: Africa, The West and the Fight Against AIDS* (New York, NY: Farrar, Straus and Giroux, 2007, at 185). See UNAIDS, *HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes* (n 12), at 7. See also DeRoche and Citron (n 9), at 167. But Epstein’s complimentary views on the responses of religious organizations in Africa, where the mode of infection is primarily heterosexual intercourse, do not apply across the board and, they, too, have rightly been criticized for the slowness of their response. For a range of press articles reflecting varied opinions about the performance of these organizations in Kenya see: *The Daily Nation*, ‘AIDS a severe test for Faiths,’ 2nd July 2005; *The Daily Nation*, ‘Muslims Slow in War on Aids, Laments Don,’ 20th October 2003; *The Daily Nation*, ‘Yes, we have HIV too, say four Clergymen’ 22nd June 2005; *The Daily Nation*, ‘Stigma Based on Moral Values,’ 19th August 2006; *The Daily Nation*, ‘Church Insistence on Abstinence Correct’ 29th November 2006. See also Githongo, John, ‘Church Must Face Reality of Condom Use,’ *The East African*, 6th December 1999.

¹⁴ For instance, in late 2003, the chairman of the Supreme Council of Kenya Muslims, Prof Abdulghafour El-Busaidy, is reported to have decried the unfortunate belief among his constituents that the HIV/AIDS epidemic was not an Islamic problem. (*The Daily Nation*, ‘Muslims Slow in War on Aids, Laments Don,’ (n 13))

¹⁵ DeRoche and Citron (n 9), at 167

¹⁶ I personally experienced one such counselling in 2004, having attended a VCT in Nairobi, partly for personal as well as research purposes. The whole process took no more than a quarter of an hour, in which the nurse who conducted the HIV test asked a series of questions while she took a blood sample and as we waited for the results to show up. They included what had prompted my decision to get tested; what my expectations were of the test; what I would do if I found whether the test was positive and, similarly, what I would do if I found out that it was negative. For privacy reasons, she explained, and so, that others such as those waiting outside the room could not hear the results, she gave me a brief course on how to read the tests result for myself, and once the outcome was revealed confirmed that I understood the read. Afterwards, I informally inquired what advice was often offered when one returned a positive result and she said that she would often discuss treatment and counselling options with patients, suggesting support organizations with whom they might want to get in touch.

¹⁷ Rachier, C. O.; Gikundi, E.; Balmer, D. H.; Robson, M.; Hunt, K. F.; and Cohen, N., ‘The Meaning and Challenge of Voluntary Counselling and Testing (VCT) for Counsellors- Report of the Kenya Association of Professional Counsellors (KAPC) Conference for Sub-Saharan Africa,’ *Journal of Social Aspects of HIV/AIDS*, Vol.1, No.3 (2004), at 176 and 177

alternatives.”¹⁸ (However, it has been argued that clinicians must avoid adopting a “power (i.e. lack of power) paradigm” in such discussions and adopt approaches that allow PLWHAs to re-imagine their reactions to infection in a manner that meaningfully helps them appreciate the strengths as well as the weaknesses of their life circumstances.¹⁹) Further, the *Kenya National AIDS Strategic Plan 2009/10-2012/13* also partly attributes the increase in costs to a proposed scaling up of counselling services.²⁰

But these proposals are likely to take years to realize and will come too late for many PLWHAs. This leaves a vacuum that is often filled by the kind of specialism, widely available and vastly more accessible in Africa, that does not fit comfortably within a biomedical framework and whose practice, effects and outcomes remain questionable, yet which seems to provide a measure of mental, spiritual or religious wellbeing of many PLWHAs.²¹

A crucial component of such wellbeing is, of course, the understanding and acceptance of members of their immediate social network, and many respondents felt it helped them better cope with their diagnosis and the consequences of the epidemic. Interviewee 13 declared that his health needs included “moral support from my friends.” The experience or fear of rejection or ostracism by many respondents has been discussed throughout this research; for instance, it will be

¹⁸ *ibid*, at 179

¹⁹ Sherr, Lorraine, ‘Women and HIV,’ in Citron, Brouillette and Beckett (eds.) (n 9), at 230. For instance, Sherr suggests reinterpreting studies which found that women were less likely to leave partner who became infected with HIV than vice versa as indicating commitment rather than powerlessness. She also proposes interpreting findings that women were more likely to attend for treatment later in the course of illness as self-sacrifice than powerlessness. (at 231)

²⁰ National AIDS Control Council (NACC), *Kenya National AIDS Strategic Plan 2009/10-2012/13 (KNASP III): Delivering on Universal Access to Services*, November 2009, at http://www.nacc.or.ke/2007/images/downloads/knasp_iii_document.pdf, accessed 09/10/10, at xiv. The document proposes targeting “children and the physically challenged” for psycho-social counselling programmes. (at 15). One of the services included in the expanded list of new outpatient services that the reformed National Health Insurance Fund (NHIF) proposes to offer is “specialised counselling”, although the content of this is unclear. (Kerich, Richard, ‘How New NHIF Package Will Benefit Members,’ *The Daily Nation*, 29th August 2010)

²¹ Joseph Amon provides the anecdotal evidence of a 19 year old female PLWHA attending a religious gathering in Uganda where the Canadian faith healer Benny Hinn was preaching. Kicked out of her home by her parents when her HIV status was revealed, she “clearly longed for more than just the medical management of her condition. She said of Hinn: “He cured me of AIDS, I can feel it. I just know”. (Amon, Joseph, *Dangerous Medicines: Unproven AIDS Cures and Counterfeit Antiretroviral Drugs*, *Globalization and Health*, 27th February 2008, at <http://www.globalizationandhealth.com/content/4/1/5>, accessed 27/05/09)

recalled that interviewee 16 wondered whether her supportive parents might not decide that since “you put yourself in these boots and it’s up to you to know how you’re going to survive.” Yet the importance of such support to a PLWHA’s mental health has been widely acknowledged.²² As Schweitzer, *et al*, stress,

Having HIV can affect other social relationships because infected adults need to make decisions regarding levels of HIV diagnosis disclosure... however, with the stigma associated with both AIDS and sexuality, [the developmental stages of HIV in adulthood] also contains aspects of adapting to, and protecting information about, a stigmatized identity.²³

Interviewee 34 reiterated the importance of social acceptance as part of his health requirements, talking of the need “to be open to people about my HIV status and the other is to be free, that is to be accepted.” Indeed, disclosure of HIV status opens up more avenues for emotional support, although Kelly, *et al*, note that it may not always forestall the onset of psychological problems.²⁴ Moreover, openness about one’s status may have fatal consequences, as cases like the 1998 brutal murder of Gugu Dlamini in South Africa prove.²⁵

The role here of HIV/AIDS support organizations in fostering community among PLWHAs is pivotal, as respondents such as interviewee 3 attested: he declared as a health need “an organization which can [provide] support, let’s say in something like stress management. You can’t do it alone unless you’re in an organization like this one, WOFAK. People share ideas so you become at least... you live positive.... So the support from organizations, not really material support but the group support, [to assist with] management of the stress, you find people accepting you in a group—those [needs] I get....” Interviewee 19 also highlighted the freedom afforded by these kinds of organizations settings, where PLWHAs could be open with each other about their status and discuss mutual concerns: “You know the only place we meet is here [at the Mbagathi District Hospital HIV clinic]. Out there, you don’t know whether a person has the illness or not. So here is where you get to talk to people and we also have those meetings for people on ARVs. Everyone stands up and says what their

²² Collins, *et al* (n 1), at Section 16

²³ Schweitzer, *et al* (n 2), at 334-5

²⁴ Kelly, *et al* (n 1), at 6

²⁵ Gugu Dlamini, a South African AIDS counsellor, was stoned to death a few days after revealing her HIV-positive status on World AIDS Day in 1998. Her killers, local teenage boys, said in court that “they had done it to punish her for bringing ‘shame on the community.’” (Epstein (n 13), at 141)

problems are and when you listen, people have so many problems.” One respondent from Kakamega, Western Kenya, alluded to the sanctuary they provided away from the suspicions and stigma encountered by PLWHAs in the more conservative, often less HIV-aware rural areas. Asked if she thought that PLWHA’s needs were being sufficiently met, she said:

I’m telling you people in the countryside are in a worse situation: there is no one to tell you that you have to accept your status.... At least here in town, we have WOFAK, I can come for counselling and they can update me on what is going on. But in the country, people have a big problem.... for those people accepting has been hard.... They don’t know what is going on, apart from that... this disease it’s a bad disease and it’s going to kill you. People even keep away from you. Like if you get married to person from a big homestead and they discover you have the illness, what happens is that the man usually leaves you and comes to town and you are one your own with no help; all people would do was come around to ask, ‘Has she died?’... (Interviewee 5)

This safe environment enhances PLWHAs’ sense of belonging to a group as well as their sense of dignity- which is closely linked to openness and recognition- and value as human beings.²⁶ The fear of stigma and discrimination that often nurtures secrecy about HIV status negates an individual’s worth and infringes her right to dignity and equality.²⁷ And in this, too, respondents like interviewee 25, noted a rural/urban discrepancy. People “go public in towns,” she said. “[They] come from their homes ... to Nairobi to talk about their status but they cannot say it at home. But when you go public in your home area, people really stigmatize you. Unless you make them understand, they wonder ‘Why are you saying it? Why do you have to say it?’”

This statement illustrates again the postcolonial citizen-subject duality and contradiction: on the one hand, the modern citizen, revealing her identity more fully, declaring, with growing confidence, ownership even of those aspects traditionally regarded as counter-normative and frowned upon. As seen in Chapter 4, she draws her privileges- which include the network of formal rights, such as equality, non-discrimination and freedom of expression, as the media, education or human rights

²⁶ See also the National Network of Post-test Clubs, which run in a number of areas in Kenya to facilitate peer-to-peer information and support for PLWHAs. (National AIDS Control Council (NACC), *UNGASS 2010: United Nations General Assembly Special Session (UNGASS) on HIV and AIDS 2010: Country Report- Kenya*, at http://data.unaids.org/pub/Report/2010/kenya_2010_country_progress_report_en.pdf, accessed 10/04/10, at 38) *IRIN PlusNews*, ‘Kenya: There’s No Substitute for Support When Taking ARVs,’ 16th July 2008, at <http://www.plusnews.org/Report.aspx?ReportId=79287> (accessed 02/05/10)

²⁷ Hunt, Paul, ‘The UN Special Rapporteur on the Right to Health,’ *Health and Human Rights: An International Journal*, Vol.7, No. 1 (2003), pp. 1-27, at 6

CSOs or advocates will likely have informed her- from her membership to the State-based national community. Owning her identity as a PLWHA within this public does not- or, rather, should not- ostracize her from it; she takes advantage of the new rights-based vocabulary and moral frame of reference promoted within this community, which allows her to claim a new set of rights. Her sense of privilege comes with the development of her subjectivity as a fully entitled Kenyan citizen. But she is also a subject of the customary, whose belief system and norms favour discretion and offer limited license for public discussion of subjects relating to sex and sexuality. Her continued membership to this traditional community, and especially her access to its privileges, is dependent on her conformity with, and adherence to, the customs that are its glue. The dexterity with which she balances these two identities dictates her success in maximizing on her dual- or multiple- identities.

In her exploration of the dignity-health nexus, Marina Chilton sees a potential link between the violation of dignity and ill-health, noting that it places “overwhelming pressure on the psyche and the body.”²⁸ Further, she highlights the negative health effects of the experience of shame, humiliation and discrimination, which many PLWHAs endure²⁹; discrimination is the corollary of stigma, the action or treatment based on stigma and directed at the stigmatized.³⁰

Schweitzer, *et al*, have called stigma “the single most important factor in producing and extending the negative psychosocial effect of HIV and AIDS.”³¹ The classical Greek genesis of the word ‘stigma’ denoted outcasts whose status was permanently marked; today’s often vague definitions associate it with difference, deviance and disreputability and it has been applied to a variety of illnesses down the ages, from incontinence to leprosy to mental illness, and also to sexually transmitted infections like syphilis, particularly.³² Tony Barnett and Alan Whiteside stress the underlying

²⁸ Chilton, Mariana, ‘Developing a Measure of Dignity for Stress-related Health Outcomes,’ *Health and Human Rights: An International Journal*, Vol.9, No.2 (2006), pp. 208-233, at 219. See also Mann, Jonathan, ‘Dignity and Health: The UDHR’s Revolutionary First Article,’ *Health and Human Rights: An International Journal*, Vol.3, No.2 (1998), pp. 31-38, at 32

²⁹ Chilton (n 28), at 33-4

³⁰ Schweitzer, *et al* (n 2), at 336

³¹ *ibid*, at 335

³² Maluwa, Miriam; Aggleton, Peter; and Parker, Richard, ‘HIV- and AIDS-related Stigma, Discrimination and Human Rights: A Critical Overview,’ *Health and Human Rights: An International Journal*, Vol. 6, No. 1 (2002), pp. 1-18, at 4. See also UNAIDS, *HIV-Related Stigma, Discrimination and Human Rights*

issues behind stigmatization, calling it “a social process: a feature of social relations, reflecting the tension, conflict, silence, subterfuge and hypocrisy found in every human society and culture.”³³ Stigma often replicates and reinforces existing social and normative patterns and inequalities; thus gender, racial, ethnic and sexual disparities can be seen repeated in AIDS-related stigma. For instance, women are more likely to be blamed and shunned as the source of infection despite the likelihood that they were infected by their husbands.³⁴ HIV-positive men may face allegations of associating with sex-workers while women may be accused of promiscuity, as highlighted, say, by interviewee 11, cited in Chapter 2.³⁵ The link between infection and immorality is one that she and a number of other female interviewees were keen to reject, declaring women “innocent” in incidents of infection arising out of sexual infidelity in marriage, arguably endorsing common-often valid- stereotypes about male and female sexuality.

Maluwa, *et al*, distinguish between ‘felt’ and ‘enacted’ stigma: the former is the shame linked to a “potentially stigmatizing condition and the fear of being discriminated against.”³⁶ ‘Felt’ stigma may be internalized by the PLWHA, who may express shame about her illness or self-stigmatize, as suggested in a number of interviewee’s response. It “can have a powerful psychological influence over how people with HIV see themselves and adjust to their status, making them vulnerable to blame, depression and self-imposed isolation.”³⁷ Studies of similarly marginalized

Violations: Case Studies of Successful Programmes (n 12), at 7; and Holzemer, W. L., and Uys, L. R., ‘Managing AIDS Stigma,’ *Journal of Social Aspects of HIV/AIDS*, Vol.1, No.3 (2004), at 166

³³ Barnett, Tony, and Whiteside, Alan, *AIDS in the Twenty-First Century: Disease and Globalization* (Basingstoke, Hampshire; New York, NY: Palgrave Macmillan, 2006) at 72

³⁴ Maluwa, *et al* (n 32), at 2. See also UNAIDS, *HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes* (n 12), at 7-8; Hunt (n 27), at 10. It is important to note also that more women than men test for HIV, partly due to the number of pregnant women who test at antenatal clinics (ANCs). (These are increasingly offered and accept HIV testing: in 2007, 70% tested, 3% were offered testing but declined, 16% were not offered testing while 11% did not attend an ANC. (Kenya National AIDS and STI Control Program (NAS COP), *et al*, *The Kenya AIDS Indicator Survey (KAIS) 2007 Data Sheet*, Population Reference Bureau website, July 2009, at <http://www.prb.org/pdf09/kaiskenyadatasheet.pdf>, accessed 10/04/10; at 5) The survey also reports that in total 41% of women had received an HIV test and the test results at some point in their lives, in contrast to 25% of men. The trend holds between the 15-24 and 25-49 age groups, but is reversed for the 50-64 group, where 14% of women and 21% of men has ever tested for HIV and received results. (at 2)

³⁵ Maluwa, *et al* (n 32), at 5

³⁶ *Ibid*, at 5-6

³⁷ UNAIDS, *HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes* (n 12), at 5

groups which apply a domination analysis reveal how society reflects back demeaning images to them, confining them in a false, warped and reduced form of subjectivity.³⁸ This shame may discourage PLWHAs from disclosing their HIV status and seeking treatment; particularly if, like commercial sex workers, homosexual men or injecting drug users, they are already ostracized.³⁹ All this reinforces the stigma and discrimination cycle and perpetuates negative stereotypes of PLWHAs as the weak, incapacitated and unproductive figures that many encounter only in the final stages of the illness.⁴⁰ Indeed, it has been suggested that the mental (ill) health consequences of HIV infection owe more to PLWHAs' perceptions about negative responses by the public to the HIV epidemic than the trauma of infection itself, further feeding the cycle of infection.⁴¹

'Enacted' stigma involves experiences of actual discrimination.⁴² PLWHAs may be subjected to discrimination in many areas, violating their rights to employment, marriage, freedom of movement and freedom from inhuman and degrading treatment.⁴³ Maluwa, *et al*, propose building up expertise within AIDS organizations and existing legal institutions to handle discrimination and HIV/AIDS-related rights issues in the community.⁴⁴ The KAPC identified a front-line role for counsellors at VCTs, for instance, to protect PLWHAs' right to privacy and confidentiality.⁴⁵ Indeed, contact with human rights advocates, some located within their HIV service centres, was one channel through which the human rights consciousness of some PLWHAs was broadened. Such steps would bolster the system of monitoring and reporting of

³⁸ See Ely Yamin, Alicia, 'Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,' *Health and Human Rights: An International Journal*, Vol.11, No.1 (2009), pp.5-21, at 13

³⁹ See Mahendra, V.S.; Gilborn, L.; Bharat, S.; Mudoi, R.; Gupta, I.; George, B.; Samson, L.; Daly, C.; and Pulerwitz, J., 'Understanding and Measuring AIDS-related Stigma in Health Care Setting: A Developing Country Perspective,' *Journal of Social Aspects of HIV/AIDS*, Vol.4, No.2 (2007). See also Holzemer and Uys (n 32), at 169

⁴⁰ UNAIDS *HIV-Related Stigma, Discrimination and Human Rights Violations: Case Studies of Successful Programmes* (n 12), at 5-6. Joseph Amon spotlights Paul Farmer's findings in rural Haiti about the effects of access to ARV in the fight against stigma and "the hope felt by his patients upon receiving the drug and experiencing the 'Lazarus'-like effects of it. But Farmer has also spoken about how the clinic's efforts include broader social support and how this act of providing care to an impoverished population can create a radical shift in perceived stigma." (Amon (n 21))

⁴¹ Kelly, *et al* (n 1), at 2

⁴² Maluwa, *et al* (n 32), at 5-6

⁴³ *ibid.* at 6-8

⁴⁴ *ibid.* at 11

⁴⁵ Rachier, *et al* (n 13), at 176 and 178

incidents of stigma and discrimination, critical to enforcing those laws that have been instituted to counteract such actions.⁴⁶

But the effectiveness of legal sanctions relies on the social and cultural norms that the law wishes to engender and enforce gaining broad societal resonance and support; the underlying prejudices and social disparities that sustain stigma and discrimination must be confronted.⁴⁷ And as a number of PLWHAs attested, these prejudices are not only to be found in the wider community but also, distressingly, much closer to home. For instance, interviewee 17 noted:

... I've heard people complaining. Some people have been rejected by their family members and as a result some have even died. In my own family, there's a sister who died because, you know, she got it in the 1980 or 90s, when people were really scared of it. She died of depression because we feared her and we kept off. But I have seen other cases, too.

Similar views were highlighted by interviewee 11:

I thank God for my family who've shown me great support- others won't even share utensils. Even they don't want to shake your hand. When they see you they say, 'that one is immoral; she moves around with a lot of men.' You really need to have strong character to get out of that kind of a state and stay positive. Also, about HIV victims who don't want to talk about it because of the kind of society we have. I have preached in so many places myself but I had heard people say, 'oh, this is a Christian. She used to preach to us but it seems she was also immoral.' That's the kind of thing I don't want to face but I wish people are educated so that the HIV-positive can speak up.

Yet the authority of the State rarely penetrates this domain.⁴⁸ AIDS becomes a prism through which wider attitudes towards sex, gender, religion and power are refracted; its effects on a PLWHA's subjectivity- on her sense of dignity and self-worth, and ultimately, on her notions of entitlement and rights- may be glimpsed in the articulation of her psychosocial needs. Unsurprisingly, thus, integrated within public awareness-raising campaigns is the concerted effort by AIDS and/or human rights organizations to reshape PLWHAs' own notions about their needs, rights and entitlements, and providing them with the means to create an alternative narrative of their illness, using a new moral frame of reference and language. Advocates have long

⁴⁶ For a discussion on attempts to measure stigma in healthcare practice, see Mahendra, *et al* (n 39). For efforts to measure stigma more widely see International Planned Parenthood Federation (IPPF), *et al*, *The People Living with HIV Stigma Index* at <http://www.stigmaindex.org/>, accessed 13/10/10, which was rolled out in 2008 but at the time of writing had yet to publish their initial round of results.

⁴⁷ Maluwa, *et al* (n 32), at 11-12

⁴⁸ Holzemer and Uys (n 32), at 169

promoted the use of terms such as ‘stigma’, ‘discrimination’ and ‘positive living’, which have widespread currency today, transporting the ideas of inequity and oppression suffered by PLWHAs into the public domain. But the language of rights and ‘empowerment’ has also had a transformative effect on individual PLWHAs, becoming a vital tool for those seeking to proactively (re)define their belief system and (re)organize their lived experiences and construct new and positive subjectivities, and re-present themselves to an often hostile public. Indeed, stigma and discrimination was among the best-known rights-related concepts among PLWHAs interviewed for this research. And as will soon be elucidated, the subtle process of constructing PLWHAs’ subjectivities is inherent, too, in the predominant biomedical framework that governs the (official) knowledge of, and provision for, their medical needs.

II. Medical Needs

Almost all the interviewees mentioned the need for medicines for opportunistic and other illnesses such as tuberculosis and malaria, and antiretrovirals (ARVs) as key requirements.⁴⁹ A number elaborated on the broad issues pertaining to their medical needs, particularly the cost of healthcare. In Kenya, the government provides approximately 50% of the formal public healthcare services through its network of hospitals, clinics and dispensaries; of the remaining half, 40% are provided by an array of independent mission hospitals, supported by various religious denominations; the private sector provide the other 10%, almost exclusively reserved to urban centres.⁵⁰ But it is on the informal sector that most may Kenyans rely for their primary healthcare needs, like the majority of other Africans: here, traditional or alternative medicine is often the main- or even only- source of primary health care.⁵¹ The WHO estimates that up to 80% of people in Africa use traditional medicines for primary health care, with nearly three-quarters of South African PLWHAs, for instance,

⁴⁹ Some were specific on the drugs they required: for example, Interviewee 30 mentioned Septrin; interviewee 2 mentioned Combivir and Stocrin.

⁵⁰ Lewis-Lettington, Robert, and Munyi, Peter, *Willingness and Ability to Use TRIPs Flexibilities: Kenya Case Study*, WHO, September 2004, at http://www.who.int/hiv/amds/countries/ken_UseTRIPsFlexibilitiesDFID.pdf, accessed 06/05/08; at 8.

⁵¹ The WHO defines traditional medicine as “health practices, approaches, knowledge and beliefs incorporating plant, animal and mineral based medicines, spiritual therapies, manual techniques and exercises, applied singularly or in combination to treat, diagnose and prevent illnesses or maintain well-being.” (WHO, ‘Traditional Medicine: Fact Sheet No. 134,’ WHO, December 2008, at <http://www.who.int/mediacentre/factsheets/fs134/en/>, accessed 09/05/08.

utilizing them.⁵² In Kenya, between 70 and 80% of principally rural-dwellers, rely on traditional medicines for their essential healthcare, with little or no access to secondary or tertiary healthcare⁵³; traditional healers outnumber modern ones by 100 to 1, according to UNAIDS.⁵⁴ No wonder, then, that the organization has urged the boosting of local responses to the AIDS epidemic, emphasizing the need to integrate the biomedical approach of modern medicine and that of traditional healers in order to harness the strengths of both these systems.⁵⁵ The deeper issues underlying this fresh perspective will be reviewed later in the next chapter.

From the late 1990s, the public and mission healthcare systems, which until then had ran largely subsidized, needs-based operations, joined the private healthcare system in imposing fees for the provision of their services, because of factors ranging from the implementation of Structural Adjustment Programmes (SAPs) imposed by the Bretton Woods Institutions (the International Monetary Fund (IMF) and World Bank), to a decrease of funds for missionary facilities. The only healthcare services not to charge were the (over one hundred) NGOs also in operation in Kenya and which cover certain key geographical areas or deal with public health concerns⁵⁶; Michael suggests that these now provide over half of the country's healthcare services.⁵⁷ Prior to this, for much of the two decades after independence during which Kenya enjoyed relatively healthy economic growth, Stephen Ndegwa argues that the country operated a "veritable welfare state," with the State's social and economic policies offering minimum guarantees in health, education, employment.⁵⁸ The recent rise in healthcare costs was captured by one interviewee who complained about the costs

⁵² *ibid*

⁵³ Lewis-Lettington and Munyi (n 60), at 9. A reporter for *The Daily Nation* writing of the plight of the isolated communities who live in the remote swathes of land in northern Kenya commented, "'Doctor' is an alien word to many sick people who often resort to traditional medicine for a cure." (Munene, Mugumo, 'Water the Only Key to Peace, Says Official,' *The Daily Nation*, 16th July 2005)

⁵⁴ UNAIDS, 'Traditional/Alternative Medicine,' 2008, at <http://www.unaids.org/en/PolicyAndPractice/HIVTreatment/TraditAlternMedicine/>, accessed 08/05/08

⁵⁵ See, for instance, UNAIDS, *Collaborating with Traditional Healers for HIV Prevention and Care in sub-Saharan Africa: Suggestions for Programme Managers and Field Workers*, 2006, at http://data.unaids.org/pub/Report/2006/jc0967-tradhealers_en.pdf, accessed 08/07/08

⁵⁶ Lewis-Lettington and Munyi (n 50), at 8. See also Ndegwa, Stephen, 'Citizenship Amid Economic and Political Change in Kenya', *Africa Today*, Vol. 45, No. 3/4 (1998), pp 351-368, at 359. The number of NGOs is most likely to have risen in the intervening years, as the discussion in Chapter 6 will suggest.

⁵⁷ Michael, Sarah, *Undermining Development: The Absence of Power Among Local NGOs in Africa* (Oxford: James Currey; Bloomington: Indiana University Press, 2004) at 8

⁵⁸ Ndegwa (n 56), at 358

(from May 2004 when the interview was conducted) at the biggest public hospital, based in Nairobi: “... Even this Kenyatta [National Hospital], which is a public hospital, is very expensive. Being an in-patient there for one day will cost you Ksh. 450 (approx. GBP 3.00) and you’ll be paying for every drug. If this was reduced it would be more fair.”⁵⁹ (Interviewee 42)⁶⁰

As such, a number of respondents mentioned medical insurance cover as a requirement, as well as the ability to see a doctor as and when necessary.⁶¹

It will be recalled from Chapter 1 that the NHIF, the State health insurance parastatal accused of mass corruption and misuse of public funds⁶², provides medical cover for its 11 million members⁶³ or their dependants, with controversial plans underway to restructure its funding and services.⁶⁴ But type and quality of in-patient services may still be determined by one’s economic power.⁶⁵

⁵⁹ As with the previous chapter, the figures of drug prices and those of other medical services are based on an exchange rate of Ksh.149.00 to 1 GBP and Ksh. 77.30 to 1 USD.

⁶⁰ The hospital has a private wing which houses about a ninth of the total bed capacity (209 of the 1,800, according to the Kenyatta National Hospital (KNH) website, although this appears to have last been updated in 2008) and it is unclear whether the respondent was referring to this, as costs from 2004 were unavailable. More recent figures show the daily bed charges in this wing to range from Ksh. 1,950 to 4,000 for adults and Ksh. 1,600 to 4,000 for children. Deposits of Ksh. 20,000 to 40,000 are applicable. (From KNH website at http://www.knh.or.ke/index.php?option=com_content&view=article&id=37%3Aprivate-wing&catid=6%3Aall-services&Itemid=2, accessed 01/05/10)

⁶¹ Interviewee 1, for instance, noted: “...[W]hen I fall sick any time, I’m supposed to run to the hospital; so I need to have at least medical cover or at least the money to go to the hospital to see a good doctor... I should eat well, [have] drugs or a doctor to check me to know my CD4 count and viral load...”

⁶² See, for instance, Kang’aru, Wachira, ‘The Poor Will Finance the Rich in New Medical Plan,’ *The Daily Nation*, 16th August 2010; Shindu, Alphonse, ‘Team Queries Use of NHIF Kitty,’ *The Daily Nation*, 28th June 2009.

⁶³ NHIF members consist primarily of formal sector employees earning a minimum Ksh.1,000-a-month salary (approximately GBP 8, per exchange rates at 31st August 2010), a portion of whose salary (currently a flat rate of Ksh. 320) is compulsorily deducted to feed the fund, but Kenya’s extensive informal sector worker and retirees may also opt into the scheme. See the NHIF website at <http://www.nhif.or.ke>, accessed 29/08/10). Voluntary contribution rates are Ksh.160-a-month (approx. GBP. 1.30).

⁶⁴ These would include: “[U]nlimited general consultation, prescribed laboratory tests and investigations, and medicines.... approved X-rays, ultrasound, CT scans, diagnosis and treatment of common ailments. It also covers ear, nose and throat diseases, management of HIV and Aids, diabetes, asthma, hypertension and treatment of sexually-transmitted diseases.... health and wellness education, specialised counselling and family planning.” (Kerich (n 20))

⁶⁵ The government contracts three separate categories of healthcare providers to implement its in-patient health plans, from comprehensive coverage in the Category A (government hospitals), for full NHIF members; full and comprehensive cover except for surgery in Category B (private and mission); and “[t]hose visiting facilities contracted under Category C (private) will continue with the current system where NHIF pays specified daily benefits under the current arrangements.” (NHIF website (n 63)). Some commentators predict a problem of demand outstripping supply for the poor trying to

Lack of medical information or knowledge about the requirements of HIV on the part of patients and even doctors was raised by one interviewee:

Also I realize that some doctors aren't very good. You have to be educated before you are put on ARVs so that you know this is for a lifetime. What is happening is that there are people who are put on 2 drugs instead of the 3, so you realize that there those who are given 2 of just one [type] and they take them. And because they don't realize, in the long run they become resistant. So there's a lot happening but it's just that PLWHAs in Kenya are not talking. (Interviewee 48)⁶⁶

Her comments highlight the authority accorded to biomedical experts despite possible gaps in their training, which some PLWHAs value over what they regard (in public, at least) as the quackery of traditional medicine. Indeed, the production of PLWHAs who can absorb biomedically-authenticated knowledge about HIV/AIDS, and question or reject alternative sources of knowledge, is often regarded by activists as key in the efforts to tackle the epidemic.⁶⁷ Further, they draw attention to issues around patients' right to information, which is recognized in paragraph 12(b) of the Committee for Economic, Social and Cultural Rights' (CECSR) General Comment No. 14 on The Right to the Highest Attainable Standard of Health (Art. 12) as pivotal in the actualization of the right to health.⁶⁸ Nahid Toubia observes:

In curative health care, most doctors and other health professionals are trained to believe that they know what is best for their patients. Patients' rights to full information and decision making power decrease in direct correlation with lowered social, economic or gender status. This is more dramatic in countries in which illiteracy is high, public health information is practically nonexistent, and the legal system is too weak to be utilized favourably.⁶⁹

access inpatient care. See Kang'aru (n 62). However, one issue he cites, of superior services being offered at private facilities for those who can afford it, is not, of course, confined to the Kenyan health system.

⁶⁶ Some of her concerns are supported by Action Aid's HIV coordinator for Western and Nyanza provinces, Ken Odumbe, in *IRIN PlusNews*, 'Kenya: Treatment Literacy Lagging Behind ARV Rollout,' 8th October 2007, Nairobi, IRIN, <http://www.plusnews.org/Report.aspx?ReportId=74697>, accessed 13/05/09.

⁶⁷ See Finn, Mark and Sarangi, Srikant, 'Articulations of Knowing: NGOs and HIV-Positive Health in India,' in Higgins, Christina and Norton, Bonny (eds.), *Language and HIV/AIDS* (Multilingual Matters: Bristol; Buffalo; Toronto, 2010)

⁶⁸ "Information accessibility: accessibility includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality..." (Committee for Economic, Social and Cultural Rights (CECSR), *CECSR General Comment No. 14 on The Right to the Highest Attainable Standard of Health*, Adopted by the 22nd CESCR on 11 August 2000, at <http://www.unhcr.org/refworld/pdfid/4538838d0.pdf>, accessed 08/05/09, Art. 12, Para. 12(b)).

⁶⁹ Toubia, Nahid F., 'Health and Human Rights: Where Do We Go From Here?' *Health and Human Rights: An International Journal*, Vol. 1 No. 2 (1995), pp. 136-141, at 137

Most of the interviewees who mentioned an aspect of medical care as a key requirement focused on the medication element, perhaps reflecting the notion that this dimension is likely to be the most obviously problematic in terms of availability and accessibility, more of which later. Additionally, it may be that other problems associated with the adequate delivery of medical services, such as the distance of medical facilities or unsatisfactory standards of care may be an issue that some respondents regarded as commonplace and therefore not worth pointing out. Also they may not have perceived such problems as resulting directly from their HIV status and uniquely affecting them as PLWHAs but as symptomatic of the general healthcare system. However, such issues were sometimes aired by interviewees, particularly the manner in which they disproportionately affected rural-dwellers. For example, interviewee 45, who had trained and worked as a nurse made the connection between people not being tested for HIV and the distant locations of hospital facilities in some rural areas:

....Some people are not ready to come out and say that they are sick. They don't go to the hospital for check-ups. So some of them like in my place, they come from very far in rural areas whereby the hospital is almost 100km away. So they are not aware of this HIV/AIDS- they're not.

The same interviewee expressed his frustration at the dearth of HIV/AIDS-specific services and facilities within easy reach of rural communities:

Those who can get the support are those in the urban areas but in the rural ones they don't know anything. Like now, I come from the rural areas in Nyamira District, about 300-400km away [from Nairobi]. Someone in the rural areas doesn't know that those drugs are not in the District hospital; VCTs are not there- they may be in the District Hospital but many people live very far away from these hospitals. The community health workers are not there to educate people that this is what you're supposed to do. They can't go there themselves because they feel they will be stigmatized- they'll start to talk about me. So I can't see that they are helping me.

Such comments highlight the rural/urban separation discussed in earlier chapters and bring to life the perceptions of some interviewees of the rural as 'the other': an unknowable or incomprehensible space with its own internal logic and systems of knowledge to which they nevertheless retain a loyalty. But there is a damning sense of its abandonment by the State and other official actors.

Interviewee 3, whose views on what he deemed as sub-standard care at Kenyatta National Hospital were cited in Chapter 2 and are recounted here, was also vocal about how the government could remedy what he saw as the sub-standard care offered in some hospitals:

The government I think can help. By improving the hospitals, by taking this thing as a serious issue... It can help a lot of people, to buy them drugs or to add more beds at Kenyatta [National Hospital]... If I am taken to Kenyatta I fear I won't last a week. The nurses there haven't the courtesy to handle people. It's better I was taken to Mbagathi [District Hospital] where the nurses have respect. I once took my sister to Kenyatta and she had to share a bed. We went to see her around noon and they were serving lunch. They brought some for her and the other lady. Imagine the other lady had died in the night, no one had noticed and they were still [serving her] food, almost 6 hours later!

Stigma and discrimination are again significant here, and healthcare workers are not immune from exhibiting society's prejudicial attitudes.⁷⁰ The respondent also raised the important question about the function of individual health workers in the realization of health rights. London suggests three ways in which their roles might be conceived within a human rights framework: firstly, employees of the State, the duty-bearer in international law, might become proxies through which it violates health rights; secondly, in contexts like South Africa, certain human rights obligations, like the prohibition of discrimination, may apply horizontally among individuals; thirdly, and much less likely to be subject to legal action, observance of human rights may be a professional requirement.⁷¹

But the issue of medication, particularly life-prolonging ARVs, exercised respondents most. ARVs, which were introduced in 1996⁷², come in multiple formulations, designed to upset the highly mutable HIV virus- the retrovirus- and limit its effects at the various stages of its life-cycle. To be effective they must be taken for the rest of a

⁷⁰ See Mahendra, *et al* (n 39), at 617-8

⁷¹ London, Leslie, 'What is a Human Rights-Based Approach to Health and Does it Matter?,' *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 65-80, at 68

⁷² UNAIDS, 'HIV Treatment,' 2008, at

<http://www.unaids.org/en/PolicyAndPractice/HIVTreatment/default.asp>, accessed 01/05/08.

Schweitzer, *et al*, quote a survey from 2002 of "1000 physicians and nurses in West Africa ... found that 20% of them felt that HIV-infected patients had behaved immorally and deserved their fate."

Further, "Oftentimes health care workers who help patients with HIV may also be stigmatized because of their association with the virus." (Schweitzer, *et al* (n 2), at 337)

patient's lifetime; discontinuation would reactivate the retrovirus.⁷³ WHO confirms that "[h]uge reductions have been seen in rates of death and suffering when use is made of a potent ARV regimen."⁷⁴

Evidence about the optimum time to start ART is inconclusive but most guidelines advise doing so only in the advanced phases of the HIV infection.⁷⁵ This requires diagnostic tests which measure the CD4 protein in patients' immune systems (the CD4 cell count) and the amount of HIV in the blood (the viral load test).⁷⁶ A PLWHA is deemed eligible if her CD4 cell count is below 250.⁷⁷ The 2007 national population-based Kenya AIDS Indicator Survey (KAIS) found that 39% of those eligible for ARV treatment knew their HIV status and were on ARVs; 4% knew they were infected but were not on ARVs; 57% were unaware of their HIV status (that is, they had never previously tested for HIV or had self-reported as uninfected based on their last test) and were not on ARVs.⁷⁸ Approximately 242,881 people received ARV therapy in December 2008, up from 177,000 (a 37% increase) in the same month the previous year.⁷⁹ These figures suggest the steady and significant increase in access to ARVs which has been reported in Kenya over the last few years: a total of 172,000 in 2007

⁷³ UNAIDS, 'HIV Treatment,' (n 72). According to WHO guidelines, optimal antiretroviral therapy (ART) generally consists of at least three ARV drugs, a fact which bears out the concerns of the peer educator interviewed above who pointed out problems with the types of drugs that she said some ill-informed patients were being given. (WHO, 'Antiretroviral Therapy,' 2008, at <http://www.who.int/hiv/treatment/en/index.html>, accessed 01/01/08)

⁷⁴ *ibid*

⁷⁵ See, for instance, advice posted by the organization AVERT, 'Starting Antiretroviral Treatment', 2008, at <http://www.avert.org/starttrt.htm>, accessed 03/01/08.

⁷⁶ See, AVERT for a layperson's explanation of the science behind infection. (*ibid.*) For a more detailed study into the HIV virus and infection see Schoub, Barry D., *AIDS and HIV in Perspective: A Guide to Understanding the Virus and its Consequences* (Cambridge: Cambridge University Press, 1999). However, concerns have also been raised that CD4 count tests alone may be misleading, as they fail to provide clear information about a patient's viral load, which may provide information about the possible presence of drug-resistant strains of HIV (see *IRIN PlusNews*, 'Kenya: Treatment Literacy Lagging Behind ARV Rollout,' (n 66)). The WHO's recommendations regarding the optimum treatment initialization stage vary: in 2006, treatment was recommended when the CD4 count fell to 200 or lower; in 2009, this threshold was increased to 350. (WHO, 'News Release: New HIV Recommendations to Improve Health, Reduce Infections and Save Lives,' 30th November 2009, at http://www.who.int/mediacentre/news/releases/2009/world_aids_20091130/en/index.html?utm_source=twitterfeed&utm_medium=twitter, accessed 01/12/10)

⁷⁷ NASCOP, *et al*, *The Kenya AIDS Indicator Survey (KAIS) 2007 Data Sheet* (n 34), at 4

⁷⁸ *ibid*. In fact, the survey recorded alarmingly high figures of overall knowledge of HIV status among adults, with the overwhelming majority (84%) of lab-confirmed HIV-positive participants unaware of their status (at 3).

⁷⁹ WHO/UNAIDS/UNICEF, *Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector, Progress Report 2009*, 2009, at http://data.unaids.org/pub/Report/2009/20090930_tuapr_2009_en.pdf, accessed 10/04/10; at 56

(a coverage of about 42% in 2007), to 236,881 in 2008 (about 55.3% of adult coverage and 26.4% for children) and 336,980 in 2009 (70.4% adult coverage and a significantly smaller 24.2% among children).⁸⁰ However, AIDS activists fear that Kenya may not meet its ARV scale-up targets or even sustain current levels of progress following a funding application rejection by the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund).⁸¹ The Global Fund accounts for around a fifth of the total global funding for HIV/AIDS programmes.⁸²

Drugs to prevent mother-to-child transmission (MTCT), through which over 90% of infections in infants and young children occur, have also been crucial.⁸³ 9 out of the 10 of the world's 2.1 million HIV-positive children under 15 years of age live in sub-Saharan Africa⁸⁴, of whom between 98,000 and 260,000 are in Kenya.⁸⁵ Interviewee 7 was grateful to the foreign NGO that saved one of her children from such a fate when asked how such organizations might assist.⁸⁶ The National AIDS Control Council (NACC) reported that in 2009 an estimated 72.3% of the 81,000 HIV-positive pregnant

⁸⁰ NACC, *UNGASS 2010: United Nations General Assembly Special Session (UNGASS) on HIV and AIDS 2010: Country Report- Kenya* (n 26), at 3 and 16. WHO/UNAIDS figures from December 2006, based on Kenya Ministry of Health reports, put the figure of people in need of ART at 290,000 with 125,000 actually accessing it- 120,000 from public sector facilities, the rest from private sector ones-, indicating around 44% of ART coverage. The same statistics also note a monthly increase of people accessing ART of about 5,000. (WHO, 2008c, *Estimated Number of People Receiving and Needing Antiretroviral Therapy, Coverage Percentages in WHO Member States*, 2008, at <http://www.who.int/globalatlas/docs/hiv/annex1web.xls>, accessed 29/04/08). Figures from the end of 2005 put the figure of those in need of ART at 273,000, with only 55,000 receiving it in the public sector and estimated 8,000 receiving it in the private sector. This represents coverage of about 23%. (WHO, *Summary Country Profile for HIV/AIDS Treatment Scale-Up*, 2005, at http://www.who.int/hiv/HIVCP_KEN.pdf, accessed 29/04/08.)

⁸¹ Activists claim that the funding application, worth USD270 million, which the country has been invited to revise and re-lodge, "could delay funds for almost a year. Because of this and other financial delays and spats with donors a report released yesterday by the Kenya Aids NGOs Consortium (KANCO) says the country is unlikely to meet set HIV targets." (*The Daily Nation*, 'Aids Infections on the Decline,' 1st December 2009)

⁸² See Garrett, Laurie, 'The Challenge of Global Health,' *Foreign Affairs*, January/February 2007, at <http://www.foreignaffairs.org/20070101faessay86103/laurie-garrett/the-challenge-of-global-health.html>, accessed 05/05/08; at 3

⁸³ WHO/UNICEF, *Guidance on Global Scale-Up of the Prevention of Mother-to-Child Transmission of HIV: Towards Universal Access for Women, Infants and Young Children and Eliminating HIV and AIDS Among Children*, 2007, at http://www.who.int/hiv/mtct/PMTCT_enWEBNov26.pdf, accessed 01/05/08; at 7.

⁸⁴ UNAIDS, '2009 AIDS Epidemic Update', 2009, at http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf, accessed 01/05/10

⁸⁵ UNAIDS, *Global Report: UNAIDS Report on the Global AIDS Epidemic, 2010*, 2010, at http://www.unaids.org/documents/20101123_GlobalReport_Annexes1_em.pdf, accessed 12/12/10.

⁸⁶ She noted, "With foreign NGOs, there are those like MSF who help. They have started giving drugs. And when I got my second child, I was helped by an overseas NGO by providing milk for the baby and nevirapine."

Kenyan children received ARVs to reduce the risk of MTCT; this figure is marginally lower than the previous year but overall a significant improvement on previous years.⁸⁷ Of the estimated 81,000 children born to infected mother in 2009, 39,482- or 49%- were getting ARVs to prevent infection.⁸⁸ Despite improvements in ART coverage generally, however, statistics show poorer results when it comes to paediatric treatment, with only about a quarter of children in need of ART being able to access it, as the figures quoted earlier relay.⁸⁹ Poor systems, which impede patient follow-up, are a major obstacle.⁹⁰ Yet accessibility of ARVs may reduce the psychological effects of an HIV diagnosis, as seen earlier.⁹¹ Interviewee 35, for instance, was encouraged by outcomes of ART in other PLWHAs: “Yes, and many of them have even greater needs and requirements. I see some who come here to collect their ARVs and they look so healthy. They give me a lot of hope. They tell me not to worry, that I too will get back my health.” Indeed, many PLWHAs form ideas about what it means to be infected from popular notions about the epidemic as a death sentence, which continued lack of universal access to ART only enhances.⁹²

⁸⁷ NACC, *UNGASS 2010: United Nations General Assembly Special Session (UNGASS) on HIV and AIDS 2010: Country Report- Kenya* (n 26), at 3 and 12. This is an increase from 2006, when UNICEF/UNAIDS/WHO figures indicated that an estimated 77,799 women were in need of ARVs to prevent PMTCT, with only 37,130 receiving them, amounting to a coverage of about 48%. (UNAIDS/UNICEF/WHO, *Children and AIDS: Second Stocktaking Report*, 2008, at http://www.unicef.org/publications/files/ChildrenAIDS_SecondStocktakingReport.pdf, accessed 01/05/08; at 42.) The Kenya National AIDS Control Council (N.A.C.C.) states in the *Kenya National AIDS Strategic Plan 2009/10-2012/13* (KNASP III) that by December 2006 nearly two-thirds of facilities were offering PMTCT to 60-70% of all pregnant HIV-positive women, and claimed to have achieved the target of its previous strategic plan (KNASP II, 2005/6-2009/10) to introduce to PMTCT to 80% of antenatal care health facilities. But the report also notes that less than a third of mothers tested are reached with Nevirapine. (NACC, *Kenya National AIDS Strategic Plan 2009/10-2012/13 (KNASP III): Delivering on Universal Access to Services* (n 20), at 11). It is unclear whether the facilities referred to in the statistic were only government facilities or all facilities across the board.

⁸⁸ NACC, *UNGASS 2010: United Nations General Assembly Special Session (UNGASS) on HIV and AIDS 2010: Country Report- Kenya* (n 26), at 12

⁸⁹ There is a discrepancy between these figures given in the UNGASS 2010 report (ibid) and those provided by the *Children and AIDS: Fourth Stocktaking Report, 2009*. (UNICEF/UNAIDS/WHO/UNFPA, *Children and AIDS: Fourth Stocktaking Report*, 2009, at http://www.uniteforchildren.org/files/CA_FSR_LoRes_PDF_EN_USLetter_11062009.pdf, accessed 05/05/10). These say that an estimated 49,000 Kenyan children were said to require ARV treatment in 2008 but only about 42% getting them (at 44). However, it must be noted that the estimates provided here have a wide range, with low estimates placing the figure at 29% and the high estimate putting it at 83%. See also WHO/UNAIDS/UNICEF, 2009, *op. cit.*, at 89. See also *IRIN PlusNews*, ‘Africa: Uneven Progress in Paediatric ART Rollout Demands More Action,’ 1st December 2009, at <http://www.plusnews.org/Report.aspx?ReportId=87278>, accessed 02/05/10.

⁹⁰ UNICEF/UNAIDS/WHO/UNFPA, *Children and AIDS: Fourth Stocktaking Report, 2009* (n 89), at 11.

⁹¹ Schweitzer, *et al* (n 2), at 338

⁹² Kelly, *et al* (n 1), at 8-9

The progressive scale-up of cheaper or free ARVs was not entirely smooth. This writer witnessed part of this process while conducting the fieldwork for this research. Over the seven or so weeks of interviewing, ARV costs at Mbagathi District Hospital (MDH) fell by 66%; thus the last respondents interviewed at the end of May 2004 were able to respond to questions about the implications of this. Also crucial to discussions here are the changes in the pricing of ARVs in public health institutions which have occurred in the subsequent years. Initially, ARV prices at MDH (and ostensibly at other government district hospital although, as interviewees revealed, this was not always the case) were Ksh. 1,500 (approx. GBP 10.07).⁹³ In May 2004 it was announced that this would then be reduced to Ksh. 500 (approx. GBP 3.36). A further decrease to Ksh. 200 (approx. GBP 1.34) was reported in early May 2005, although this applied in only one hospital, MDH.⁹⁴ In 2006 this was halved to Ksh100 (approx. GBP 0.67), before President Mwai Kibaki announced a complete fee-waiver.⁹⁵

Implementation hiccups aside, these announcements, had they occurred during the interviewing process, would undoubtedly have altered many responses and this should be borne in mind in the analysis of interviewees' reactions to ART costs. Nevertheless, a number still give an idea of the kind of answers that might have been elicited, as some respondents were already receiving free ARVs from Médecins Sans Frontières (MSF). A facility known as the Comprehensive Care Centre, jointly ran by the Kenya Ministry of Health and MSF Belgium, was inaugurated in April 2005, by which time it was already serving 1,850 patients, with ARVs provided free but costs of about USD 5 levied for tests and other drugs.⁹⁶ In addition, there were responses from PLWHAs who had been purchasing ARVs from the more expensive private health sector and others who were trying to switch from private to public healthcare who commented on the difficulties they encountered. Thus the range of interviews

⁹³ The government had announced in September 2003 that ARVs would be available at all District Hospitals by the end of that month. It was added that patients would have to pay for the drugs although the cost would be reduced; at the time the cheapest drugs cost Ksh 3,000 (approx. GBP 23). (*The Daily Nation*, 'State accused of betrayal on Aids medicines,' 17th September 2003)

⁹⁴ *The Daily Nation*, 'Aids Infections on the Decline,' (n 81)

⁹⁵ *IRIN PlusNews*, 'Kenya: ARVs Now Free in Public Hospitals,' 2nd June 2006, at <http://www.plusnews.org/Report.aspx?ReportId=39654>, accessed 03/01/08

⁹⁶ *IRIN PlusNews*, 'Kenya: Health Centre to Treat HIV/AIDS Patients Inaugurated,' 28th April 2005, at <http://www.plusnews.org/Report.aspx?ReportId=38495>, accessed 06/05/08

offers a broad spectrum of opinions about the impact of the pricing differences on PLWAHs' lives.

The primary reasons cited for lack of universal access to ART in Kenya and elsewhere are, broadly speaking, the prohibitive cost of ARVs and the absence of a reliable healthcare infrastructure to adequately implement the necessary components of the treatment programmes.⁹⁷ Even though several respondents felt the provision of health requirements was their personal responsibility, with ARVs as with nutrition the reality was that many were dependent on family members or their wider social network despite the perception by some that they had become or were becoming burdensome. Once again this reflects a major disconnect between the ideal often promoted by CSOs and donor agencies and assimilated by PLWHA of the 'empowered', self-reliant PLWHA able to exercise healthy options, and the real socio-economic obstacles many encounter.⁹⁸ Indeed, Gabriel Rugalema has noted the various levels of consultation that typify decision-making about the deployment of resources to tackle illness or death expenses: bolstering his critique of so-called 'coping strategies,' he observes that these choices often leap from the realm of the individual or household and encompass the wider kinship group.

Such decisions are therefore not always contained within the 'walls' of the household. In some situations, individuals (mostly males, including those sick from AIDS) may make decisions about what assets should be disposed of and what kind of treatment should be sought - regardless of the short or long-term costs to the rest of the household members. In others, husbands and wives may consult on the best course of action. In yet others, it is the wider [kinship-based] therapy managing group that manages the resource utilisation of the afflicted households, sometimes without even consulting household members.⁹⁹

This underscores the real corporate nature of the realization of healthcare for many- far from the rhetoric of the atomized individual imagined by human rights instruments- and exposes the complexities of decisions and actions at the lowest strata of the healthcare pyramid, far removed from the legislative guarantees of individual health rights from the State. The role and significance of kinship and other

⁹⁷ UNAIDS cites these two factors as key stumbling in the efforts towards universal access to ART, in UNAIDS, 'HIV Treatment,' (n 72)

⁹⁸ Finn and Sarangi (n 67), at 248-9

⁹⁹ Rugalema, Gabriel, 'Coping or Struggling? A Journey into the Impact of HIV/AIDS in Southern Africa', *Review of African Political Economy*, Vol. 27, No. 86 (2000), pp. 537- 545, at 541

social networks in bridging the gap between the ideals and reality of the State-individual human rights compact is once again underlined.

The government is perhaps conscious, however, that such ties cannot solely, infinitely, absorb the social welfare pressures wrought by the AIDS epidemic, for it recently initiated a scheme to provide cash transfers to enable orphans and vulnerable children in poor households to remain within these families. 12,500 reportedly benefitted in 2007, with a target of 70,000 set for 2009; these efforts attracted funding from the World Bank worth \$US50 million, to be scaled up to cover 100,000 households by 2012.¹⁰⁰

But while the above-mentioned obstacles to universal access of ART do apply and were highlighted in interviews, as will be seen shortly, they also suggest of a more nuanced understanding of the underlying problems. Several respondents identified a lack of political will to meet PLWHAs' healthcare needs. A number voiced doubts about the government's capacity to handle the HIV/AIDS crisis altogether, suggesting it was symptomatic of its general attitude towards the welfare of ordinary citizens; some of these views were seen in Chapter 4. It is in these statements and opinions that the ongoing transaction between the State and its citizen-subjects and the ruptures that pervade this central relationship in the human rights dynamic can be seen. The interviews reflect the range of opinions about where the equilibrium in this relationship lies, where it *ought* to lie and how the ideal balance can be struck. They provide useful pointers to the nature of some the conversations that have been taking place in Kenya, and the fact that they are focussed on PLWHAs allows one to speculate legitimately about how the HIV/AIDS epidemic may be impacting on this conversation. This discussion will be explored in even greater detail in chapters 7 and 8.

For now, it is in the decision whether to start the life-prolonging ART that PLWHAs encounter the first critical impact of its cost. The process towards treatment is stalled early on due to the prohibitive cost of diagnostic tests.¹⁰¹ This point was cited by the

¹⁰⁰ UNICEF/UNAIDS/WHO/UNFPA, *Children and AIDS: Fourth Stocktaking Report, 2009* (n 89), at 24

¹⁰¹ See Barnett and Whiteside (n 33), at 367

director of the N.A.C.C., Patrick Orege, who in 2005 stated that the \$26 cost imposed by public health centres for the laboratory tests was a significant factor in hindering the uptake of ART.¹⁰² This was borne out by respondents 25 and 48: the former, offering her opinion on the September 2003 ARV subsidization announcement that promised to halve drug prices, noted: “There are very few hospitals with the drugs.... And they are not even free because you have to go and have your CD4 count done, which is very expensive.” Interviewee 48 said she had attended the event at which this announcement was made to the public:

The way the government is treating PLWHAs who are supposed to be on ARVs, from the stories I hear from my colleagues, it’s not easy to access the treatment from the government. I hear it’s cost-sharing but all the same it’s not easy to even be recruited into that programme and then you know when you’re in the [government cost sharing] programme there are many things that have to be done: your CD4 count has to be tested, your viral load has to be tested, your liver has to be tested, they have to know whether you’re anaemic and so on. ... unlike in MSF Belgium, where we get all these tests for free. ... [T]hey should also be willing to do those CD4 counts for free and the viral test. You know it’s very expensive, for CD4 count you pay Ksh 7,000 (approx. GB£47). Viral load you pay Ksh. 10,000 (approx. GB£67).

There is a huge discrepancy between the costs of the diagnostics tests (which are not specified here) as stated by the N.A.C.C. director and that given by interviewee 48 for both the CD4 count and viral load. Further, another different figure from early May 2005 is mentioned in a newspaper article cited earlier, which also reports the lowering of CD4 test costs to Ksh. 200 (approx. USD 2.60), down from Ksh. 500 (approx. USD 6.50).¹⁰³ This highlights the elusiveness of objective costing and there is no way to account precisely for these differences. However, there may be a few possible explanations: the figures cited by the interviewee may be incorrect (she herself said that she was offered the tests free by MSF Belgium, and therefore the prices she quoted may be based on hearsay) or they may have been deliberately exaggerated. It is also possible that some of the charges mentioned by the interviewee were, in fact, accurate but for the private healthcare sector rather than the often-cheaper public.¹⁰⁴ These inflated costs may also be, indeed, from a public

¹⁰² *IRIN PlusNews*, ‘Kenya: Costly drugs and tests block AIDS treatment’, 9th February 2005, at <http://www.plusnews.org/Report.aspx?ReportId=38182>, accessed 03/01/08.

¹⁰³ *The Daily Nation*, ‘Cost of Aids drug down to Sh200,’ 11th May 2005

¹⁰⁴ In a discussion paper for the Institute of Policy Analysis and Research (IPAR), Wassuna Owino noted that 62% of respondents who had taken part in his investigation declared a preference for public health service facilities for, among other reasons, being cheaper than the private sector. (Owino, Wassuna, *Public Health Sector Pricing Policy: The Question of Fee Adjustments* (Nairobi: IPAR, December 1998) at 17.

healthcare facility where there has been a documented decentralized and highly uneven pricing system.¹⁰⁵ A 2007 report carried online by *IRIN/PlusNews* noted that while viral load tests were supposed to be free, hospitals outside Nairobi still charged USD 25 for them, adding that CD4 count tests were free but unavailable in rural areas.¹⁰⁶ One respondent, interviewee 8, even stated that a relative had not gone for the HIV test itself because even a payment for this had been demanded:

...My brother is sick. I left him completely unable to do anything. But I know the problem just by looking at him..... No [he has not yet been tested].He was told that it would cost Ksh250 at the VCT to get tested and yet he was not aware. When I spoke to him I told him that those people are not supposed to charge. But he is sick... he hasn't gone back because of the money.

The cost of diagnostic tests is one of the measures that the NHIF hopes to eliminate as part of its ambitious aims to provide universal comprehensive outpatient cover.¹⁰⁷ However, it is likely that the implementation of these changes will be slow and uneven, if government policy on subsidized (and then ostensibly-free) ARVs is any guide.

Beyond diagnostic testing, many PLWHAs may still have apprehensions about commencing life-prolonging treatment because their use also means the start of a lifetime commitment to an expense that is beyond their reach. As one respondent put it:

Now, if you take the drugs, you live. So what are you to do if you are unable to pay for the drugs? Isn't that a problem? We have been told that once you start taking the drugs, you cannot stop. You have to take them for the life. So if you cannot afford them, what are you to do? (Interviewee 19)

Such a start-stop approach to ART is detrimental to an individual's health but also for the inroads that have been made so far in tackling the virus. Lack of adherence, that

¹⁰⁵ See *ibid*

¹⁰⁶ *IRIN PlusNews*, 'Kenya: Treatment Literacy Lagging Behind ARV Rollout,' (n 66). It must be noted that this report also mentions that 160,000 PLWHAs are said to have benefited from the government's free rollout of ARVs, a figure that appears to be attributed to an official in Kenya's Ministry of Health's (MoH), Dr Lyndon Marani. This figure is considerably higher than the 120,000 (already mentioned in this paper) supplied by WHO for December 2006 and based on the MoH's own figures, for those receiving ARVs from public sector health facilities, which presumably includes those getting the drugs for free or otherwise. The numbers mentioned in the IRIN report are even greater than the highest estimate supplied in WHO report. This discrepancy is hard to account for, even when one considers that the MoH/WHO figures are for December 2006 and the IRIN report is dated almost a year later.

¹⁰⁷ Kerich (n 20)

is, failure to take drugs according to strict instructions, has been a documented cause of the rise in drug-resistant strains of the HIV virus.¹⁰⁸

For those still having to pay for their drugs whether in part or in full by the time the interviews were conducted, ART often accounted for their greatest, or one of the their greatest, expenses. The cost of ARVs given by interviewees varied widely from Ksh. 4,000 (approx. GBP 27) a month to Ksh. 60,000 (approx. GBP 403), which one respondent, interviewee 47, said she was paying when she first started receiving ART in 2000. Having exhausted her savings in the process, her usage was now irregular:

I've been buying them ever since I knew I was sick. And even when I started buying in 2000, they were very expensive. I used to [pay] Ksh. 60,000 a month from chemists in Kenya! I even have the receipts to prove it. I bought until I exhausted all my savings and just stopped taking them. So when I used to get some money I'd buy some more. I have not been consistent in taking them because they were not affordable.

Because of competing expenses, a number of PLWHAs stated that they had often elected to prioritize their other needs, especially nutritional ones, as seen in the previous chapter, and forgo drugs:

...[E]ven with the medication, sometimes I have to limit that so that I can be able to pay the school fees. Sometimes I even look at my payslip and think to myself, it is better to just stop taking this medication and die. You look at your bills and by the 2nd of every month it's almost as if you didn't get any salary at the end of the previous month. But then you feel ill and so you go and buy the drug. But because of that, you are unable to buy food; your child has told you that they don't have books for school. So it's difficult. (Interviewee 30)

Indeed, interviewee 5 appeared to be suggesting that starting some PLWHAs on ARVs raised false hopes in those who would soon find themselves unable to continue with the treatment due to other pressing financial concerns. She declared: "You go for the ARVs, you don't have enough food to eat, you cannot even afford to buy fruit, you have stress about house rent, and then somebody puts you on ARVs. It's like it's not helping you." However, it is likely that she would have altered her views if she were later able to access free ART. Nevertheless, her views are a bitter testament to a situation that faces millions: available but inaccessible life-prolonging treatment.

¹⁰⁸ See IRIN report of drug-resistant HIV strains in Kenya due to lack of adherence caused by low rates of literacy in HIV/AIDS treatment (*IRIN PlusNews*, 'How New NHIF Package Will Benefit Members,' (n 20). See also some interviewee responses: Interviewee 40, for instance, admitted: "Sometimes you don't find the drugs- I sometimes have to buy drugs to last me just four days, in the hope that I'll find more before those run out." Interviewee 26 said, "I get the drugs from my family. They contribute. At times I get late in buying them because I have to wait for the money to become available."

Other hidden costs rendered accessing ART anything but free.¹⁰⁹ A number decried the transport costs incurred just to get to hospital for their check-ups and medication: ... [I]f you're not working, not getting anything per day and living from hand to mouth, even if ARVs are reduced to Ksh. 60 (approx. 40p) or 50 (approx. 34p) per day... it's still difficult. Because even if it's free, the centre where he is going to collect the drugs- at the moment I'm telling you, we've been having appointments at Kenyatta [National Hospital], at Mbagathi, still someone misses, and the appointment maybe is free. This is because of the bus fare and you can't even walk. So because of the additional costs, it still won't work perfectly even if it is under cost-sharing. So as much as someone would like to come and collect ARVs if they are being offered for free, they can't make it. So who do you blame- you blame [the PLWHA]. (Interviewee 3)

Interviewee 25 reiterated these concerns: "Like now I've come all the way from Murang'a [nearly 90km away by road travel] to here. If they were available in Murang'a, it could be cheaper. But now you have to take transport to come here for treatment and that is quite expensive."¹¹⁰ This issue also highlights the problems of a poor health infrastructure and the bias against rural areas in public service provision. Once again this underlines the urban focus of the central State and likely bolsters the view that it is remote and disconnected from the rural areas where the vast majority live. As will be seen later, the resulting gap has been filled by traditional medicine. This rural-urban imbalance sometimes produced perverse situations: the cost to one interviewee of her subsidized ARVs, for instance, which at the time was still Ksh. 1,500 (approx. GBP 10), was only fractionally higher than her transport costs. She stated that she travelled from her home in a town in Western Kenya called Migori, which is over 300km away from Nairobi by road. The cost of her return journey was between Ksh. 1,000 and 1,100 (between approx. GBP 6.70 and 7.40).¹¹¹

Yet there seemed to be no criticism of the failure by providers, where the drugs were free, to factor these hidden costs into their programming and take steps to

¹⁰⁹ See Farmer, Paul, 'Challenging Orthodoxies: The Road Ahead for Health and Human Rights,' *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 5-19, at 7 and 8.

¹¹⁰ Similar remarks were reported in the press in December 2009, from a woman who was receiving free ART along with her child at MDH. The woman is quoted as saying: "I come from very far and I just walk to this place because I have no money to take a matatu [public transportation]. But at times when I feel like giving up, the desire to see her alive makes me force my tired legs to carry on. To me it is a journey of life." (*IRIN PlusNews*, 'Africa: Uneven Progress in Paediatric ART Rollout Demands More Action,' (n 89))

¹¹¹ "The drugs [are] what I'm not usually getting," she said. "Where I come from the drugs are not available and it is very far. And to get these drugs it's really expensive and I am jobless. But I come for the clinic although the fare is now very difficult for me to get." (Interviewee 8)

compensate for them. The fact that they are a real and documented obstacle to successfully accessing ART and that several PLWHAs raised this without prompting points, as with proper nutrition, to the often narrow definitions applied by CSOs and governments to what constitutes the much-touted successful treatment programmes. But it may also suggest that for these and perhaps other PLWHAs their notions of what they might be entitled to did not include the additional costs of accessing the ART: true, they might recognize them as potentially- if not outright-prohibitive but their expectations of assistance do not extend to them. Given the sceptical views that emerged especially regarding the government's provision for their healthcare needs, these PLWHAs may have simply adjusted their expectations downwards to only limited assistance from the State and other providers at best; anything more may have been perceived as a bridge too far. The State's historic inability or unwillingness to provide- its past record of performance- may therefore be seen as crucial in shaping future notions of entitlements among PLWHAs and the public in general.

Interestingly, too, some PLWHAs were uneasy about the prospect of freely available medication despite the broad consensus in favour of free or affordable ART. One, who had contracted HIV after a sexual relationship while a student abroad, appeared to associate this viewpoint with the circumstances by which she had become infected, but also speculated about why medication for another infectious disease, TB, was offered free unlike ART. After stating that she was buying her ARVs for Ksh. 1,500 (approx. GBP 10) at the time of the interview under the government's cost-sharing system, down from Ksh. 6,000 (approx. GBP 40), she said of the system:

Since we were careless enough to fall in this mess, that's why we're wearing these boots- maybe we should pay a little money. But what about those people who genuinely can't afford? There are so many people in the slums who can't afford. So I think... like TB treatment- maybe it's because TB is airborne, that's why they give free medication!
(Interviewee 16)

This is revelatory about how attitudes, also held by some PLWHAs themselves, towards sex as the primary mode of HIV infection may intersect with the construction of notions of entitlements to healthcare. It will be recalled that interviewee 11, who became infected after a rape, spoke of not having got the virus "rightfully." That

some PLWHAs might feel paying for ARVs is a punitive measure of sorts because of certain internalized feelings of shame and guilt is disquieting.

Interviewee 30 believed that the cost attached to the management of the disease might deter those who might otherwise consider engaging in risky behaviour, declaring: “Even I agree that we should pay something small. Because if you provide humans with something for free, some people will start treating this illness as if it is a joke, a game. If you hear about the way some people contract this illness, they put themselves in risky situations.” Disclosing that she had contracted HIV from her unfaithful husband, she emphasized that he had been her only sexual partner since their marriage. Although she felt the government should reduce the amount they required patients to pay she warned interestingly that:

[I]f [ARVs] are given out for free, those who get it for free *will cause problems* because the number who are ill are so many. Everyone will demand the medicine and they will use force if they have to. It is better that we pay something small for it, even those of us with very little money. And that will limit the numbers who contract the disease.

The words “will cause problems” have been italicized here because the actual words she used directly translate from the Kiswahili in which the interview was conducted as “will cause a war.” She seemed to be suggesting that lack of universal access for all that need ARVs might result in conflict if they are free only to some. Her views may be attributable to the obscurity of the selection process by which eligibility for free ART is decided. Hence she may have perceived pricing as a leveller: payment as the criteria for exclusion may seem more transparent and fairer.

Such notions might make sense in the Kenyan context where social or political capital is often used overtly or covertly to determine who gains access to social goods, particularly those that come from the State. But suspicion extends to other actors: indeed, during the patients’ group session I attended at Mbagathi Hospital (see Chapter 2), some patients claimed that some local PLWHA CSOs applied ethnicity as a criteria for membership, favouring co-ethnics and/or specifically excluding other groups. Yet the respondent above appeared unaware that even the ability to pay for the subsidized drugs is itself predicated on the same inequalities she hoped to see obviated, thereby perpetuating them and reinforcing the categorization of PLWHAs

into have-ARVs and have-nots. This undermines the notion of solidarity among PLWHAs: as interviewee 14 noted despite declaring herself satisfied with the way her own needs were being met: “I still feel there should be uniformity. Because there is a category that is getting the drugs for free, another has to buy them, another can’t access them....” There were further cleavages between those who, because their means permitted it, had previously been able to access ART privately before seeking to benefit from the vastly cheaper or free medication subsequently available in the public sector.¹¹² Additionally, as noted elsewhere, lack of uniformity in the government roll-out of subsidized or free ARVs meant the scheme was available in some hospitals (often urban ones) and not others. Interviewee 1 attested to this erratic approach: he said that even though he had heard of the announcement of the scheme in September 2003 he had yet to hear of anyone who had actually been able to buy the drugs at the reduced rate by the time he was interviewed in April 2004: He noted,

The people I know buy them at Ksh.4,000 a month (approx. GBP 27), and this is someone who is not working, they cannot even pay house rent. How can you pay for that drug? It’s a problem. ... [The government] said that [that they would be paying for part of the ARV costs] but they are not doing that because we’ve lost so many patients. I know of relatives.... They didn’t have that money, they didn’t know of how to go about it. At least me I’m enlightened about how to take care of myself, but it reaches a point without those drugs I won’t be able to go on. So the government whatever they said they are not doing it. People are still suffering. ... Well, it’s not right because all the fingers on my hand are not equal, that means, everyone is not equal financially; some people don’t have totally, others have.

It is also worth mentioning attitudes about the government’s justification for its initial cost-sharing programme, which was, of course later amended to full subsidization of ARVs. Indeed, a number of those interviewees who supported it appeared to have genuinely absorbed the government’s rationalization, accepting that the cost levied on patients would help sustain the programme. Rather than have no drugs at all, they reasoned, it was a better to ask patients for a partial payment. For instance, interviewee 33 declared that “paying something small, as long as we keep getting the

¹¹² There was a presumption among some of these respondents that entry into the subsidized ARV programme is open to anyone who can pay. When asked about the government programme at MDH interviewee 32 said: “That’s why I come here. But there are some problems: if you had taken some medicine before you find that they can’t put you on the same programme.” The hospital policy on the cost-sharing scheme, as outlined to the author by a nurse in the HIV clinic, dictated that if a patient had started on the medication privately, there was a *prima facie* assumption that she could afford to get the drugs privately and therefore was not qualified to get on the programme.

drugs, is ok. It would be worse if we didn't pay anything but stopped getting the drugs altogether." Interviewee 25 too, said: "[Cost-sharing] is good because you have to pay a little to sustain the programme because they cannot keep up. There are so many people who are HIV-positive they can't meet their needs. We have to cost-share. But at least they can reduce the amount." Interviewee 26 stressed that he was able to buy his drugs only because of the contributions made by his family, and yet although he sometimes had to wait for the money to become available before he could buy the drugs, he still supported the idea of paying a fee for them, declaring, "[T]o make a small contribution is not a bad thing."

Other respondents of a similar opinion clearly displayed political allegiance to Mwai Kibaki's then-new government (which had succeeded Daniel arap Moi's in the 2001 general election). Interviewee 16, noted earlier, gave "thanks to this new government" for slashing ARV prices to the "affordable" level of Ksh. 1,500. Interviewee 40 was especially emphatic and appeared to blame the previous regime's infamous corruption and looting for the lack of progress in provision of ART. She, too, reflected a belief in the genuineness of the government's reasons for subsidized rather than altogether-free ART:

[Cost-sharing] is a good a thing so that the drugs will be available. If the government says that this is necessary to sustain the programme, then it must be so. You know, this government started off without money. You know the previous leader used to use the money for his own ends! So if they tell us to give something small, then we'll do it, as long as the drugs will then be available. If we refuse and the drugs cease, how will we survive? Once you become used to them, it's difficult to live without them. I was at a meeting at WOFAK recently and I saw people who had been on the drugs for 20 years, they were fit and strong. Some came to that meeting and I thought they were just visitors- they looked so healthy. I couldn't believe it! The drugs are really important.

And although interviewee 14 accepted the government's justification for cost-sharing "for the moment," she nevertheless felt "they should push for something better. This is a life-long thing and this aspect of it is what makes it difficult because if today I lose my job, I'll die the next month."

The implicit trust displayed by some in declarations by the State and other institutions of authority has been discussed in Chapter 4; the examples cited above illustrate to how the State's messages and policies may mould individual expectations and notions

about entitlements to rights. They also illustrate how these ideas may be modified and manipulated by a State which offers only partially or unevenly benefits it publically undertakes to provide more fully and universally, especially in conditions where the status quo is one of lack. To be sure, many PLWHAs did question the government's trustworthiness, expressing dissatisfaction at how it had handled the AIDS epidemic. The provision of ARVs continues to be a particular focus for advocates and yet the narrative of access to ARVs- or lack thereof- embraces entities and discourses much further afield, which are even less wieldy for local actors like the PLWHAs interviewed for this research. It exemplifies the new dynamics of the health and human rights dialogue, no longer confined to the rights-holding individual and the duty-bearing State in which she claims citizenship. It also illustrates the multiple audiences to whom State actions- or inactions- are directed and the various platforms, local and international, on which it plays out the roles of statehood.

III. Traditional Medicine, Healthcare and Construction of the Subject

The difficulties of accessing biomedical treatment make it necessary to locate alternative medicine in the debate about the management of the HIV/AIDS epidemic. Low-income countries such as Kenya and South Africa are still grappling with a poor health infrastructure. This, having already been undermined by such initiatives as SAPs two or three decades earlier¹¹³, is further weakened by the AIDS epidemic.¹¹⁴ Nor do such countries appear to have benefited as much as expected from the surge in global public health funding for HIV/AIDS, as will be seen in the next chapter.¹¹⁵ Even though the focus remains on improving the formal health sector, it is still unavailable or inaccessible to many. Thus alternative sources of healthcare cannot be taken lightly.

Several interviewees, it will be recalled, lamented the paucity of healthcare facilities in rural areas and the financial strain of hidden costs incurred to access the mostly urban-centred health facilities, not to mention the impact of long commutes on

¹¹³ See Mohindra, K.S., 'Healthy Public Policy in Poor Countries: Tackling Macro-economic Policies,' *Health Promotion International*, June 1 2007; Vol. 22, No. 2 (2007), pp. 163-169

¹¹⁴ UNAIDS, *Ancient Remedies, New Disease: Involving Traditional Healers in Increasing Access to AIDS Care and Prevention in East Africa*, June 2002, at http://data.unaids.org/Publications/IRC-pub02/jc761-ancientremedies_en.pdf, accessed 05/05/08; at 9

¹¹⁵ Garrett (n 82), at 1

health. Undoubtedly countless many have no alternative but to resort to those resources most readily available to them. But the two regimes are not entirely incompatible: UNAIDS has documented case studies in East Africa where biomedical advances, modern scientific technical know-how and expertise in traditional herbal medicine were being used to promising effect.¹¹⁶ One study featured various projects undertaken by WOFAK, the local NGO some of whose clients were interviewed for this research (although not on this issue), who were fostering an evolving symbiotic, cross-referral relationship between traditional healers and nurses or doctors with biomedical expertise. Included in this matrix was the Kenya Forestry Research Institute (KEFRI), whose technical expertise and capacity to source and sample herbal raw materials was crucial in helping to validate age-old remedies for such AIDS-related illnesses as herpes zoster.¹¹⁷

While it is true that even here the standard of validation, the gateway to wider recognition and the possibility of greater investment, remains rooted in the Western understanding of biomedicine, it is worth noting the change in approach that their inclusion represents. This view is sustained despite the fact that the study indicated that traditional healers were being forced to adapt to particular Western methods and approaches in their work- such as greater transparency in their methods and operations- as well as submitting their remedies to scientific scrutiny in order to gain the endorsement that comes from participation in such projects. Far too often their role in the narrative of the HIV/AIDS epidemic has stalled on the image of healers as 'quacks' and purveyors of crude, dangerous misinformation which at best rolls back progress on education about the epidemic and at worst encourages HIV infection.¹¹⁸ Interviewee 5 appeared to suggest in one of her responses that part of the problem

¹¹⁶ UNAIDS, *Ancient Remedies, New Disease: Involving Traditional Healers in Increasing Access to AIDS Care and Prevention in East Africa*, (n 114)

¹¹⁷ *ibid*, at 12

¹¹⁸ Witness for instance Malawi's draft law aimed at prohibiting the operation of traditional healers and religious leaders who encourage their adherents to abandon ART with the claim that their remedies or prayers will cure them of AIDS (Reuters, 'Malawi Drafts Laws Against "Healers" of AIDS', 26th February 2008, <http://uk.reuters.com/article/healthNews/idUKL2648848420080226>, accessed 07/07/08). See also reports of myths, said to be perpetuated by traditional witchdoctors, which have led to the child rapes, that sex with a virgin will cure AIDS (Swindells, Steve, 'Myths Blunt Africa's Fights Against AIDS,' *Alert Net*, 2nd December 2003, <http://www.alertnet.org/thefacts/reliefresources/107036097535.htm>, accessed 07/07/08). See also Campbell, Catherine, *'Letting Them Die': Why HIV/AIDS Prevention Programmes Fail* (Oxford: International African Institute, 2003), at 26-7

lay in the lack of information about these alternative medicines, which, coupled with plausible reports of conmen selling miracle 'cures' for AIDS left PLWHAs even more suspicious of anything not endorsed by biomedicine¹¹⁹:

We also need education because I'd like to be updated on these HIV information. Like herbal medicines: there are people claiming that they have cures and you really wish that you knew more so you can decide whether to go and get it. But we are not updated. And because there are conmen, you can be given anything. So we need to be educated.

An unquestioning faith in anything that purports to being biomedically certified can, of course, be dangerous, as there is now a thriving market in counterfeit ARVs and other medical products.¹²⁰

There is also a greater appreciation of the role of traditional healers beyond the merely curative: they constitute the traditional locus of power that co-exists alongside the modern State and many occupy powerful positions of trust and authority within the community, of which States are sometimes wary, to the possible detriment of patients.¹²¹ But their status undoubtedly makes them good conduits for information on health and other social matters.¹²² Alexander Butchart identifies the mid-1970s as the period when this mutation in the power politics of the body took place, the suppression of traditional healers began to recede and a more favourable attitude began to gain currency.¹²³ This situation is especially familiar in rural areas, the seat of the customary, even though, as the above-mentioned UNAIDS study in

¹¹⁹ Amon (n 21). He points out that, "[i]n some cases, government endorsement of unproven 'cures' has created confusion regarding the legitimacy of AIDS medicines, and governments and international organizations have done a poor job separating out their appropriate recognition of the important role played by traditional medicines in physical and psychosocial care, from the dangerous and modern day hucksterism that AIDS 'cures' represent." He argues that campaigns to encourage ART uptake and discourage the use of untested 'cures' are currently undertaken primarily by NGOs and PLWHA networks, but a wider range of stakeholders including "public and private sector Western medical providers, traditional healers, and mass media," must get involved.

¹²⁰ See *ibid.* Amon notes that, "The US Food and Drug Administration estimates that counterfeit drugs account for 10% of the international market and according to the WHO the proportion may be 25% of the market in developing countries In 2004 the Kenyan newspaper 'The Nation' documented an active informal market for ARVs, including AIDS cures and counterfeit drugs, in Tsavo Road in Nairobi."

¹²¹ Amon writes: "Even those governments that adopt pragmatic and 'progressive' AIDS policies... may find that criticizing unproven AIDS cures can be misunderstood as criticizing traditional medicines and can be politically risky. Consequently, most governments do nothing as 'cures' are promoted openly – in newspapers, on the radio, on billboards and other outlets." (*ibid.*)

¹²² UNAIDS, *Ancient Remedies, New Disease: Involving Traditional Healers in Increasing Access to AIDS Care and Prevention in East Africa*, (n 114).

¹²³ Butchart, Alexander, *The Anatomy of Power: European Constructions of the African Body* (London; New York: Zed Books, 1998), at 90

Kenya observes, many healers have migrated to urban centres.¹²⁴ Their status is historical, a residue of pre-colonial social organization. That they remain relevant today tells a more subtle tale than just one of poor penetration of formal health infrastructures in rural and remote areas: it demonstrates the enduring traditional social structures and power systems especially, but not exclusively, in rural settings.

This holds true despite the fact that, in the age of globalization, official strategies on HIV/AIDS awareness-raising even in rural areas are framed wholly within a Western understanding of disease which is grounded in its science, with information about the pathology of the illness a key plank. As Altman has noted, “[g]lobal mobilization around the demands of a biomedical emergency meant the further entrenchment of Western concepts of disease, treatment and the body,” concepts which were quite removed from how many societies understood illness.¹²⁵ This may be diametrically opposed to the more obscure, sometimes mystical processes of alternative medicine, for which the UNAIDS study recommended transparency.

Yet even as those PLWHAs with access to formal healthcare continue to absorb new information which constructs their illness and their subjectivities very much within the entrenched biomedical paradigm, as illustrated by interviewees’ awareness of the range of diagnostic tests and ARV brand names, many may well be complementing their visits to biomedical healthcare centres with trips to traditional healers. This possibility is acknowledged in a UNAIDS study.¹²⁶ This may be because, firstly, certain aspects of biomedicine, as it developed in former colonies like Kenya, may prove unsatisfactory for PLWHAs. As Vaughn asserts:

The ‘problem’ with biomedicine as it emerged at the end of the nineteenth century is seen to be its reliance on a process of objectification of the body, and a resulting sense of alienation on the part of the person whose body it is, and who is constructed as the ‘patient’. This scientific method, it is argued, has the effect of removing health and illness from the social context in which they are produced, and in which they

¹²⁴ UNAIDS, *Ancient Remedies, New Disease: Involving Traditional Healers in Increasing Access to AIDS Care and Prevention in East Africa*, (n 114), at 16

¹²⁵ Altman, Dennis, in Weeks, Jeffrey; Holland, Janet, and Waites, Matthew (eds.), *Sexualities and Society: A Reader* (Cambridge: Polity Press, 2003), at 188-9. See also Ely Yamin, Alicia, ‘Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care,’ *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 45-63, at 47

¹²⁶ UNAIDS, *Collaborating with Traditional Healers for HIV Prevention and Care in sub-Saharan Africa: Suggestions for Programme Managers and Field Workers*, (n 55), at 7

belong, to another level which is both internal to the individual but also outside her or his control. Not only does it cause those who are ill to feel powerless and alienated but, it is also argued, this way of viewing the production of disease is also inefficient.¹²⁷

This sense of “alienation” and “powerlessness” can be seen in the interviewee earlier who decried the care offered in Kenyatta Hospital; yet patients may be fearful of challenging inadequate care from the often overworked and underpaid hospital staff, lest they are deprived of medical care in future.¹²⁸ The personal service offered by traditional medicine may be preferable and such patients may often form long-term relationships with the healer.¹²⁹ Traditional medicine, in its capacity to encompass the care of the physical body as well as the spiritual and psychological elements discussed earlier in the chapter, may conform more closely with many people’s perceptions of their illness as well as conceptions of their own subjectivities.¹³⁰ As one of the UNAIDS studies quoted here notes, “[t]raditional healers form longterm innovative and participatory support groups, which have proven successful in prevention, care and support to HIV-infected and –affected people.”¹³¹

And yet biomedicine’s preoccupation with the body as a discrete organism into which an informed, self-monitoring patient inputs the correct treatments and cures (witness responses regarding prescribed foods and medications) may in fact further facilitate the patient’s conceptualization of herself as the atomized entity at the heart of human rights.¹³² Indeed it has been argued that the combined health sciences actively sought to produce a very particular subject in the post-war period: a ‘knowing’,

¹²⁷ Vaughn, Megan, *Curing Their Ills: Colonial Power and African Illness* (Stanford, California: Stanford University Press, 1991) at 5

¹²⁸ Mhloyi, Marvellous, ‘Health and Human Rights: An International Crusade,’ *Health and Human Rights: An International Journal*, Vol.1, No.2 (1995), pp. 125-127, at 127

¹²⁹ The UNAIDS case study notes that among the lessons learnt by WOFAK were: “Communication with traditional healers calls for face-to-face contact, especially in the case of ceremonies and during the use of herbal medicines.” (UNAIDS, 2002, *loc. cit.* at note 146)

¹³⁰ This was certainly the case amongst some of the South African mine workers interviewed by Catherine Campbell. See Campbell (n 118), at 26

¹³¹ UNAIDS, 2002, *Ancient Remedies, New Disease: Involving Traditional Healers in Increasing Access to AIDS Care and Prevention in East Africa*,’ (n 114), at 16

¹³² But see Ely Yamin, who suggests the obstacles the predominant biomedical paradigm places on efforts to effect a rights based framework, arguing that it detaches health from its social, cultural, economic and political determinants, narrowing the perspective and arguably placing pressure on patients for whom the officially-sanctioned remedies for ill-health may be largely or entirely inaccessible. (Ely Yamin, ‘Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care,’ (n 125), at 47)

rational and increasingly individualized subject who shared the same neoliberal roots as the subject of modern human rights theory.¹³³ As Finn and Sarangi observe, "...central to behavior change models and health promotion discourse is the self-managing individual who is exhorted to take responsibility for his or her own life satisfaction and well-being through making healthy lifestyle decisions and maintaining them."¹³⁴ And since the PLWHA must begin to perceive herself as a discrete, unfettered individual in order to entertain the notion of possessing health privileges that adhere to her simply by virtue of her individual identity as a human being, and which may be claimed against the State and other individuals, including those within her social network, biomedicine's contribution in framing the human being or the human body is arguably crucial.

Accessing medical help from two sources so opposed in their construction and treatment of the disease and the self appears contradictory: on the one hand, these actions indicate patients' embracing of 'modernity', of which biomedical science is an icon. This is exemplified by the PLWHAs' determination to observe instructions about medicine, diet and the rituals of biomedical care (hospital tests, appointments, etc), which are often only hampered by financial cost and lack of availability. Further, disparate value judgments are attached to the type of knowledge acquired and applied by PLWHAs: for biomedical knowledge is not just regarded by its adherents as accurate, it is 'right'; its consumption is an essential tenet in the empowerment paradigm of health promotion exemplified especially in relation to HIV/AIDS.¹³⁵

Yet some patients' actions may be characterized as a rejection of- or at least considerable scepticism about- that same 'modernity', a retreat, perhaps, into mystery and superstition, an informed choosing of the 'wrong' knowledge. This is arguably reflected in a patient's submission to traditional medicine in all its aspects, some of which continue to eschew Western standards of proof and validation and involve more unquantifiable methods such as divination. Indeed, some commentators have argued that such "non-compliance" with official prescriptions is sometimes the last form of influence- of participation- asserted by the marginalized,

¹³³ See Finn and Sarangi (n 67), at 234-5

¹³⁴ *ibid*, at 242

¹³⁵ *ibid*, at 244

who use their “exit” choice as a form of protest or leverage against poor provision of services by powerful actors such as governments or corporations.¹³⁶ The probability of multiple sourcing of healthcare by some of the PLWHAs interviewed for this research (though, regrettably, as noted in Chapter 2, this information was not sought) is not irreconcilable and should not surprise. They are no different in this sense from the South African mineworkers who Campbell noted traversed multiple health systems “without tension or a sense of contradiction, oscillating between representatives of Western biomedicine (hospitals, clinics pharmacies, private general practitioners) and traditional healers (diviners, herbalists and faith healers).”¹³⁷

These accommodations recall the complex subjectivity and fluid identity of Mamdani’s postcolonial citizen-subject. The modern citizen-subject is aware of the paramount authority in the fields of disease and modern medicine of the biomedical experts in the urban realm; many of the PLWHAs interviewed are shown to have largely submitted to this authority. They distinguish themselves from those among them who are perceived still to be in thrall to ‘backward’ notions about disease and the self. Witness interviewee 6 who advocated correcting the superstitions of ‘his people’ in the rural areas: “When someone comes to see you at hospital, tell them that you have the virus. But my people are very interesting. They ‘say so-and-so has been bewitched. He has grown so thin that he cannot even swallow saliva.’ And they stick to that.”

The biomedical institutions that frame and produce the widely subscribed information and knowledge actively embed this construct of the enlightened patient. And every use of this knowledge by PLWHAs, health practitioners, CSOs involved in treatment and prevention advocacy, who have been so influential in the construction of PLWHAs’ subjectivities, further reproduces and ingrains this aspect of their identity. This is a chain of production of ‘truth’ in the Foucauldian sense and every

¹³⁶ Rubincam, Clara and Naysmith, Scott, ‘Unexpected Agency: Participation as a Bargaining Chip for the Poor,’ *Health and Human Rights: An International Journal*, Vol.11, No 1 (2009), pp. 87-92

¹³⁷ Campbell (n 118), at 26

restatement of scientific orthodoxies not only authenticates them but the status of those who assert and apply them.¹³⁸

As such, the predominance of the biomedical paradigm- of any one paradigm- can be problematic, appearing to be divisive and exclusionary of those who still frame illness differently but are nevertheless infected or affected by it.¹³⁹ The PLWHA who acquires and accepts biomedical categorizations of illness perceives herself, and is often perceived by the mainstream health fraternity, as “an ‘empowered’ individual, one who learns how to articulate and act on this embodied knowledge. Overtly contrasted with this enabling knowledge is ignorance and inactivity that allegedly lead to dependency, sickness and death.”¹⁴⁰ These latter characteristics, seen often in this research, were often attributed by PLWHAs, who were thus self-identifying as among the enlightened or ‘empowered’, to (intellectually and culturally) distant ‘others’, often resident in the rural areas, whose failure to consume the ‘correct’ or ‘right’ knowledge they appeared to regard as an abdication of their responsibilities to personal wellbeing and to wider public health; indeed, to freedom.¹⁴¹

Further, the suppression of non-biomedical notions of medicine and the body deprives the holders or adherents of such knowledge of an equal voice in representing their health concerns, fails to recognize them as valid producers of knowledge, and bars them from partaking in a debate in which they have an equal stake and whose outcomes affect their own health.¹⁴² This contracts the space within which they can contribute to the public discourse, and restricts their participation, that is, “the right and responsibility of people to make choices and therefore, to have power over decisions which affect their lives”¹⁴³ In effect, it limits their citizenship. This discussion is revisited in greater detail in Chapter 7.

¹³⁸ Gordon, Colin (ed.), *Power/Knowledge: Selected Interviews and Other Writings 1972-1977/ Michel Foucault*, (Brighton: Harvester Press Ltd, 1980) at 131. See also Finn and Sarangi (n 67), at 239

¹³⁹ See Ely Yamin, ‘Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care,’ (n 125), at 47

¹⁴⁰ Finn and Sarangi (n 67), at 246

¹⁴¹ *ibid*, at 248

¹⁴² See Ely Yamin, ‘Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,’ (n 38)

¹⁴³ *ibid*, at 7. See also Halabi, Sam Foster, ‘Participation and the Right to Health: Lessons From Indonesia,’ *Health and Human Rights: An International Journal*, Vol. 11, No. 1 (2009), pp. 49-59, at 49

And yet, as noted throughout, for all the primacy they might accord to biomedicine, PLWHAs remain rooted in the very realm which validates and sustains the authority of traditional medicine, its practitioners and its systems of knowledge: the customary. To disregard or discard the ways of knowing that prevail in this sphere, in favour of 'erudite', 'alien' ones which are inaccessible to those whose traditional role it is to articulate and validate them, may be interpreted as undermining those roles or rejecting of the choices (often the sole or primary option) of other members of that community. This could be seen as a disruption of social order and stability. It may result in social dislocation from the very material and psychosocial resources that PLWHAs become increasingly reliant upon to cope with their illness. It would revoke the licence which many of them, already carrying a divisive, stigmatizing illness, require to invoke the age-old but diminishing matrix of privileges and obligations. And with the cost of ART and general care of PLWHAs already shown to strain finances and relationships within the immediate social network, these considerations cannot be ignored. Indeed, the next chapter now looks at the individual and collective relationships that PLWHAs have formed with entities further afield to provide for their medical needs, and how the complex emerging dynamics may yet again have redefined the contours of the wider debate on citizenship, entitlement and rights.

Chapter 7: AIDS, Civil Society Organizations and Donors: Redefining Citizenship and the Role of the State

Having outlined in the previous chapter the role of civil society actors and donors in the AIDS narrative, this chapter now looks at how the epidemic and the divisive debate around access to treatment have broadened and entrenched these actors in the local and global delivery of healthcare.

As this chapter illustrates, this intervention underlines how the human rights discourse, access to treatment campaign, and growth of civil society organizations (CSOs) have come to exemplify the globalization phenomenon, and how the involvement of CSOs have transfigured the individual-State dynamic and re-mapped the boundaries of citizenship. The chapter also demonstrates how the issue of access to ARVs revealed anew the potency of human rights as a modern rhetorical tool and as the moral framework of choice for a range of actors seeking broader validation and support for their positions. It also exemplified the malleability of human rights, as opposing sides co-opted favourable tenets as weapons.

Both local and foreign non-governmental organizations (NGOs¹) have emerged and thrived in this febrile environment and are the most visible embodiments of the phenomenon of 'civil society'; as such, although this research defines the phrase 'civil society' more broadly, they tend to dominate this chapter's analysis of the role of CSOs, not least because it is on NGOs specifically that interviewees for these research were asked comment. NGOs have been increasingly active in Kenya since the 1990s.²

¹ An NGO is defined very simply and broadly here as "an organization not belonging to a government and without a profit motive." (Glasius, Marlies and Kaldor, Mary, 'The State of Global Civil Society: Before and After September 11,' in Glasius, Marlies; Kaldor, Mary; and Anheier, Helmut (eds.). *Global Civil Society 2002*, (Oxford: Oxford University Press, 2002) at 5.) The kind of NGOs discussed in this research in relation to HIV/AIDS may also be embraced in Sarah Michael more precise definition of NGOs as "independent development actors existing apart from governments and corporations, operating on a non-profit or not-for-profit basis with an emphasis on voluntarism, and pursuing a mandate of providing development services, undertaking communal development work or advocating on development issues." (Michael, Sarah, *Undermining Development: The Absence of Power Among Local NGOs in Africa* (Oxford: James Currey; Bloomington: Indiana University Press, 2004) at 3).

² See, for instance, Nyamu-Musembi, Celestine and Musyoki, Samuel, 'Kenyan Civil Society Perspectives on Rights, Rights-Based Approaches to Development, and Participation,' *IDS Working Paper 236* (Institute of Development Studies (IDS): Brighton, Sussex, December, 2004), at 3-4

But as this chapter shows the globalization of the health and AIDS industries, and the expansion of CSOs' and donor influence, are much more complicated than the interviewees for this research suggested. As will be seen, the PLWHAs often compared these actors' performance in the delivery of healthcare with that of the State. Indeed, their involvement appeared to shape interviewees' expectations about entitlements to healthcare as well as perceptions about the very legitimacy of the institution of the State. This chapter juxtaposes these discussions and contentious aspects of CSO and donor intervention with the largely positive reviews which these actors received from interviewees. As such, it provides an empirical context for an interrogation into how these actors, with their increased emphasis on rights-based approaches, have seemingly managed to annex the human rights project to reassert the individual's rights to socio-economic goods and services and the State's obligations to provide them.

Yet, these actors have also appeared to fudge the nature of their own obligations to individuals: legal duties or mere acts of charity? The net outcome, it is argued here, is that they may have contributed to the production of notions of entitlement of a particular quality, and by extension particular ideas of citizenship and arguably a particular kind of State, too.

I. Contextualizing Access to Treatment

The Kenyan government, unlike neighbouring Uganda, had been slow in reacting to the HIV/AIDS epidemic that had been sweeping through sub-Saharan Africa since 1980s, the period when the "once relatively silent epidemic of HIV" began its transformation into "a visible epidemic of AIDS."³ There were widespread reports of whole villages decimated by a mysterious disease in areas like Rakai in South-Western Uganda and others along the Tanzanian border.⁴ The fuller story of how the epidemic initially fanned out throughout the continent because of a combination of the chaos of armed conflict (primarily between Tanzanian and Idi Amin's Ugandan forces),

³ Ogden, Jessica, *et al*, 'Expanding the care continuum for HIV/AIDS: bringing carers into focus,' *Health Policy and Planning*, 2006 21(5): 333-342, at 336

⁴ See, for example, Shilts, Randy, 'AIDS at 25: Fear of Epidemic in the Mud Huts', *The San Francisco Chronicle*, 4th June 2006, a reprint of his original article from 25th October 1987, at <http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2006/06/04/MNAIDS04SHILTS3.DTL>, accessed 04/05/08

poverty and many other historical, cultural, social, economic and geographical factors, is well recounted by Alan Barnett and Tony Whiteside and others and cannot be done justice here.⁵ Unlike the patterns of infection in the West at the time, where the key groups affected by the illness were homosexuals, haemophiliacs and intravenous drug users, Africa's HIV epidemic was spread largely through heterosexual intercourse and affected the general population; there is, however, evidence today of widening patterns of infection through injecting drug use and men who have sex with men.⁶

While Uganda reacted by embarking on an awareness-raising campaign to deal with its growing public health crisis throughout the 1980s and 1990s, spurred on by a proactive approach from political, religious and civil society leaders, Kenya's President Daniel arap Moi denounced reports of HIV/AIDS as a ploy to undermine the country's tourism industry in 1986.⁷ It was not until 1999, 15 years after the first case of HIV was detected in the country and with Kenya's adult infection rates at an estimated 13.5% or 1.9 million people, that the president declared the disease a national emergency and heralded a significant policy shift in the government's approach to HIV/AIDS.⁸ The president endorsed the use of condoms in HIV prevention, thereby breaking with the stance still adopted by the powerful religious lobby.⁹ However, many lamented the cost in lives due to the initial lack of leadership from the government, with stark comparisons being made with Uganda, where infection rates

⁵Barnett, Tony and Whiteside, Alan, *AIDS in the Twenty-First Century: Disease and Globalization* (Basingstoke, Hampshire; New York, NY: Palgrave Macmillan, 2006). See also Epstein, Helen, *The Invisible Cure: Africa, The West and the Fight Against AIDS* (New York, NY: Farrar, Straus and Giroux, 2007).

⁶ In Kenya, there is evidence of this, especially in urban centres. See UNAIDS/WHO, *2007 Epidemic Update: Sub-Saharan Africa*, UNAIDS, 2008, at http://data.unaids.org/pub/Report/2008/jc1526_epibriefs_ssafrica_en.pdf, accessed 04/05/08; at 13-14. But social and religious stigmatization of behaviours that are often rejected as 'unAfrican' has often stymied prevention and treatment efforts among these groups. See, for instance, Kiama, Wanjira, 'Homosexuality and AIDS: A Double-edged Sword', *The Daily Nation*, 26th June 1998, in which police authorities were reported to have accused an awareness-raising community organization of PLWHAs of "recruiting" homosexuals; homosexuality is an offence in Kenya. See also *The Daily Nation*, 'Why HIV Spreads Faster Among Gays,' 1st December 2009, in which David Kuria, manager of the Gay and Lesbian Coalition of Kenya (GALK), outlines the dangers to HIV prevention and treatment efforts of the continued criminalization of homosexuality and the failure to include the gay community in HIV/AIDS strategies.

⁷ *The Daily Nation*, 'Kenya@40' series (n 7), 13th November 2003

⁸ Githongo, John, 'Church Must Face Reality of Condom Use,' *The East African*, 6th December 1999

⁹ Kimani, Dagi, 'Kenya's Aids Hype Fine, But too Late for 2m Victims,' *The Daily Nation*, 20th December 1999

had slowed down and even reversed.¹⁰ There were also contradictory messages from the Kenyan president: in a 2001 speech to the Kenya Pharmaceutical Society he revealed a continued resistance to importing condoms into the country saying “[a]s President I am shy that I am spending millions of shillings importing *those things* [emphasis added],” and that Kenyans were better off refraining from sex, “even if it was only for two years,” endorsing this as the best way to control the epidemic.¹¹ The effect on PLWHAs of the influential religious lobby’s initial response to the illness has been discussed, and the cross-section of religious leaders united in their denunciation of condom-use noted, with some of them even conducting condom-burning exercises at a time when an estimated 110 people-a-day were dying from AIDS in Kenya.¹² Meanwhile, the Catholic Church aggravated matters by claiming that condoms encouraged rather prevented the spread of HIV.¹³

Consequently, Kenya was rather a late-comer into the debate about universal access to ARVs, whose politics entered the public sphere and became part of the conversation about the epidemic in Kenya. The decisive surge from 1996 onwards in efforts to increase access to ART followed evidence of remarkably reduced death rates and hospital admission due to AIDS complications in North America and Western Europe¹⁴; for though ART had been first introduced in 1986, it was not until a decade later that this evidence began to become available. For many PLWHAs living outside these relatively wealthy regions at the time, the drugs would have been primarily accessed through the private health sector and so available only to a tiny minority.

¹⁰ See Kimani, Dagi, ‘Aids Has Come of Age, But Does Anyone Care?’, *The Daily Nation*, 7th June 2001

¹¹ Barnett and Whiteside (n 5), at 343

¹² On 20th September 1997, auxiliary Bishop of Nairobi, Alfred Rotich, is reported to have led a group of Catholic youths in just such an event during a pro-life meeting at Nairobi’s Uhuru Park. (*The Daily Nation*, ‘Kenya@40’ series (n 7))

¹³ See Bradshaw, Steve, ‘Vatican: Condoms Don’t Stop Aids,’ *The Guardian*, 9th October 2003, at <http://www.guardian.co.uk/world/2003/oct/09/aids>, accessed 12/09/09. The church claimed that condoms “have tiny holes in them through which HIV can pass - potentially exposing thousands of people to risk. The church is making the claims across four continents despite a widespread scientific consensus that condoms are impermeable to HIV.” A senior Vatican spokesman is reported to have asserted on a BBC *Panorama* programme that “‘The Aids virus is roughly 450 times smaller than the spermatozoon. The spermatozoon can easily pass through the ‘net’ that is formed by the condom. These margins of uncertainty... should represent an obligation on the part of the health ministries and all these campaigns to act in the same way as they do with regard to cigarettes, which they state to be a danger.”

¹⁴ Barnett and Whiteside (n 5), at 364

HIV/AIDS statistics were a powerful if sometimes controversial tool for advocates in their efforts to focus money and minds on treatment and prevention. James Chin has claimed that HIV prevalence figures were initially deliberately overestimated, either as a result of the “naïve” best intentions of AIDS advocates or the “political, social, economic or personal agendas” of “experts.”¹⁵ For example, following the 2003 Kenya Demographic and Health Survey (KDHS) report, “...prevalence... was reduced from 2.3 million to 1.2 million...[I]f we accept that the 1.2 million figure was the more accurate prevalence, then HIV prevalence in Kenya was overestimated by about 100 percent.”¹⁶ Of the hike in the late-1990s of UNAIDS’s HIV prevalence figures for sub-Saharan Africa, which was pegged at 9%, he adds: “I was told by a colleague involved with developing HIV prevalence estimates for UNAIDS that there was a clear administration decision made in 1997 to use the higher range of HIV estimates rather than the lower or mid-range that were used by GPA [Global Programme on AIDS, UNAIDS’s institutional predecessor]/WHO.”¹⁷ Elizabeth Pisani rejects Chin’s claims, differentiating “making up” figures and “beating [them] up”; but she also admits, and, indeed, stands by these actions, arguing it was a necessary and successful way of creating the urgency among governments that was woefully lacking at the time¹⁸:

How would we convince rich countries to stump up cash for AIDS? By making them feel the heat of the epidemic as it blazed across one continent and flared in others, by painting a compelling picture of the devastation left behind, by infecting them with the same urgency that coursed through the corridors of the upstart UNAIDS.¹⁹

Indeed, treatment (and prevention) campaigns in Kenya and other parts of sub-Saharan Africa were amplified in the late 1990s and the new millennium. The acceleration of globalization played a key role, with momentum built by the “activism [that] was spilling over national borders and creating international links among various activist groups around the globe.”²⁰ News spread within the emerging communities of PLWHA groups across the African continent about the AIDS policies of

¹⁵ Chin, James, *The AIDS Pandemic: The Collision of Epidemiology with Political Correctness* (Oxford; Seattle: Radcliffe Publishing, 2007) 138

¹⁶ *ibid.*, at 128

¹⁷ *ibid.*, at 127

¹⁸ Pisani, Elizabeth, *The Wisdom of Whores: Bureaucrats, Brothels and the Business of AIDS* (London: Granta Publications, 2008), at 22

¹⁹ *ibid.*, at 20

²⁰ Seckinelgin, Hakan, ‘Time to Stop and Think: HIV/AIDS, Global Civil Society, and People’s Politics,’ in Glasius, Marlies; Kaldor, Mary; and Anheier, Helmut (eds.). *Global Civil Society 2002*, (Oxford: Oxford University Press, 2002) at 121

governments elsewhere: as Altman and others have noted, it was not just the movement of workers, money and goods that was freed up and eased by the advancing globalization; governments found that in the age of the electronic media, ideas could no longer be contained. The same process that had aided the spread of the virus would now drive the campaign for its management.²¹ This is clear in one interview where the respondent based her claims of entitlement to healthcare from the government on her citizenship (although she was rather over-optimistic about public attitudes to PLWHAs in other countries):

Well, I'm a Kenyan, and let's say I'm not working and there's a major thing like AIDS, they should take care of such people because we've heard of countries like Uganda, South Africa: they really take good care of people who are positive while here in Kenya it's a problem. Stigmatization is still there.... (Interviewee 1)

Local PLWHAs utilized information about how other governments were tackling their epidemic in their efforts to pressurize their own government's inadequate responses. Moreover, the access to treatment movement was undoubtedly helped by the casting of big, wealthy pharmaceutical companies- 'Big Pharma'- as the pantomime villains of the access to treatment campaign, which offered perhaps an even more potent rallying point than the characteristically immobile, impoverished African governments. The paradigm shift towards treatment from 1996, which came to dominate the global discourse on how to manage the HIV/AIDS epidemic and which some have criticized as sapping energy from the debate about, and funding for, prevention²², inevitably put the medical sector²² in the spotlight and led to calls for their greater responsibility.²³ To critics, 'Big Pharma' represented the skewed economic might of the industrialized nations and, alongside other multinationals, had become prime targets for anti-globalization protesters.²⁴ Reports abounded of the iniquitous ART pricing policies, from which Kenya was not exempt.²⁵ Elsewhere, in

²¹ Altman, Dennis, 'Globalization, Political Economy and HIV/AIDS,' in Weeks, Jeffrey; Holland, Janet; and Waites, Matthew (eds.), *Sexualities and Society: A Reader* (Cambridge: Polity Press, 2003) at 187

²² See, for example, Campbell, Catherine, '*Letting Them Die: Why HIV/AIDS Prevention Programmes Fail*' (Oxford: International African Institute, 2003) at 6

²³ Tarantola, Daniel, 'The Shifting HIV/AIDS Paradigm: Twenty Years and Counting,' *Health and Human Rights: An International Journal*, Vol.5, No. 1 (2000), pp.1-6, at 4

²⁴ See Chandhoke, Neera, 'The Limits of Global Civil Society,' in Glasius, *et al*, *op.cit.*. See also Seckinelgin, *op.cit.*

²⁵ Rosalind Petchesky writes: "Studies by MSF and UNAIDS in 2000 revealed that Pfizer was selling Diflucan for (US)\$18 per pill in Kenya- a country 'that averages \$5 per citizen per year' in its national health budget- whereas the generic version of fluconazole produced in Thailand cost 60 cents. Pfizer's wholesale prices for the same drug ranged from \$8.52 in Kenya to \$9.78 in the US, \$11 in France, and

2002 MSF reported that Roche, the Swiss pharmaceutical company, charged more for its ARVs in poor countries such as Guatemala and Ukraine than in industrialized Switzerland. The report also put the annual cost of Roche's drugs to a PLWHA in Cameroon at over 7 times the per capita income.²⁶ In another report, MSF accused pharmaceutical companies of exploiting an access to treatment forum to seek new markets in the Asia Pacific region.²⁷ Treatment was not a choice for those who needed it, the NGO asserted elsewhere, declaring that "medicines are not Barbie dolls or CDs, but a matter of life and death."²⁸ Nevertheless, as Altman noted, a state was effectively emerging of two epidemics: one for the rich and another for the poor.²⁹ This economic-based bifurcation of the epidemic had resulted in an equal bifurcation, deemed hypocritical by some commentators, of the strategies proposed and then applied to confront the epidemic in the rich and poor world; they argued it amounted to the simple formula: "drugs for us, condoms for you."³⁰

The allegation that pharmaceutical companies prioritized profits over lives was captured by President Mbeki's spokesman, although his comments have to be seen in the context Mbeki's contentious views which also opposed the use ARVs. In 2000 he declared:

Like the marauders of the military industrial complex who propagated fear to increase their profits, the profit-takers who are benefiting from the scourge of HIV/AIDS will disappear to the affluent beaches of the world to enjoy wealth accumulated from a humankind ravaged by a dreaded disease... Sure, the shareholders of Glaxo Wellcome [the company which makes (the AIDS drug) AZT] will rejoice to hear that the SA government has decided to supply AZT to pregnant

\$27 in Guatemala- all for a gross yield of around \$1 billion a year for the company. The pattern of higher prices in some developing countries than Europe and North America is not unusual; nevirapine was found in these studies to cost \$430 per 100 units in Norway compared with \$874 in Kenya." (Petchesky, Rosalind, *Global Prescriptions: Gendering Health and Human Rights* (London; New York: Zed Books, 2003), at 108)

²⁶ Médecins Sans Frontières, 'AIDS Patients in Poor Countries Pay Higher Prices for Roche's Drugs Than People in Switzerland,' 15th November 2002, at http://www.msf.org/msfinternational/invoke.cfm?component=pressrelease&objectid=013E49F3-B70A-4C07-881E3E214A97FFAD&method=full_html, accessed 07/05/08.

²⁷ Médecins Sans Frontières, 'MSF Queries Pharma Motives on AIDS in the Asia Pacific,' 25th September 2002, at http://www.msf.org/msfinternational/invoke.cfm?component=pressrelease&objectid=927B10D8-F70B-4EF1-9AAF3634E9BF045&method=full_html, accessed 07/05/08.

²⁸ Médecins Sans Frontières, 'The Access Campaign at Two Years: Translating Success into Lasting Solutions,' at http://www.msf.org/msfinternational/invoke.cfm?component=article&objectid=2B12E558-B028-4403-AF7EAA88B18BA819&method=full_html, accessed 07/05/08.

²⁹ Altman (n 21), at 192

³⁰ Seckinelgin (n 20), at 127

women who are HIV-positive. The source of their joy will not be concern for those people's health, but about profits and shareholder value.³¹

These sharp criticisms cannot be divorced from the broader controversial policies of the government in which Parks Mankahlana served, but the profit potential of pharmaceutical companies and the prioritization of certain communicable diseases by the donor countries in which many of these companies are based have been linked by others.³² But perhaps the most well-known figure in Mbeki's inner circle to cast doubt on the use and effectiveness of ARVs was health Minister Manto Tshabalala-Msimang. Her claims that South Africans were much better off eating beetroots and garlic to deal with HIV/AIDS rather than taking ARVs, which she considered a 'poison,' earned her nickname 'Dr. Beetroot'.³³ Such attempts to discredit ART were perhaps not merely an effort to justify the South African government's inadequate commitment to HIV/AIDS treatment and inform the opinions of those as yet unpoliticized by vocal CSOs conducting AIDS-related activities, like Treatment Action Campaign (TAC)³⁴: it appeared to be the basis of HIV policy.³⁵ Yet the traditional medicine, as will be discussed momentarily, must be located as complementary to, not necessarily instead of, biomedical interventions.

Big Pharma's main defence of their costing of ART was and is often related to the need to recoup research and development (R&D) expenses through the (international) protection of their patent rights. This they regarded as just

³¹ Parks Mankahlana quoted in Epstein, *op.cit.*, at 108. Ironically, Mr. Mankahlana was to die that year, at the age of 36, allegedly of an AIDS-related illness. See Makoe, Abbey, 'Mbeki's Shock in the Face of Death,' *The Sunday Independent*, 28th October 2000.

³² See Shiffman, Jeremy, 'Donor Funding Priorities for Communicable Disease Control in the Developing World,' *Health Policy and Planning*, Vol. 21, No. 6 (2006), pp. 411-420.

³³ See Butler, Katherine, 'A President in denial, a ravaged nation denied hope,' *The Independent on Sunday*, 10th August 2007, *The Independent*, at <http://www.independent.co.uk/news/world/africa/a-president-in-denial-a-ravaged-nation-denied-hope-460967.html>, accessed 05/05/08; BBC, 'Aids experts condemn SA minister,' BBC, 6th September 2006, at <http://news.bbc.co.uk/1/hi/world/africa/5319680.stm>, accessed 05/05/08.

³⁴ In the late 1990s, the Pharmaceutical Manufacturers' Association (PMA) of South Africa and 39 drug companies sued the SA government over its institution a law that would permit the importation cheaper drugs, which they alleged would violate patent rights. The lawsuit was dropped in 2001, under pressure from the TAC and others. See International Centre for Trade and Sustainable Development (ICTSD), 'Drug Companies Drop Case Against S. Africa,' 24th April 2001, at <http://ictsd.org/i/ip/39983/>, accessed 24/04/10. See also Petchesky (n 25), at 88-9

³⁵ South Africa has the highest number PLWHAs in the world, estimated at 5.6 million in 2009. (UNAIDS, *Global Report: UNAIDS Report on the Global AIDS Epidemic, 2010*, 2010, at http://www.unaids.org/documents/20101123_GlobalReport_em.pdf, accessed 12/12/10; at 16). The 2009 estimated prevalence rate among 15-49 year-olds was 17.8% (UNAIDS/WHO, 'South Africa,' 2012, at <http://www.unaids.org/en/Regionscountries/Countries/SouthAfrica/>, accessed 03/01/12)

compensation for the risk entailed in embarking on the lengthy process of developing a drug that may never be approved for use. Without such incentives, it was argued, there would be little motivation for the industry to engage in the kind of research that underpinned the discoveries of new medicines; the loss would be everyone's but particularly the very group that activists sought to represent.

But some have argued that such calculations were based on some inaccuracies which were then applied across the board and repeated in subsequent reports. They mask such aspects as the substantial public subsidies from universities and government agencies for pre-clinical research that these corporations often enjoy.³⁶ Petchesky also notes the two contradicting arguments made by 'Big Pharma': on the one hand the protection of international patents, without which it is suggested research incentives would dry up; on the other, that these corporations claim that poorer countries would also gain from such a system as it would bring opportunities for new technologies and investment and patent guarantees of their own. Yet almost all current patents are held by companies based in developed countries; similarly nearly all patents granted by the US in the two decades between 1977 and 1996 belonged to applicants from only ten industrialized countries. Consequently, an estimated \$20 billion dollars annually flows from South to North in fees for technology use.³⁷ In Kenya, one newspaper editorial did not think the narrative of the villainous, opportunistic Western pharmaceutical company was the full story, though: it blamed part of the treatment crisis on the government's pre-existing poor national healthcare policies which the HIV/AIDS epidemic had helped highlight rather than create.³⁸

Rights arguments interlaced the debate and expanded the site of struggle, and typical of the subject's characteristic malleability, different groups emphasized certain rights over others.³⁹ Those who could deploy the rights rhetoric most effectively to bolster

³⁶ Petchesky (n 25), at 79. See also Médecins Sans Frontières, 'Fatal Imbalance: The Crisis in Research and Development for Drugs for Neglected Diseases,' 9th October 2001, at http://www.msf.org/msfinternational/invoke.cfm?objectId=3D264BB1-EA84-423E-97190AB4F9F9CEE6&component=toolkit.report&method=full_html, accessed 07/05/08.

³⁷ Petchesky (n 25), at 78

³⁸ *The Daily Nation* 'Make Drugs Accessible to All,' 18th August 2005

³⁹ See Yash Ghai, in Twining, William (ed.), *Human Rights, Southern Voices: Francis Deng, Abdullahi An-Na'im, Yash Ghai and Upendra Baxi*, (Cambridge, UK ; New York : Cambridge University Press, 2009), at 123

their arguments found they had one of the most compelling weapons on their side. As Tarantola notes, “[t]he rights to the highest available standard of health, to care, to the product of scientific progress, and to international solidarity have been invoked in efforts to make new therapies accessible to the majority of the world population living with HIV.”⁴⁰ On this basis, AIDS activists advocated for the procurement of generic ARVs, which, devoid of R&D expenditures, could be cheaply mass-produced and sold at affordable prices to needy countries which lacked the capacity to produce them themselves, such as Kenya.⁴¹ India’s Cipla, for example, offered generic drugs at a fraction of the annual cost charged by Western pharmaceuticals.⁴² On the other hand, the rights of patent holders over their intellectual property, provided by TRIPs, the 1994 Agreement on Trade-Related Aspects of Intellectual Property Rights, were highlighted. The agreement was reached under the auspices of the World Trade Organization’s (WTO), one of the international organizations which came to symbolize what many perceived as the dark side of globalization and its entrenchment of global economic and political inequalities.⁴³ Fundamental questions were raised about stratification and prioritization of rights: which trumped which?⁴⁴ To TAC and others health rights outranked the property rights of pharmaceutical companies.

Petchesky asserts that “[i]n both its origins and its potential consequences, the TRIPs agreement ... favours the economic and technological hegemony of the North.”⁴⁵ She contends that a radical remedy might be required to institute a more equitable

⁴⁰ Tarantola (n 23), at 3. For more on the provisions and language in Article 25, see Claude, Richard Pierre and Issel, Bernardo W., ‘Health, Medicine and Science in the Universal Declaration of Human Rights,’ *Health and Human Rights: An International Journal*, Vol. 3, No. 2 (1998), pp. 127-142, at 137-8

⁴¹ Kenya’s own fledgling pharmaceutical industry had been left with almost no capacity to take on the production of generic ARVs because of, among other reasons, poor investment, deteriorating infrastructure and lack of ingredients; domestic production of ARVs, it has been argued, may not have served to reduce the cost of the drugs but it would have boosted their availability. (Lewis-Lettington, Robert and Munyi Peter, *Willingness and Ability to Use TRIPs Flexibilities: Kenya Case Study*, WHO, September 2004, at http://www.who.int/hiv/amds/countries/ken_UseTRIPsFlexibilitiesDFID.pdf, accessed 06/05/08; at 12-13). This meant that the country was overwhelmingly reliant on countries like India for its supply.

⁴² Sihanya, Ben, ‘Patents, Parallel Importation and Compulsory Licensing of HIV/AIDS Drugs: The Experience of Kenya (Case Study 19)’, in Gallagher, Peter; Low, Patrick; and Stoler, Andrew L. (eds.), *Managing the Challenges of WTO Participation: 45 Case Studies*, WTO (2005), at http://www.wto.org/english/res_e/booksp_e/casestudies_e/case19_e.htm, accessed 08/05/08

⁴³ See Chandhoke (n 24), at 40-41.

⁴⁴ Tarantola (n 23), at 3-4

⁴⁵ Petchesky (n 25), at 77-8

regime, suggesting that poorer countries may need to exit the system and “return to old-fashioned concepts of the public domain, or the common good, including essential medicines and health services as a ‘global public good.’”⁴⁶ For one prominent Kenyan commentator, too, the notion of fair trade propounded by supporters of the WTO rules was a “hoax”, and the inequality and hypocrisy of the international trade system was captured perfectly by this legal regime, which, he argued, sought to preserve the status quo and perpetuate a kind of neo-colonialism.⁴⁷ It is a narrative which not only reveals the globalization of the HIV/AIDS treatment narrative, but which, as seen in Chapter 4, has often been linked with that of HIV/AIDS. TRIPs was due for ratification in the poorest countries by 2006 although the wisdom of doing so was questioned by many commentators.⁴⁸ The question became to what extent developing-nation members of the WTO could set aside or bypass the requirements of TRIPs and similar agreements in order to respond to their public health emergencies without being threatened with retaliatory sanctions by industrialized nations, where ‘Big Pharma’ have constituted influential lobby groups.⁴⁹

In Kenya, the gradual process of enforcing patent laws had been taking place since the enactment of the Industrial Property Act in 1989. This legislation was reviewed a decade later to ensure compliance with Kenya’s TRIPs obligations, agreed by President Moi’s government. With the HIV/AIDS epidemic now a greater government priority than it had been in 1989, there were concerns that streamlining Kenya’s patent laws with TRIPs without including public health safeguards would be

⁴⁶ *ibid*, at 116

⁴⁷ Mutua, Makau, ‘WTO rules are mere neo-colonial schemes,’ *The Daily Nation*, 30th July 2006. See also criticisms by Jamaican economist Mariama Williams (quoted by Petchesky), who remonstrates with Southern governments for their compromises with those of the North, which have seen the former “trapped into [a] pervasive market access framework that pushes [them] to sacrifice everything for very minor entry into the markets of the North.” (Petchesky (n 25), at 116)

⁴⁸ Bosely, Sarah, ‘Taking on the Drug Dealers,’ 16th September 2002, *Médecins Sans Frontières*, at http://www.msf.org/msfinternational/invoke.cfm?component=article&objectid=A90B92CC-8AFD-4833-AD8E36239F3B2389&method=full_html, accessed 07/05/08.

⁴⁹ For instance, an attempt in 2001 by the US government to institute legal action against Brazil for the latter’s move in setting aside patent law and granting licenses for the manufacture of generic drugs was widely criticized. It was feared that a decision against Brazil might have significantly and disastrously set back its exemplary access to treatment programme. Presumably, this move by the US was also designed to cause a rethink in other States who might have been considering taking a leaf out of Brazil’s efforts. (See *Médecins Sans Frontières*, ‘US action at WTO Threatens Brazil’s Successful Aids Programme,’ at http://www.msf.org/msfinternational/invoke.cfm?component=pressrelease&objectid=DB833ACA-9D3E-43D7-AA534FD650EC71BD&method=full_html, accessed 08/05/08)

detrimental to its belated HIV/AIDS treatment programme. The Minister for Medical Services at the time, Dr Amukowa Anagwe, is quoted as stating: “I think the Government’s mood is that of the Member of Parliament who asked, ‘How can we be denied access to drugs that prolong life when our people are dying?’”⁵⁰

Kenyan PLWHAs protested outside the Indian High Commission in Nairobi, anxious that the WTO rules that might curtail their supply of generic drugs from India, which, at USD 20-a-month were eminently cheaper than the USD 395-a-month that the patented version of the drugs commanded.⁵¹ In the end, local and international pressure groups, first in 2002 and again in 2006, convinced the Kenyan government to scrap the planned amendment to the 1989 Act that would reportedly have seen the cost of first-line ART rise by over 1000%.⁵² This outcome appears to support the argument by some commentators that TRIPs is not, in fact, an unyielding set of enforceable rules, unresponsive to political realities; that such considerations, more than the interpretation of lawyers, will ultimately determine the meaning and scope of the rules.⁵³

II. CSOs, Donors and ARVs

The interviewees for this research who received partially- or fully-subsidized ARVs did so thanks to government schemes or programmes ran by NGOs such as MSF, all largely enabled by financial support from overseas. UNAIDS reports that there is no country ownership of the HIV/AIDS programme in Kenya because it is 98% foreign-funded.⁵⁴ Since the 1990s, NGOs have increasingly become the preferred conduit for the disbursement of resources from donor agencies, be they affiliated to national governments, multilateral agencies or charitable organizations. This shift away from conducting funding through official or government channels to private or primarily CSO channels was prompted by concerns over poor governance in many recipient

⁵⁰ Lewis-Lettington and Munyi (n 41), at 9

⁵¹ Telewa, Muliro, ‘HIV Kenya protest at patent law’, *BBC Online*, 18th March 2005, <http://news.bbc.co.uk/1/hi/world/africa/4361863.stm>, accessed 06/05/08.

⁵² Ngujiri, Philip, ‘Reprieve as Karua acts to keep Aids drugs cheap,’ *The Daily Nation*, 28th July 2006

⁵³ Petchesky (n 25), at 80

⁵⁴ See UNAIDS, ‘Kenya Country Situation,’ July 2008, at http://data.unaids.org/pub/FactSheet/2008/sa08_ken_en.pdf, accessed 01/01/10.

States.⁵⁵ Indeed, the PLWHAs on the MSF programme at MDH invariably praised the organization. It will be recalled that interviewee 19 emphasized in Chapter 3 (at the end of the paragraph containing note 68) the importance of MSF's intervention, particularly following the death of her husband and desertion by her affinal kin. She added: "I am in Nairobi and I rely on one of my sisters who is abroad. But you know even that help, even though someone sends you something like Ksh3,000 (approx. GBP 20), that won't take you very far. So I can say that without this place [MSF], I wouldn't be able to survive." She was not alone in attributing her survival to the organization. Another, interviewee 37, said: "People like MSF help a lot. I was in bed for 3 years, unable to get up, because doctors used to prescribe drugs for me that I couldn't afford to buy."

The explosion of health-linked CSOs since HIV/AIDS became the pre-eminent concern in global public health has been one of the phenomena of the last decade, although development organizations' involvement in Africa dates back to the pre-colonial era.⁵⁶ Many interviewees' appeared to be familiar with the acronym 'NGO', that embodiment of the CSO. A number voluntarily named many AIDS NGOs they knew of or had dealt with. Apart from WOFAK, which was naturally mentioned by at least the first batch of respondents, who were its clients, other local NGOs were listed, for example by interviewee 25: "The NGOs are really doing a good job for PLWHAs. There are now NGOs being ran by PLWHAs- we have KENWA, TAPWAK [The Association of People with AIDS in Kenya], WOFAK, NEPHAK [Network of People Living with HIV/AIDS in Kenya] and they are enlightening us. You go there and meet other PLWHAs, and at least you feel you're not alone. They are really encouraging us." The Kenya AIDS NGOs Consortium (KANCO) lists hundreds of member CSOs, including registered NGOs, community-based organizations (CBOs)⁵⁷, faith-based organizations

⁵⁵ *ibid*, at 6. Nevertheless, donor States continue to provide State budgetary support, with accountability remaining a key concern. (See Nyamu-Musembi, Celestine and Cornwall, Andrea, 'What is the 'Rights-Based Approach' All About? Perspectives from International Development Agencies,' *IDS Working Paper 234* (Institute of Development Studies (IDS): Brighton, Sussex, November, 2004), at 11)

⁵⁶ See Michael (n 1), at 8

⁵⁷ Sarah Michael applies the criteria of scope to distinguish CBOs from NGOs: the former, she notes, are community founded and oriented and "tend to remain focussed very locally and to operate with little formalised structure, using the time and resources of community members to undertake their activities." (Michael (n 1), at 3)

(FBOs), PLWHA support groups and other public and private sector organizations.⁵⁸ The number of NGOs in general has sky-rocketed from just 100 in 1990 to 4,800 in 2007; 4 in 10 are said to be based in Nairobi, substantiating complaints, voiced also by some respondents', as will be seen shortly, of rural neglect.⁵⁹

The exponential rise in the number of actors and particularly CSOs involved in HIV/AIDS issues has heralded a massive increase in funds for HIV/AIDS projects, with some of the best-endowed and most visible donors being the Bill and Melinda Gates Foundation⁶⁰ and former US President Clinton's Clinton HIV/AIDS Initiative (CHAI), which was instrumental in negotiating the lowering of ARV costs.⁶¹ There have also been numerous initiatives by individual or groups of wealthy nations to improve access to ART, such as the controversial former US President George W. Bush's President's Emergency Fund for AIDS Relief (PEPFAR; more of which later) and the G8's programme aimed at achieving universal access to ARVs by 2010.⁶² Alongside this is the unique Global Fund, which disburses to various countries funds drawn largely from government and private philanthropic and corporate sources, although it operates independently of any government or the UN system.⁶³ In addition there are numerous campaigns by intergovernmental agencies focussing on access to treatment, such as the WHO's 2003 '3 by 5' campaign, which sought- but woefully failed- to achieve access to ARVs for 3 million PLWHAs in low- to middle-income countries by 2005.⁶⁴

⁵⁸ See the KANCO website at <http://www.kanco.org>. For the contributions of CBOs to local healthcare, see, for example, Molyneux, C.S.; Huchkins, B.; Chuma J.; and Gilson, L, 'The Role of Community-based Organizations in Household Ability to Pay for Health Care in Kilifi District, Kenya,' *Health Policy and Planning*, Vol. 22 (2007), pp. 381–392.

⁵⁹ *IRIN PlusNews*, 'Smaller AIDS organisations struggle for transparency,' 4th June 2007, <http://www.plusnews.org/Report.aspx?ReportId=72532>, accessed 08/07/08.

⁶⁰ Laurie Garrett notes that 6 years after the Foundation came into existence in 2000 it had given away \$6.6 billion to global health programmes. (Garrett, Laurie, 'The Challenge of Global Health,' *Foreign Affairs*, January/February 2007, at <http://www.foreignaffairs.org/20070101faessay86103/laurie-garrett/the-challenge-of-global-health.html>, accessed 05/05/08; at 2)

⁶¹ See CHAI's website, www.clintonfoundation.org. See also Barnett and Whiteside (n 5), at 367

⁶² See WHO, 'Universal Access to HIV/AIDS Prevention, Treatment and Care,' 2012, at <http://www.who.int/hiv/topics/universalaccess/en/index.html>, accessed 12/03/12. However, since these countries made financial commitments towards this goal, they have been widely criticized by various NGOs and activists for failing to live up to their promises.

⁶³ Garrett (n 60), at 3

⁶⁴ See WHO, 'The 3 by 5 Initiative,' 2007, at <http://www.who.int/3by5/en/>, accessed 01/05/07.

Despite this increase in human and financial resources, some respondents feared that the explosion in numbers of AIDS NGOs and CBOs (from whom they are often indistinguishable⁶⁵) in Kenya would exacerbate the kind of misuse and misappropriation of AIDS monies that has left over GBP 30 million from the Global Fund unaccounted since 2002.⁶⁶ They raised the phenomenon of ‘briefcase’ NGOs or CBOs, fake organizations set up purely to profit from this windfall.⁶⁷ Interviewee 47, for instance criticized NGOs, noting that they “can and should help, but you find that they are very greedy! They only want to make money and get rich. The foreign ones,” she suggested, “can do better than the local ones. Nowadays we even have ‘briefcase’ NGOs! ... Anyway, Kenya is just a corrupt place.”⁶⁸ Such remarks reveal the same anxieties about the behaviour of CSOs that many Kenyans have regarding State actors.

Interviewee 47’s last statement echoes a point made by John Githongo, former head of the Kenya national chapter of the global anti-corruption organization Transparency International. In 2000 he argued that Kenyans had a general awareness of corruption as a national problem and its negative effects on the country’s economic

⁶⁵ CBOs and NGOs can be defined similarly, but they tend to more local reach, emerging within a community to cater for its particular needs, and are more loosely structured and regulated. (Michael, *op. cit.*, at 3-4). However, see Celestine Nyamu-Musembi and Samuel Musyoki on efforts to improve the participatory and governance structures in a number of CBOs in Kenya. (Nyamu-Musembi and Musyoki (n 2), at 12)

⁶⁶ See *The Daily Nation*, ‘Aids Infections on the Decline,’ 1st December 2009. The report cites a KANCO report which says that “Kenya has so far lost Sh3.8 billion in donor money meant for HIV/Aids programmes released from the Global Fund since 2002. Another grant of Sh9.7 billion meant for Round 7 funding is yet to be released because of the country’s ‘poor absorption capacity and reporting.’”

⁶⁷ In a report featured on *IRIN PlusNews*, Freda Njeri, a Kenyan woman who runs a HIV/AIDS self-help group described how such operations run: “‘Some CBOs help less and keep large amounts of money for themselves,’ she said. Njeri, who is also HIV-positive, related how the founder of one group she worked for, Alice Kiragu (not her real name), wrote several proposals for large amounts of money intended to care for the group’s more than 150 HIV-positive members. ‘Alice received 350,000 shillings (US\$5,000) from the government in 2001 and 520,000 shillings (\$7,428) from Plan Kenya [a development NGO] in 2004, but the members never saw the money,’ Mama Joseph said. By the time the group’s members finally realised the funds were being embezzled, Kiragu had left Kawangware. According to Mama Joseph, Kiragu has apparently started another group supporting HIV-positive people elsewhere in Nairobi.’ (*IRIN PlusNews*, ‘Smaller AIDS organisations struggle for transparency,’ (n 59))

⁶⁸ Elsewhere, a member of the public, in a letter to the editor of a local daily in 2006, supported the then-Health Minister Hon. Charity Ngilu’s condemnation of corrupt NGOs and urged authorities to take firm action against them saying: “... the public understood exactly what the minister was talking about. ... And we have reasons to believe that such rip-offs are not uncommon.... It is up to the National Aids Control Council to strive and set high standards of transparency, accountability and responsible leadership among the NGOs. It must ensure zero tolerance to corruption.” (Wafula, James, ‘Flush Out All Bogus Aids Groups,’ Letters, *The Daily Nation*, 23rd August 2006.)

development and its institutional structures.⁶⁹ This may account for the above respondent's notions that home-grown organizations, that is, those locally founded and largely staffed by locals⁷⁰ were less trustworthy than foreign ones. This comparison was raised by other interviewees, with corruption and nepotism cited against local groups. For instance, interviewee 29 said:

The overseas [NGOs] help a lot. But I have a problem with the local ones. Once people join these local NGOs, all they do is help themselves and their own families. And yet they did not form that organization with their family but when it is up and running, it now becomes theirs and their families. If when we started the organization it was you and me and not you and your brother and your mother, then it should not become your private possession once we start running.

Interviewee 37 spoke of similar nepotistic tendencies: "Some [NGOs] help but others do not help everyone- they help according to those they know. Like where I live, in Dagoretti [in Nairobi], I hear there are projects to help PLWHAs but I have never gotten help. When I have gone to ask about it I am told that the project is over. It's very hard to come across information advertising these NGOs."

Such views may have been based on the respondents' own experiences with NGOs but they were similarly likely to have been influenced by common perceptions and numerous press reports about the prevalence of such activities especially among some local CBOs, an issue which Githongo commended the Kenyan press for highlighting.⁷¹ But the distinction between local and foreign organizations is arguably unfair: the former's practices are widely reported, and thus to an extent transparent and perhaps the familiar national narrative of corruption and mismanagement too easily appended to them. The internal workings of the latter, meanwhile, often remain obscure. Moreover, they are largely accountable to a different, foreign audience. Arguably such distinctions are also evidence of the enduring postcolonial

⁶⁹ Githongo, John, 'Corruption: Are We Innocent?', presentation delivered on 25th October 2000 at a gathering for the Kenya Museum Society, Nairobi, available online at Transparency International – Kenya Chapter, at <http://www.tikenya.org/>, accessed 22/06/08 .

⁷⁰ Michael (n 1), at 5

⁷¹ Githongo, John, 'The Challenges of Tackling Corruption', Public Lecture, Economics Students' Association, at <http://www.tikenya.org/documents/MoiUniversityPublicLecture13-10-00.doc>, accessed 06/07/08; at 4. *The Daily Nation*, for example, reported that some the CBOs through whom the NACC had sought to implement its national HIV/AIDS programmes were nothing more than ghost organizations, with one hundred of them under investigation at the time of the report in August 2005. (*The Daily Nation*, 'How Aids Money is "Eaten"', 3rd August 2005.) Another article reported MPs' warning of a Kshs. 1billion (nearly GBP7million) loss to fake organizations, adding that the NACC rarely monitored recipient CBOs to verify appropriate use of funding. (*The Daily Nation*, 'Fake Groups Fleecing State of Aids cash, claim MPs,' 1st August 2005)

inferiority complex highlighted by Peter Ekeh.⁷² But they are also likely to have been influenced by the dearth of a robust public debate about the role of foreign actors in local development affairs. Nyamu-Musembi and Cornwall point out a general accountability deficit among NGOs and bilateral agencies, and the former in particular, to aid recipients.⁷³ They question the validity of donor organizations' claims of having transformed local communities "from passive beneficiaries to rights-holders."⁷⁴

Yet the very local knowledge and experience of the maligned indigenous organizations means they are better positioned to identify local needs and formulate and implement strategies that are more sensitive to prevailing mores and customs, thus enhancing the sense of local ownership and inclusivity and long-term project success.⁷⁵

As earlier mentioned, some interviewees were also critical of NGOs' urban bias, complaining of limited service coverage in rural areas. Interviewee 5's opinions, seen in Chapter 5 (in the text following note 129), highlighted this. Another respondent, interviewee 32, from Kibwezi in Eastern Province said: "I can only add that I think that people in the rural areas are neglected a lot. A lot of NGOs and the government are concentrating on the urban areas. So many are dying in the rural areas." Interviewee 45 longed for a well-endowed NGO in his locality to provide the confidential VCT services that were currently unavailable, even offering to advertise its benefits: "In fact [NGOs] are the people we are looking for because especially in my area I know how people are suffering. We would like to get a NGO, even if it's an international one, which can help. We have a small one which is equipped with some drugs for immunization and ante-natal clinics but if we can get someone who can come with a VCT, I can even be able to offer myself to help those in my home-area to tell them how good it is to go there and get tested because it's confidential and no one will disclose it unless you do it yourself or someone else tells." It was an issue that interviewee 25, a volunteer with a local branch of an international NGO, expanded

⁷² Ekeh, Peter P., 'Colonialism and the Two Publics in Africa: A Theoretical Statement,' *Comparative Studies in Society and History*, Vol. 17, No.1 (1975), pp. 91-112, at 96 and 101-2

⁷³ Nyamu-Musembi and Cornwall (n 55), at 47

⁷⁴ *ibid*

⁷⁵ Michael (n 1), at 116

upon: her comments in Chapter 6 will be recalled (in the text following note 27), in which she noted the higher risk of stigma faced by those who went public with their HIV status in rural areas. Urban centres, she argued, offered safer environments for those wishing to live openly but increased NGO activity in rural areas might help change attitudes here:

There is a lot to be done in the rural areas. As much as we talk about AIDS, for example, people still don't know how to handle PLWHAs. There's a lot of stigma.... And women are so much affected by HIV/AIDS, they don't really know their rights. A husband may go anywhere and sleep with anybody and then come and infect you. You don't want to leave because of the children. So I think for people in the rural areas, now is the time that NGOs should go into the villages because that is where the problem lies... And they should treat the symptoms first: like people are getting AIDS because of practices, ignorance, people don't really care. When you tell people you are HIV-positive they don't believe you. They say you have been given money to go and cheat them. If you talk about condoms they say 'I can't use them; why should I use them?' We should be taught about preventive measures because many are getting infected in the villages because of ignorance or lack of good information.

Some respondents, like interviewee 16 who complained about the extensive programme focus on slum-dwelling PLWHAs⁷⁶, also expressed dissatisfaction with some NGOs' presumptions in their mapping of needs. This is a criticism, perhaps, that programmes designed to suit foreign-based donor specifications may lack a full appreciation of the local context, a discussion addressed at length shortly.

But perceptions about NGOs were overwhelmingly positive. Given the concerns voiced by many respondents about the cost of living with HIV/AIDS, the enthusiastic support of the range of services offered by CSOs in general was unsurprising. Interviewee 2, for instance, gave examples of the variety of interventions that NGOs were involved in: "Actually, local NGOs have really done good work, that much I must say. As it is, there are so many NGOs that are running these programmes of HIV and you can find they're helping orphans, they're helping widows, some of the people are getting drugs free... so I can say they're doing a good thing." Despite its own efforts in the reduction of ARV costs and other initiatives, the entity whose legitimacy seemed to suffer most from any comparison was the government. Its belated entry into the campaign against AIDS may partly account for this reaction but there may be other

⁷⁶ Despite her approval of the assistance that NGOs often offered to PLWHAs she complained: "Yes, there are many [health] supplements which I've heard about, which are being given by NGOs but they only help many people from slums, I think. They have pilot programmes in slums, they don't think like we people who live in these other places have problems but we do!"

reasons, not least cumulative perceptions about the State's untrustworthiness and unreliability in addressing its citizens' welfare concerns. One respondent, interviewee 6, felt NGOs had helped validate the existence of PLWHAs by turning the spotlight onto their situation:

...[W]ithout [NGOs] there wouldn't be anything like AIDS programmes in existence. But since they've started their initiatives, that is their responsibility for now; because we have a problem and someone has said, 'I'll help them'. Helping us is coming out and saying, 'I'll give you medicine, you'll talk to me.' And you see that makes an HIV-positive person feel so good- to see that you're recognized and you feel there is hope.

Another, citing the government's reputed selectiveness in its distribution of social goods said, "I think [NGOs] have a better heart than the government- they don't help according to who it is; they just help human beings!" (Interviewee 34). Interviewee 36 attributed to NGOs a similarly saintly character: "When they say they'll help, they really do. They have clean hearts."

The greater visibility and involvement of CSOs, often wealthy, foreign-based and funded, and ostensibly driven purely by altruism (as their sophisticated public relations machinery often maintains) has provided an alternative entity against which to evaluate the performance of the State, particularly in the delivery of social goods and development at national level. Positive interventions by CSOs burnish the reputations of individual organizations and the industry in general while highlighting the State's deficiencies. Crucially, they also redefine citizens' ideas about the role of the State and create certain expectations about what it *should* be doing; for in comparing NGO and State performance, interviewees were arguably also questioning the perceived absence of the State in what many thought was its rightful business of providing for their health needs, alluding to an abdication of its obligations. With effective circularity, such grievances can and have then been skilfully harnessed by advocacy groups and channelled towards pressuring governments worldwide to address PLWHAs' needs. As such, CSOs' activities have not only moulded the actions of governments but they also seem to have been instrumental in shaping individual and collective notions of entitlement and rights.

Crucially, however, more contentious narratives about CSOs and overseas donors appear either obscure or unimportant to many PLWHAs. For one, there are fundamental disparities of power between local and foreign organizations, in the capacity to determine and dictate the agenda for development assistance. The gap in financial clout may be the most obvious but Michael, in her investigation of NGOs, asserts that an NGO's real power is defined by this capacity for agency and it is here that the real disparity lies. She argues that local NGOs lack the "ability... to exert [their] influence over others to further [their] ends, rather than [their] ability to accrue the resources necessary to force others to comply with [their] will."⁷⁷ For her, indigenous organizations may have influence within their local domains but will remain powerless until they can exert it at the international level over the foreign donors and governments on whom, in absence of local donors, they are almost entirely reliant.⁷⁸ She is rightly distrustful of the idea of any meaningful 'partnership' between international NGOs and their local protégés, arguing that it only shrouds the inherent power relationship that governs them. The stream of resources and demands is often one-sided, with foreign NGOs little altering their approach at the behest of local 'partners', if at all.⁷⁹ Ultimately, the marginalization of local CSOs mirrors the marginalization of their local constituents. These debates, evidence of which was absent in most interviewees responses, are fundamental for PLWHAs already facing socio-economic and political exclusion and for whom the addition of a new layer of actors in the health and rights fields should not represent yet another degree of separation between them and the power to make and effect choices.

To be sure, at local if not supranational level Nyamu-Musembi and Musyoki noted in 2004 increased efforts by human rights organizations in Kenya to foster community participation and develop a more community-informed agenda. This shift, they argued, was prompted by an integration of socio-economic rights to their formerly exclusively civil and political rights focus. But they also cautioned that these trends were very much at their inception, stressing the need to transcend the dominance by professionals which currently characterized rights advocacy and embrace strategies that emphasize participation and building communities' capacity to advocate for own

⁷⁷ Michael (n 1), at 19

⁷⁸ *ibid*, at 19-20

⁷⁹ *ibid*, at 21, and 121-122

their rights.⁸⁰ As Laura Turiano and Lanny Smith assert, this would help upgrade their status from merely that of “beneficiaries”, a position which embeds notions of dependency on, and deference to, supposedly magnanimous organizations and agencies.⁸¹

These are precisely the kind of issues that the now-ubiquitous rights-based approach to the delivery of healthcare and development is concerned with.⁸² In contrast to a needs-based framework, which “focuses on securing additional resources for delivery of services to marginalised groups,” rights-based approaches overtly politicize the prevailing global inequalities in control of and access to resources, supporting claims to them from the marginalized.⁸³ Yet the 1986 UN Declaration on the Right to Development, which sought to map out specific obligations towards redressing North-South imbalance and impose a collective duty on all States, proved divisive and its provisions have been consistently stymied by wealthy Western governments, with many maintaining that development assistance should be voluntary.⁸⁴

This asymmetry is reflected in global public health priorities, which are almost entirely defined by overseas-based CSOs and subsequently percolate into, and are directly reflected by, national health policy. Ilona Kickbusch and Evelyne de Leeuw, for instance, have argued that the advent of international co-operation in the health field, a result of borderless international health crises like HIV/AIDS, produced two significant trends: the previously-noted burgeoning of actors in the global health arena and a “subtle but systematic erosion of internal sovereignty” in this field. The latter raises an interesting debate: for among the causes of this sovereignty deficit, they highlighted the actions of transnational corporations, healthcare reform strategies designed by the international financial institutions, the World Bank and International Monetary Fund (IMF), and the primacy accorded to bilateral aid

⁸⁰ Nyamu-Musembi and Musyoki (n 2), at 14 and 15

⁸¹ Turiano, Laura and Smith, Lanny, ‘The Catalytic Synergy of Health and Human Rights: The People’s Health Movement and the Rights to Health and Health Care Campaign,’ *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 137-147, at 142

⁸² Nyamu-Musembi and Cornwall (n 55), at 1. For a brief background to the development of rights-based approaches, see 6-7

⁸³ *ibid*, at 2-3

⁸⁴ *ibid*, at 8-9

agencies' priorities.⁸⁵ Other commentators have also highlighted the prominent role of business today in shaping living standards and economic development, which they argue must not be obscured by the focus on State obligations.⁸⁶ The battles between governments and pharmaceutical companies (over ARV accessibility), and insurance firms (over health cover for PLWHAs), are cases in point.

Scrutinizing the wider processes by which changes in health policy are effected at supranational level and the role of prominent foreign-based CSOs in influencing donor behaviour is crucial. It must be clarified that it is not the intention here to criticize any efforts aimed at drumming up support for increased AIDS funding; nor is it suggested that HIV/AIDS is an undeserving target for attention. The aim is merely to highlight the broader factors that influence national health policy and budgetary priorities and underscore the not-so-benign role played by foreign State and extra-State actors in this process, from the selection and sanctioning of these preferences, their local promotion and validation, and finally their implementation. For countries like Kenya are frequently compelled to give form to public health decisions articulated elsewhere, which may indeed align with national requirements, but which also may not.

Shiffman outlines an analysis often used to explain donor behaviour in global public health funding, the influence of other actors.⁸⁷ He writes:

...[Donor] states like individuals, exist in an international society, where they are subject to socialization processes. They may not initially know what they want but come to hold particular preferences as a result of socialization by other state and non-state actors into commonly held norms. For instance, a state originally may not prioritize a health cause such as polio eradication, but come to adopt the cause

⁸⁵ Kickbusch, I., and de Leeuw, E., 'Global Public Health: Revisiting Health Public Policy at the Global Level,' *Health Promotion International*, Vol. 14, No.4 (1999), pp. 285-288, at 286

⁸⁶ Mark Heywood and Dennis Altman give the example of the widely-adopted policy document, the *HIV/AIDS and Human Rights: International Guidelines*, whose recommendations are primarily directed at the State, as not reflecting current realities. (Heywood, Mark and Altman, Dennis, 'Confronting AIDS: Human Rights, Law, and Social Transformation,' *Health and Human Rights: An International Journal*, Vol.5, No.1 (2000), pp.149-179, at 171) See also Office of the United Nations High Commissioner for Human Rights (OHCHR/UNAIDS, *International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version*, 2006, at http://www2.ohchr.org/english/issues/hiv/docs/consolidated_guidelines.pdf, accessed 27/04/09). See also Ely Yamin, Alicia, 'Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,' *Health and Human Rights: An International Journal*, Vol.11, No.1 (2009), pp.5-21, at 11

⁸⁷ Shiffman (n 32)

because domestic health officials learn at international health gatherings that other countries are pursuing this goal and they are likely to be left behind.⁸⁸

In this atmosphere, he adds, the agenda of individuals and organizations are vital; and it is this, the global policy framework, which he argues predominates once the other two- recipient need and provider interest- have moulded the donor's initial choices.⁸⁹ The knock-on effects of increased donor funding may include an improvement throughout the recipient country's health infrastructure, shoring up its capacity to cope with other health issues.⁹⁰ In addition, as Shiffman also points out, spotlighting major public health issue like HIV/AIDS may help focus attention on the general health concerns of the poor.⁹¹

Yet the surge in donor funding for the AIDS epidemic has had some negative consequences, as commentators like Garrett have pointed out. Better-funded HIV/AIDS programmes have not automatically meant a general improvement in a country's public healthcare system as much of this money is spent on stand-alone projects, ensuring it remains firmly within this appointed niche.⁹² Moreover, these cash-rich international CSO-led programmes create direct competition in the local market for health goods and services. They suck crucial personnel away from the already-weak local health system as many governments are unable to match the remuneration packages they offer.⁹³ In Kenya's case, donors' efforts to rebuild the country's collapsing personnel numbers- an estimated 15% of its health workers between 1994 and 2001- appear to have been focused solely on HIV/AIDS-related

⁸⁸ *ibid*, at 412

⁸⁹ *ibid*, at 412-3

⁹⁰ Shiffman, Jeremy, 'Has Donor Prioritization of HIV/AIDS Displaced Aid for Other Health Issues?', *Health Policy and Planning*, Vol. 23, No.1 (2008), pp. 95-100, at 96

⁹¹ *ibid*

⁹² Garrett (n 60), at 4

⁹³ Leonard S. Rubenstein draws on his own experience of this for example: "I have seen this myself in a donor-supported HIV prevention program for teenagers with its own mobile testing facility on the same premises as a maternity clinic that delivered 400 babies a month, but which lacked both voluntary testing kits for HIV (and other diseases) and protective equipment for the midwives; the mobile facility was unavailable to them. Elsewhere health workers are recruited from public clinics to jobs in specialized AIDS programs. These... problems ... cry out for a human rights approach from their origins, a demand for action to assure that programs for preventing and treating people with HIV/AIDS strengthen, and certainly not undermine, health systems to fulfil the right to health for everyone." (Rubenstein, Leonard S., 'How International Human Rights Organizations Can Advance Economic, Social, and Cultural Rights: A Response to Kenneth Roth,' *Human Rights Quarterly*, Vol. 26, No.4 (2004), pp.845-865, at 852-3)

projects.⁹⁴ A 2005 announcement reporting the recruitment by CHAI of 120 nurses in Kenya was proudly advertised as a “major boost to the war on AIDS”⁹⁵; Garrett would argue it is a further depletion of a general healthcare system which in the last ten years has lost “1,670 physicians and 3,900 nurses to emigration, and thousands more nurses have retired...”⁹⁶ Malawi is worse off, having lost “53% of its health administrators, 64% of its nurses, and 85% of its physicians- mostly to foreign NGOs, largely funded by the U.S. or the British government or the Gates Foundation...”⁹⁷

There is also scepticism about the very efficacy of some donor-inspired health programmes. A prime example is PEPFAR’s abstinence-centred HIV prevention programme in Uganda, criticized by some as potentially retarding the country’s progress in combating the epidemic. Condom-use has been a highly effective prevention strategy but a reported condom shortage in the country (firmly denied by the Ugandan government) was attributed by Stephen Lewis, the UN Secretary General’s Special Envoy for HIV/AIDS in Africa, to PEPFAR and “the extreme policies that the administration in the United States is now pursuing.”⁹⁸ Jones and Norton, who analyze the debate in the context of contestations over the truth about the origins, spread and control of the epidemic, underline the role of the conservative, religious fundamentalist forces at the heart of sexual health discourse during the Bush administration. Advocates for a proven, comprehensive approach to prevention were pitted against the “global policy-makers, policy analysts, senior advisors and some researchers who rallied behind PEPFAR, [and] were often involved in PEPFAR policy and implementation”⁹⁹ This starkly illustrates a dilemma often faced by funding-recipient countries: to reject or implement generously-funded programmes based on policies that may bear little or no relationship to the lived experiences of their local target audiences, and accept the broader consequences of their choices.

⁹⁴ Garrett (n 60), at 5. See also Farmer, Paul, ‘Challenging Orthodoxies: The Road Ahead for Health and Human Rights,’ *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 5-19, at 11 on similar problems elsewhere in Malawi and Haiti.

⁹⁵ *The Daily Nation*, ‘Clinton Hires 120 Local Nurses to Fight HIV/Aids,’ 24th July 2005

⁹⁶ Garrett (n 60), at 5

⁹⁷ *ibid*

⁹⁸ Altman, Lawrence K., ‘U.S. Blamed for Condom Shortage in Fighting AIDS in Uganda,’ *The New York Times*, 30th August 2005

⁹⁹ Jones, Shelley and Norton, Bonny, ‘Uganda’s ABC Program on HIV/AIDS Prevention: A Discursive Site of Struggle,’ in Higgins, Christina and Norton, Bonny (eds.), *Language and HIV/AIDS* (Multilingual Matters: Bristol; Buffalo; Toronto, 2010), at 158

The role of overseas CSOs and other actors in the development and implementation of global public health programmes, therefore, with its mixed outcomes for health systems at the national level, are worthy of far more cautious endorsement than that lavished by some of the respondents quoted above, and may even conflict with the interests of the locals among whom they work.

Moreover, it is necessary to critique and publicize the legal and moral framework of the provision of international assistance and the power processes that “determine which issues that affect health get decided- and which issues are never brought to the table because they are systematically blocked.”¹⁰⁰ While the primary duty-bearers envisaged by the key international human rights instruments on socio-economic rights are States, it must be recalled that their provisions came into being decades before the ascendancy of non-State actors in this field. Further, it must not be forgotten that these organizations have become vital vehicles for funnelling development assistance from the same wealthy donor States whose role Art. 2(1) of the legally-binding International Covenant on Economic, Social and Cultural Rights (ICESCR) seeks to delineate.¹⁰¹ Arguably, then, in such circumstances they act as extensions of the State. Unsurprisingly, given how ill-defined the obligations of Art. 2(1) remain, the poor enforcement of the ICESCR and the geopolitical interests that largely dictate decisions about assistance¹⁰², wealthy donor States are often less inclined to highlight the legal obligations- rather than mere moral principles- that

¹⁰⁰ Ely Yamin (n 86), at 7. See also de Vos, Pol; de Ceukelaire, Wim; Malaise, Geraldine; Pérez, Dennis; Lefèvre, Pierre and Van der Stuyft, Patrick, ‘Health Through People’s Empowerment: A Rights-based Approach to Participation,’ *Health and Human Rights: An International Journal*, Vol. 11, No. 1 (2009), pp. 23-35, at 25

¹⁰¹ This explicitly requires its 160 parties- including most of these very States- to “undertake to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means...” (Office of the United Nations High Commissioner for Human Rights (OHCHR), ‘International Convention on Economic, Social and Cultural Rights (ICESCR),’ 1966, at <http://www2.ohchr.org/english/law/cescr.htm>, accessed 16/05/09). For signatories and ratifications, see UN, ‘Status: Chapter IV Human Rights: International Covenant on Economic Social and Cultural Rights (ICESCR),’ United Nations Treaty Collection (UNTC), 2012, at http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-3&chapter=4&lang=en, accessed 16/05/09.

¹⁰² Ely Yamin Alicia, ‘Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health,’ *Health and Human Rights: An International Journal*, Vol. 10, No. 2 (2008), pp. 1-20, 4

underpin their interventions¹⁰³, and the inadequacy of their efforts.¹⁰⁴ Moreover, they may deliberately impede inquiries into their own roles in sustaining global health inequalities, choosing instead to focus on the responsibilities and performance of the local government. Indeed a rights-awareness survey reviewed in the next chapter indicates that there is greater recognition of socio-economic rights at grassroots level in Kenya, suggesting, perhaps, awareness of the government's legal obligations to fulfil its own citizens' socio-economic rights such as health. Yet the respondents' comments featured above suggested less familiarity with any obligations compelling other key actors to offer assistance, beyond perhaps moral ones, which as their principal cultural and/or religious belief systems may dictate, oblige the stronger/richer to assist the weaker/poorer.

The status quo undoubtedly contributes to public perceptions that their healthcare needs are just that: needs, which can be satisfied by charitable interventions from foreign donors or CSOs, rather than rights, entitlements underwritten by law or at least by moral obligations founded on powerful notions of human dignity¹⁰⁵; Maina Kiai, then-head of the Kenya National Commission on Human Rights (KNCHR), highlighted this issue, arguing the government, too, had encouraged this misconception through its promotion of *Harambee* and its inference that community self-help can substitute the fulfilment by the State of its legal obligations.¹⁰⁶ Further, that recipients should be grateful for these charitable interventions especially in light of the invariably inadequate performance of their own governments.¹⁰⁷

The development discourse acknowledges the inherent dysfunction within the donor/recipient relationship and there have been global-level attempts to get parties

¹⁰³ See, for instance, the U.K. government international development agency DfID's insistence that its development assistance "based on a moral- not legal- obligation to alleviate poverty." (Nyamu-Musembi and Cornwall (n 55), at 9)

¹⁰⁴ See Ely Yamin, Alicia, 'Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care,' *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 45-63), at 54

¹⁰⁵ Nyamu-Musembi and Cornwall (n 55), at 3

¹⁰⁶ Interview with Maina Kiai, 26th May 2004

¹⁰⁷ DFID has been criticized for using talk of a 'rights-based approach', for instance, to "tone down reference to 'human rights' that might otherwise be perceived as 'too political' by certain governments. [Its] engagement with the right to *development* has been careful to emphasise the obligations of *national* governments, and suggests that DFID is rather more vague about their own human rights obligations as indeed those that they may have to people in the countries to which DFID gives development assistance." (Nyamu-Musembi and Cornwall (n 55), at 36)

to adhere to such precepts as ownership, alignment and mutual accountability.¹⁰⁸ In the meantime, the status quo continues to undermine the long-term success of development projects and embed the exclusion of many marginalized peoples.¹⁰⁹ And the latter is closely related to issues at the core of this research: citizenship and rights. It is to these linkages that the discussion now turns.

III. AIDS, Civil Society and the State/Citizen-Subject Dialogue

a) Defining 'Civil Society'

The debate about the delivery of healthcare raises a number of wider issues about the vertical relationship between a State and its citizens, as well as the horizontal relationships between the various extra-State actors who make up 'civil society'. Though this phrase is referred to often here, it is not the task of this research to review the breadth of literature devoted to it or indeed to attempt to reconcile the various accounts of its origins or conceptual evolution. However, a preliminary definition, quoted in Chapter 1, can be provided by Charles Taylor. In this definition, civil society "stands in contrast to 'the state'... a web of autonomous associations, independent of the state, which bound citizens together in matters of common concern, and by their mere existence or action could have an effect on public policy."¹¹⁰ But despite this working definition, Taylor accepts in his exploration of the evolving relationship between society and the State that the concept of civil society is "more complex and many-faceted" than a mere distinction between the two.¹¹¹ He regards as unsatisfactory and simplistic a unified notion of 'civil society' compellingly arguing that, as it has developed in the West, it transcends the simple ideas of "a general will or a politics-free sphere".¹¹²

Indeed, this complexity is appreciated by John Comaroff and Jean Comaroff and others in *Civil Society and the Political Imagination in Africa: Critical Perspectives*, who

¹⁰⁸ See Organization for Economic Co-operation and Development (OECD), *The Paris Principles on Aid Effectiveness (2005) and the Accra Agenda for Action*, 2008, at <http://www.oecd.org/dataoecd/30/63/43911948.pdf>, accessed 17/07/09. See also Ely Yamin, *loc. cit.* at note 109.

¹⁰⁹ Nyamu-Musembi and Cornwall (n 55), at 47

¹¹⁰ Taylor, Charles, *Philosophical Arguments* (Cambridge, Massachusetts; London, England: Harvard University Press, 1995), at 204

¹¹¹ *ibid*, at 206

¹¹² *ibid*, at 224

write of a concept that is impossible to pin down, incoherent even, which does not represent just one thing or one idea, and whose possibilities lie in its very elusiveness.¹¹³

In this spirit, though the dominance of NGOs in the CSO landscape is rightly acknowledged, it is understood that this landscape is more amorphous, encompassing broader public domains or “arenas in which people and ideas come into public view, and from which people derive a sense of having a world in common.”¹¹⁴ Many of the interviewees for this research are part of this nebulous sphere. Explicit membership of, or association with, an CSO is not seen as a criteria for locating them within civil society; many self-identified as part of less formal associations, such as local self-help groups in which the specific health and human rights concerns linked with their illness were discussed, thus carving for themselves new public spaces where “secular social purpose could be articulated and carried out.”¹¹⁵ The processes by which they attempt to address these concerns, individually or collectively, have necessarily brought them into contact with the State in its various manifestations and oblige them to negotiate with it. As such, their responses are part of the broader conversation about the State’s changing role and provide clues into the fluid boundaries of this civic space.

This broad definition of civil society rejects a few presumptions which potentially narrow the avenues of discussion: for instance, there is no presupposition that the interface between the State and civil society is necessarily hostile; nor that the latter necessarily seeks to depose the former. But the presumption of a distinct boundary between State and society is sustained though it has been criticized as a production of the State itself¹¹⁶, and Taylor rightly underlines the nuances involved in any notion of conceptualizing civil society as independent from the State, “because there are

¹¹³ See Comaroff, John L. and Comaroff, Jean, ‘Introduction,’ in Comaroff, John L. and Comaroff, Jean (eds.), *Civil Society and the Political Imagination in Africa: Critical Perspectives* (London: University of Chicago Press, Ltd, 1999)

¹¹⁴ Cornwall, Andrea, ‘Making Spaces, Changing Places: Situating Participation in Development,’ *IDS Working Paper 170* (Institute of Development Studies (IDS): Brighton, Sussex, 2002), at 5

¹¹⁵ Taylor (n 110), at 218

¹¹⁶ See Karlström, Mikael, ‘Civil Society and Its Presuppositions: Lessons From Uganda,’ in Comaroff and Comaroff (eds.) (n 113), at 114

different definitions of what this independence involves...”¹¹⁷ The primary contribution of PLWHAs’ responses is in highlighting how their (shifting) subjectivities have influenced the framing and articulation of health needs vis-à-vis other entities, in particularly the State. Also, their definitions of ideas commonly associated with a “civil” society- “moral being, citizenship, community and polity” ¹¹⁸, are of interest; these were not explicitly sought in the interviews but respondents often intimated at them. Ultimately, the interviews reveal how PLWHAs’ experiences, filtered through their multiple identities- based on sex, age, class, ethnicity, nationality, race and, most pertinently, perhaps, as PLWHAs- have moulded their subjectivities and understanding of these fundamental terms.

b) Redefining the State and the Citizen-Subject

The first point to note with reference to the triangular relationship between the State, non-State actors and the citizen-subject is that one must be cautious not to overplay the role of CSOs in the provision of social goods in Kenya. While they have been crucial to increasing availability and access to ART for PLWHAs, their reach is limited: many in need of the drugs still go without and many interviewees who accessed them did so through their own efforts or by calling upon their informal private networks. Moreover, as seen throughout, NGOs are unlikely to be providing PLWHAs’ myriad other needs such as nutrition. However, because the sector plays a vital part in the provision of healthcare, a function associated by many with the State, it is necessarily interpolated in the State and citizen-subject dynamic.

Secondly, one of the consequences of the AIDS epidemic has been the production of a significant PLWHA community. Pioneers such as Jonathan Mann recognized early on that AIDS was more than a medical-clinical issue: it had significant social, political and economic dimensions; and yet the debate on interventions has been long dominated by the former.¹¹⁹ Decoupling AIDS from the strictly medicalized framework of the early part of the epidemic, which saw PLWHAs primarily as patients, and locating it within its socio-economic contexts has expanded the understanding of the disease.¹²⁰

¹¹⁷ Taylor (n 110), at 223

¹¹⁸ Comaroff and Comaroff (n 113), at 8

¹¹⁹ Barnett and Whiteside (n 5), at 77-8

¹²⁰ Seckinelgin (n 20), at 122

PLWHAs, whose involvement has been central to this transformation, have widened the civic space. Though commentators such as Pisani rightly warn against presuming community amongst PLWHAs and the notion that the commonality of their ailment necessarily means unanimity and cooperation on all matters (differentials like gender, sexuality, ethnicity, race, class, and nationality ensure plurality of voice¹²¹), the very fact that differences in opinions and ideas are being articulated proves the expansion of the dialogue space.

Evidence of active engagement in the conversation can be seen in their responses. Their very particular vantage point as PLWHAs may colour their opinions but it nevertheless enriches the broader dialogue on these issues, a discussion that will dominate the last chapter. Some commentators have appeared to attach specific articulated goals and outcomes to definitions about who is to be classified as a member of civil society.¹²² But in-keeping with an unbounded definition of civil society, that is not the view here; it is the notion of a sphere where the legitimacy and limits of State power is discussed that promises the more robust debate.¹²³ PLWHA groups as part of civil society have reclaimed the AIDS debate and used it to carve out a space in the public arena. They have transformed it into a vehicle for greater social and political participation, one through which pertinent issues such as the rights of PLWHAs have entered the public agenda. These spaces started out as- and many remain- “claimed” or “demanded” rather than “invited” spaces, that is, platforms that were “demanded, created, claimed, or chosen by communities or social movements themselves” rather than being under the effective control of government or another “authority.”¹²⁴ But the PLWHA movement is now firmly established globally and is shaping individual and collective notions about PLWHAs, their needs, rights and entitlements in many countries.

It must be cautioned, however, that many of its goals remain unfulfilled and there is a need for a constant renewal of impetus. Some of these problems may be inherent in

¹²¹ Pisani (n 18), at 185. See also Ely Yamin, ‘Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,’ (n 86), at 13

¹²² See, for instance, Monga, Célestin, *The Anthropology of Anger: Civil Society and Democracy in Africa*, (London: Lynne Rienner Publishers, Inc., 1996)

¹²³ Comaroff and Comaroff (n 113), at 31

¹²⁴ Ely Yamin, ‘Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,’ (n 86), at 12

the processes of pluralizing the political space: as they bring within their influence greater numbers of the excluded, these strategies also exercise various forms of social control over them that ultimately inhibit dissent and blunt their radical edge. The discussion in Chapter 5 on the predominance of the biomedical paradigm is a good example. This actually shrinks the participatory space and may in fact enhance the marginalization of those affected.¹²⁵

Moreover, the PLWHA movement must resist the trap of morphing into a “solidarity of exclusion,” which, as Mann observed, develops among members of a group confronted with discrimination and brutality. “This inward thinking, while providing some psychological and practical benefits to members of the group, yields only short-term relief, and is ultimately self-defeating.”¹²⁶ Groups such as TAC in South Africa have been successful in attracting support from beyond the PLWHA community. But more than broadening networks with other groups, it may be increasingly beneficial for the movement to nurture strategies that expand its agenda, too, to include issues that transcend those faced by the group and embrace, for instance, the general health policy and infrastructural issues that affect Kenyans at large. Once again, TAC, whose campaigns now include efforts for the improvement of conditions for health workers, provides an example.¹²⁷

Thirdly, PLWHAs’ experiences and perceptions of NGOs were insightful about how horizontal interactions among non-State actors may influence the vertical ones between the citizen-subject and the State. Many respondents, interviewee 8, for instance, thought NGOs better than the State at providing medicines and healthcare services. She said: “You know, NGOs are better than government. They have the freedom to go to people’s homes. They are not like nurses who have no time to go to people’s homes.” Others, as has been seen, even thought that NGOs demonstrated more concern for citizens’ welfare. This suggests that some respondents were making direct comparisons between the two entities without possibly questioning the fundamental differences in their nature and mandate and its implications. At times

¹²⁵ *ibid*, at 11

¹²⁶ Mann, Jonathan, ‘Health and Human Rights: If Not Now, When?’, *Health and Human Rights: An International Journal*, Vol.2, No.3 (1997), pp.113-120, at 116

¹²⁷ London, Leslie, ‘What is a Human Rights-Based Approach to Health and Does it Matter?’, *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp.65-80, at 73

they appeared to view their roles as interchangeable, not merely advocates or interlocutors for PLWHAs but a tag-team of sorts at least with respect to the provision of ART, working in concert and/or substituting for each other when one actor was unable- or unwilling- to meet the needs of PLWHAs: Interviewee 11, for example, said, “NGOs can do a lot. Because they can help the government subsidise these drugs so that when the patient is asked to pay some money, it is not too much... They should help. If they team up with the government, plus everyone else, even well-wishers, if they all give they can really make the country and better place for HIV patients.” Interviewee 39 said: “I think if they have funds they can help. They can subsidise funds for the drugs.... If they have funds, they should.” For these respondents, the notion appears to be that NGOs and other civil society actors can and should step into the breach on occasions where States are overwhelmed by citizenry demands. Meanwhile, Interviewee 3 expressed a desire to see the government take the lead in projects involving NGOs. However, illustrating the perceived lack of agency that several respondents exhibited in relation to the government, he suggested that NGOs might be wary of such partnerships because of the government’s poor record in governance and financial mismanagement:

Interviewee 3: [NGOs] can help if they see the initiative the government is also taking.

Additional question:

Interviewer: So it has to start with the government?

Interviewee: Yes. They should be able to say, ‘We have tried this much, gotten this far. Now, if you can help us with this bit, we can move up to this point.’

Interviewer: How do you think NGOs can help?

Interviewee: If it were me organizing things, the NGOs would work together with the government, but most of them fear working with the government nowadays, like I was told at a certain NGO here, they want to do their project on their own, they want no involvement by the government. They said if they did it with the government, they won’t reach their target because once you start involving the government, you won’t run your accounts, so it’s difficult for them. And you won’t push the government! The problem is money.

And yet while many thought that the State was obliged to provide for their health needs, either through its responsibility to its taxpayers or citizens, or on moral grounds (though a number, as will be seen in Chapter 8, were sceptical that these obligations could be enforced against a recalcitrant State) most saw NGOs’

interventions as merely charitable, seemingly absolving them of any duty-bearing role and declaring these actors under no compulsion to offer it. Comments included: “They should [help], but voluntarily; it’s the government that should. Theirs [NGOs] should be voluntary.” (Interviewee 17); “Yes, they can help us if they want because they have been helping us [but] it should be voluntary.” (Interviewee 19); “They absolutely not should be compelled to help! They volunteer their help and the resources are not their own- they beg on behalf of those in need. So they should not be compelled, just requested.” (Interviewee 36); No, [NGOs] should not be compelled! They should just volunteer to help.” (Interviewee 49); “These [organizations] just volunteer to help so they shouldn’t be compelled. (Interviewee 35); “They should not be compelled to [help]. If they feel it’s right to help, they should.” (Interviewee 22).

Those who felt that NGOs should assist them in getting their health entitlements were adamant that where funds had been sought and given in the recipients’ (PLWHAs) name they must be put to their intended purpose. For instance, interviewee 44 said:

Yes [NGOs should be compelled to assist] because the help they offer is because people have those human rights. They ask for donations and say that they need to help people so when they get the donations, they must use them to help people, because they have claimed it in my name. For example, people are starving in my birth-place in Ukambani [Eastern Kenya]. They are also dying because they’ve eaten contaminated grains. If an NGO goes abroad and says they want funds from donors to go and help these people dig boreholes for water so that they may be able to grow their own crops, they should then be compelled to help us because they have acquired those funds in our name and for our use. So any NGO that gets funding specifically to help PLWHAs, they should be then compelled to help.

Other responses included: “They should [be compelled to help]. I hear they get money to help but sometimes they use the money for themselves or they help those they want to help but not others. (Interviewee 37); “Yes, [NGOs] should be compelled to help. They should be followed up, even if it’s by the government, because if they volunteered to help people then they should.” (Interviewee 23); Yes, they should be compelled assist [because] we should help those we pledged to help when the organization was founded.” (Interviewee 29).

Perversely, then, the preferred agent of the delivery of healthcare entitlements for many was also the one that most did not consider obligated to act; the implication of their preference would be to reduce the foundation of their claims to healthcare from an entitlement in law to mere goodwill.

Fourthly, in a relatively recent development, CSOs have been keen to emphasize an important component of citizenship: participation. The right to participate has been dubbed “the right of rights” as it is seen as instrumental to achieving other rights.¹²⁸ Its role is anticipated by the principle international human rights covenants¹²⁹; as Ely Yamin puts it, “participation goes to our most fundamental understanding of being human and to the purpose of rights.”¹³⁰ In global health, the rhetoric, if not always the practice, of participation has been part of the discourse for some decades now, with various models of community-centred alternatives to State-led public health and development paradigms emerging in the 1970s.¹³¹ In the intervening decades the concept of community participation waned “as it came to be perceived as a convenient means to compensate for the failure of states to make significant improvements related to primary health care.”¹³² In Kenya the power to organize any grassroots movements that fostered citizen participation was greatly stifled by repressive governments. This only changed with the local and international political convulsions of the late 1980s and 1990s. It took even longer- the late 1990s- for the

¹²⁸ Halabi, Sam Foster, ‘Participation and the Right to Health: Lessons from Indonesia,’ *Health and Human Rights: An International Journal*, Vol. 11, No. 1 (2009), pp. 49-59, at 49. See also Ely Yamin, ‘Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,’ (n 86), at 6. Nyamu-Musembi and Cornwall, for instance, point out that the Department for International Development (DfID)’s naming of the right to participate as a right itself was a radical step. (Nyamu-Musembi and Cornwall (n 55), at 35) However, they rightly note that focusing on the enabling aspects of rights, such as enhancement of participation and bolstering ‘civil society’ advocacy, is not a substitute for demanding the respect and protection of specific rights like health (at 36). They remind us that rights can be applied as an avenue to increase citizen-subjects’ capacity to claim rights for themselves and overcome the challenges to the realization of rights, but that this is not the same as holding the State and extra-State actors to account for failing to address socio-economic rights violations (at 46).

¹²⁹ See Halabi (n 128): “In the context of the ICCPR, the right to participation has generally been taken to mean the right to organize a political party, to vote, or to freely express political opinions. Other treaties define participation as the right to participate in cultural life; or, the right of children to participate in decision-making processes affecting their interests. The ICESCR casts participation as part of the right to health both as an “underlying determinant[] of health” and as a right to have a say in health matters, generally.” (at 51)

¹³⁰ Ely Yamin, ‘Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,’ (n 86), at 6

¹³¹ *ibid.* See also De Vos, *et al* (n 100), at 23-4. See also Halabi (n 128), at 49

¹³² De Vos, *et al* (n 100), at 24

development sector to adopt participation as a key element in the delivery of its services, a shift that Nyamu-Musembi and Musyoki attribute to the impetus on the local scene for constitutional change which the sector could no longer ignore, and the influence of major international development players who began to integrate advocacy and rights-based approaches into their work.¹³³ As a result, organizations like Oxfam and ActionAid have sought to build the capacity of various groups and marginalized communities in Kenya to engage with State institutions as a fundamental aspect of a rights-based approach, in order to make government more accountable.¹³⁴ Indeed, Nyamu-Musembi and Musyoki illustrated the transformative effect of grounding the practice of participatory development, observing that some communities had started to extend their demands for accountability beyond the State to other actors, including the organizations they worked with.¹³⁵ The renewed emphasis on participation can undoubtedly be linked to the globalization of CSO activities, for in acquiring an international character as part of their multi-level restructuring, which many CSOs have done, they have been forced to become more conscious of their wide-reaching impact and more explicitly account for the “different cultural, political, and economic settings, [which come with] often with very different problems and organizational tasks”¹³⁶

It is therefore worth interrogating how CSOs may be re-shaping the boundaries of citizenship. To start with, the global character of many of those involved in HIV/AIDS and/or human rights activities, and their role in cultivating transnational “social and economic communities”, has contributed to the expansion of “the institution of citizenship” from its conventional single dimension, so that now it has diverse aspects

¹³³ Nyamu-Musembi and Musyoki (n 2), at 4

¹³⁴ *ibid*, at 10-12

¹³⁵ They noted: “It is only a matter of time before communities use these same opportunities for the purpose of questioning the very NGOs and professional groups that are facilitating those opportunities. In fact, this has already begun to happen. In a CARE-supported horticultural farming initiative in Makueni district, farmers demanded and now have a right to inspect CARE’s books of account relating to the initiative. In some areas ... people have formed “people’s parliaments” at the local level which pressure the local MPs and other authorities to take appropriate action. However, they have gone beyond this set of actors to approach “youngish professional people” from the area to ask them what they have (or could) put back into their communities. The CLARION official we interviewed said he saw no reason why these same forums cannot be used to demand accountability from an even broader set of actors including aid organisations and private enterprises, which would expand the conventional arena of human rights accountability.” (Nyamu-Musembi and Musyoki (n 2), at 12)

¹³⁶ Anheier, Helmut, and Themudo, Nuno, ‘Organisational Forms of Global Civil Society: Implications of Going Global,’ in Glasius, Marlies; Kaldor, Mary; and Anheier, Helmut (eds.). *Global Civil Society 2002*, (Oxford: Oxford University Press, 2002) at 207.

“only some of which might be inextricably linked to the national state.”¹³⁷ Drawing on the work of other commentators, Saskia Sassen concludes: “Whether it is the organization of formal status, the protection of human rights, citizenship practices, or the experience of collective identities and solidarities, the nation state is not the exclusive site for their enactment. It remains by far the most important site, but the transformations in its exclusivity signal a possibly important new dynamic.”¹³⁸ It is an assertion borne out in this research by the interviewees’ comments which reveal their enthusiasm for the pathways now presented by CSOs for activism on behalf of PLWHAs’ access to treatment and other rights.

It is also worth investigating how CSOs impact on existing patterns of exclusion which bar large numbers from participation, and thus citizenship. Do they in fact replicate these patterns when so many PLWHAs, for instance, appear to hope- even expect- they will neutralize them? For the contours of the civic space in which they operate are socially-produced, the result of the power matrices that have been analyzed throughout this research.¹³⁹ Nyamu-Musembi and Musyoki note a greater demand for participation at grassroots level in Kenya and underscore that struggles here “emphasise that rights are not simply about attaining tangible desired outcomes (such as piped water and a garbage collection system) but that rights are also about taking part in the processes that shape and achieve those desired outcomes: a right to active and meaningful participation in the process of shaping the realisation of rights, so to speak.”¹⁴⁰ Their anecdotal evidence of community advocacy initiatives illustrated that sustaining grassroots human rights campaigns requires genuine participation, be it the right to meet freely and discuss grievances, to take part in decision-making whose outcomes affect them, to information, or to transparency from relevant governmental or non-governmental bodies implementing such decisions.¹⁴¹

¹³⁷ Sassen, Saskia, ‘Global Cities and Diasporic Networks: Microsites in Global Civil Society,’ in Glasius, Marlies; Kaldor, Mary; and Anheier, Helmut (n 136), at 232-3

¹³⁸ *ibid*, at 234

¹³⁹ Ely Yamin ‘Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,’ (n 86), at 12. See also Cornwall (n 114), at 6

¹⁴⁰ Nyamu-Musembi and Musyoki (n 2), at 22

¹⁴¹ *ibid*, at 22-23

Yet persistent structural barriers to participation and citizenship, many with pre-colonial foundations, exclude those with limited social, economic and political capital, such as women and the poor, from fully taking part in public life. Such exclusion not only determines access to social goods but the extent to which one can contribute to the dialogue about their provision and distribution. CSOs within the AIDS sector have already been successful in providing ART to a vast numbers of poor for whom such treatment would be otherwise inaccessible. By focusing on women, children and orphans, local groups like WOFAK help redress their historical marginalization. Through such efforts, CSOs have helped open up platforms upon which PLWHAs may advocate their positions, thus extending the frontiers of the civic space to include a previously excluded group.

On the other hand, however, CSOs can be rightly accused of preserving rather than reversing some patterns of exclusion established by State actors. For instance, their invariably urban-based nerve centres deepen the geographic, social, economic and political isolation of rural and remote communities. Elsewhere, local organizations may be especially susceptible to the charge of maintaining that contentious exclusionary factor of ethnicity, as seen in some interviews. Some faith-based organizations, too, may hold forth adherence to a particular set of values as a barrier to accessing their services. These examples underline how the process of expanding access to socio-economic goods like health may itself be a vehicle for entrenching existing inequalities and prevailing norms. As Lynn Freedman asserts, while public health and human rights may be “powerful, modern approaches to defining and advancing human well-being,” they have also “at times been powerful tools for maintaining the status quo, reinforcing hierarchies of power and domination based on race, gender, and class.”¹⁴²

Nor must it be forgotten that CSOs’ ties to powerful financial benefactors, though crucial to their survival, may in fact hinder meaningful participation and citizenship at grassroots level: for they may restrict their ability to fully effect a rights framework

¹⁴² She gives the example of population control movements, which claimed to promote women’s rights to control their fertility yet sought to limit this “freedom” with the “responsibility” to make choices that adhered to government population policies. (Freedman, Lynn P., ‘Reflections on Emerging Frameworks of Health and Human Rights,’ *Health and Human Rights: An International Journal*, Vol. 1, No 4 (1995), pp. 314-348, at 315)

which, as Ely Yamin underlines, addresses the concern that, “the power to decide what gets decided can be a greater constraint on the choices of others than the ability to overcome opposition. Therefore, it is important to consider not just who gets their way within policy debates or participatory forums, but how the agenda and the boundaries of participation are set.”¹⁴³

Fifthly, commentators like Mamdani dispute the extent of civil society’s impact in postcolonial Africa, arguing that it remains an urban phenomenon which fails to take into account the regime of the customary through which the majority rural population- the ethnic public- is incorporated and ruled.¹⁴⁴ They challenge the view that Africa’s crises are rooted in the ‘underdeveloped’ or ‘weak’ civil society.¹⁴⁵ Karlström criticizes the off-handed dismissal and scant analysis of African forms of association, such as kinship groups, as potential and effective interlocutors in the State’s dialogue with the citizen-subject.¹⁴⁶ The power structures of the rural sphere explored in Chapter 3 undoubtedly represent a locus of power whose fundamental values are at times diametrically opposed to those which CSOs ostensibly promote. As Mamdani observes, these authorities have not shied away from denying rights in the name of preserving custom.¹⁴⁷ How CSOs go about claiming this sphere is of great interest, with the centralizing power of the ethnic, which sometimes exerts a greater influence than the State, inhibiting the growth of some of the contingents of civil society in the rural sphere. For instance, Taylor underlines the significance in the evolution of the *idée* of civil society of “voluntary associations...[which] give us the taste and habit of self-rule.”¹⁴⁸ Such associations were highly restricted in Kenya’s colonial period especially, and were less prevalent particularly in the rural sphere. But they have also been restricted in the numerous post- independence power struggles. And yet they are “essential for political purposes. But if they are to be real loci of self-rule, they have to be nongigantic and numerous, and exist at many levels of the polity. This itself should be decentralized, so that self-government can be practiced

¹⁴³ Ely Yamin, ‘Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,’ (n 86), at 10

¹⁴⁴ Mamdani, Mahmood, *Citizen and Subject: Contemporary Africa and the Legacy of Late Colonialism*, Princeton, NJ: Princeton University Press, 1996) at 295

¹⁴⁵ See also Comaroff and Comaroff (n 113); Karlström (n 116)

¹⁴⁶ Karlström (n 116), at 111

¹⁴⁷ Mamdani (n 144), at 293

¹⁴⁸ Taylor (n 110), at 222

also at the local and not just the national level.”¹⁴⁹ The stagnation of this aspect of the evolution of civil society has thus arguably held back the mobilization of ethnic public.

And yet this public and its realm cannot entirely remain impervious to the influence of civil society, not least due to the fluidity with which numerous Kenyans navigate between the urban and rural sphere. Many values endorsed by civil society, such as human rights principles, are increasingly familiar to Kenyans, as human rights awareness surveys suggest, and thus have space to flourish in the rural sphere. Yet problems remain: some of the messages at the core of public health campaigns against HIV/AIDS, for instance, such as those which seek to eradicate risky practices and the underlying values they promote- female circumcision, wife inheritance, child marriages are prime examples- are often fiercely opposed in those communities where such customs are common.¹⁵⁰ These objections are often ciphers for something deeper: resistance to interference with the social configuration of this realm. The contestation of a particular public health policy or human rights campaign reveals the power struggle between the authorities in these rural communities and the independent locus of power represented by CSOs who advocate these positions. This underlines the importance of Mamdani’s bifurcation thesis; the differently-configured urban sphere creates an easier environment for various elements of civil society to promulgate norms and ideas that may be deemed controversial, if not downright unpalatable, elsewhere.

It is partly in recognition of these underlying conflicts that CSOs and other health actors now accept that they must actively seek to co-opt local community-members into their operations, as the WOFAK/UNAIDS project on the integration of traditional medicine in AIDS care, reviewed in Chapter 5, noted:

Without the involvement of community stakeholders in the implementation and follow-up of collaborative initiatives, collaborations may fail to achieve their intended far-ranging goal, beyond immediate project participants, thus they may not last and/or truly benefit the community. Involving community leaders and project

¹⁴⁹ *ibid*, at 222-3

¹⁵⁰ See Kenyan MP Beth Mugo’s stern denunciation of forced female circumcision of school girls in the remote West Pokot district of northern Kenya in a letter to *The Daily Nation*, published 25th July 2005: “...I must also remind the MPs that they voted for the Children's Act and they have a duty to protect children. It is a pity that the Provincial Administration could be intimidated as if there is no law in this country. This is an inhuman and criminal act and the culprits should be punished....” (Mugo, Beth, MP, ‘FGM is Barbaric and Retrogressive,’ Letter, *The Daily Nation*, 25th July 2005)

beneficiaries from the inception of activities allows for community ownership, interest in sustainability, and increased collaboration at all levels.¹⁵¹

As seen earlier, the capacity of these local stakeholders to articulate priorities and really dictate change at a policy level is questionable.¹⁵² But this concession may also indicate some recognition of the essential fallacy of the notion of the atomized individual, and power of the community as the main site of individuals' sexual and social experiences and of the formation of their identities and subjectivities, as Campbell underscores.¹⁵³ But this interaction between rural communities and CSOs has surely been mutually transformative: the injection of a rights discourse into the examination of cultural practices like female circumcision and wife inheritance spotlights the individual: the tangible consequences and costs to individual well-being of intangible social, cultural, economic and political forces. The subsequent vigorous public debate has also allowed Kenyans, many of whom have at least one foot in the rural sphere, to probe the nature and limits of customary power and the values it endorses.

Yet a fundamental quandary of citizenship remains which problematizes the gradual erosion of the customary through the denigration of the normative framework which underpins it. Does this process disregard too readily the legitimate desire by all societies, be they rural- or urban-based, for an identity and a sense of cohesion? As Mamdani has noted, those in the urban-based civil sphere may be able to draw on their membership or citizenship within the Nation for a sense of identity¹⁵⁴; thus seeking to undermine that which serves a similar function for the ethnic public-custom- arguably diminishes that which gives them a similar sense of belonging, association, participation. And yet equally, if not more, undesirable would be the kind of compromises that would accept the perpetuation of suffering often justified in the name of preserving religious or cultural norms.¹⁵⁵

¹⁵¹ UNAIDS, *Collaborating with Traditional Healers for HIV Prevention and Care in Sub-Saharan Africa: Suggestions for Programme Managers and Field Workers*, 2006, at

http://data.unaids.org/pub/Report/2006/jc0967-tradhealers_en.pdf, accessed 08/07/08, at 15

¹⁵² See, for example, Garland, Elizabeth, 'Developing Bushmen: Building Civil(ized) Society in the Kalahari and Beyond,' in Comaroff and Comaroff (n 113), and Seckinelgin (n 20)

¹⁵³ Campbell (n 22), at 3

¹⁵⁴ Mamdani (n 144), at 292

¹⁵⁵ In his critique of the universalism-versus-relativism bifurcation, Baxi rightly notes that universal human rights norms, which prescribe uniform rights for all human beings, do not account for the

Finally, as mentioned earlier, it has been argued by Kickbusch and de Leeuw and others that CSOs and donors may undermine State sovereignty and legitimacy, particularly its authority in setting the national health agenda. Agatre Okuonzi and Joanna MacRae, writing on Uganda's national health policy but who could just as easily be commenting on Kenya, similarly assert:

Donor influence in policy development raises a number of questions concerned less with the technical merit of alternative policy options for such issues as health financing strategies and the composition of essential drugs lists, than with issues of accountability, sovereignty, information, sustainability and appropriateness in the health policy domain.¹⁵⁶

The place of the citizen-subject in this dynamic is crucial to the debate about the pursuit of a right to health, as the last chapter will further elaborate. Some commentators see a broader erosion of State sovereignty, an undermining of the nation State itself and its replacement with structures that have no clear lines of accountability.¹⁵⁷ And yet others argue that some of the programmes adopted in the prevention and management of the AIDS epidemic, especially those which seek to encourage safer sex, actually extend the State's reach in the private sphere, even though they may be conveyed through the auspices of CSOs.¹⁵⁸ According to this view, the epidemic has enabled the State to entrench the theatre of sexual interaction as a legitimate space for its involvement in the name of preventing a sexually transmitted illness with no cure. The effect of this incursion may be that the State's values, which in Kenya remain rooted in conservatism and paternalism, are imparted more freely and enforced through programmes and policy messages, disadvantaging those who fall outside the parameters of propriety. The impact on traditionally-marginalized groups such as women, or much more recently-prominent groups such as men who have sex with men, may be their further isolation.

cultural contexts within which many experience their day-to-day lives and as such risk appearing irrelevant. Nevertheless, he argues, the human rights enterprise must be willing to identify "non-consensual and therefore illegitimate orders of pain and suffering imposed by the civil society and the state." He contends that what is required is "a human rights-responsive and responsible relativism, one that interrogates the contemporary human rights paradigm in its endless renegotiations of its own foundations." (Baxi, Upendra, 'Voices of Suffering and the Future of Human Rights,' *Transnational Law and Contemporary Problems*, Vol.8, No. 2 (1998), pp.125-169, at 153-4)

¹⁵⁶ Okuonzi, Agatre and MacRae, Joanna, 'Whose Policy is it Anyway? International and National Influences on Health Policy Development in Uganda,' *Health Policy and Planning*, Vol. 10, No. 2 (1995), pp. 122-132, at 130

¹⁵⁷ See Chandhoke (n 24), at 35-53.

¹⁵⁸ See, for example, Altman (n 21), at 189

The impact of eroded State sovereignty is more complicated in the bifurcated State if indeed, “in some parts of the world NGOs and international agencies provide the only effective governmental structure,” as Altman argues.¹⁵⁹ Those incorporated within the urban-based national public may utilize existing avenues for participation and citizenship which enable a political dialogue with the State about, say, the provision and distribution of social, economic or political goods. To be sure, this may have produced only limited success and perhaps only to a limited few; nevertheless (nominal) legally-guaranteed paths of participation such as the right to vote remain. But as CSOs and international agencies have evolved into a focal point of power themselves, with only a limited number of Kenyans able to piggy-back on them as a vehicle to the articulation and realization of their own goals, the field of engagement has been reconfigured, participation reduced and much of the power to affect change concentrated elsewhere, that is, as Chandhoke, Garland and others bluntly state, abroad. Even for those with a stronger allegiance to the national public, the levers of power which control these new set of actors may prove more inaccessible than those of the historically unwieldy Kenyan State. This constriction of the participatory space, as Ely Yamin argues, has a colossal bearing on the dignity and well-being of the marginalized.¹⁶⁰ The apparent magnanimity of the overseas actors does not camouflage the fact that “[i]f health is a matter of rights, it cannot be considered a handout, and the people who receive services are not objects of charity from their own governments or from the G-20; they are agents who have a role to play in the definition of programs and policies that structure the possibilities for their own well-being.”¹⁶¹

At the other end, the ethnic public, rooted in a sphere whose conservative, rigid systems of power render it less vulnerable to incursions by civil society, may draw more people to it because of the relative certainties and continuity of the customary, particularly in times of socio-economic and political turmoil. This may further strengthen allegiance to localized customary authorities in their on-going power

¹⁵⁹ *ibid*, at 193

¹⁶⁰ Ely Yamin, ‘Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,’ (n 86), at 9

¹⁶¹ *ibid*, at 6

contest with the national State: for the opportunities that the customary realm offers for participation, association- citizenship- may be perceived as more feasible. The price that the powerbrokers in this domain may exact for membership- allegiance to prevailing authority, reinforcement of exclusion based on ethnicity, gender and factors intrinsic to this sphere, indeed, the enforcement of practices and values that are abhorrent to human rights norms- may once again redraw the citizen-subject boundaries, adding new layers to the subjectivities of PLWHAs and Kenyans at large and recalibrating notions about entitlements and rights. Just how embedded such notions are will be one of the issues addressed in the last chapter.

Chapter 8: Deconstructing Subjectivity and Constructing Notions of Entitlement and Human Rights in Kenya

This chapter provides a detailed analysis of PLWHAs' responses in relation to rights and locates them in the broader, globalized human rights discourse.

By analyzing the interviewees' general human rights awareness and comparing and contrasting it with a more widespread survey on similar issues conducted by the Kenya Human Rights Commission, this chapter is able to illuminate discrepancies that may be accountable to their identity as PLWHAs. Further, the interviews are employed to identify and interrogate three key themes which emerge from respondents' conceptualization of rights: humanness, dignity and citizenship.

As the chapter illustrates, many interviewees often appeared to define these three fundamental concepts from their unique perspective as PLWHAs, giving weight to the suggestion that HIV/AIDS is significant to their subjectivity and their imagination of entitlements and rights. To start with, there is evidence of how a stigmatizing illness may affect PLWHAs' notions of what it means to be a human being with a certain worth and entitlements accruing. The chapter then highlights the tensions between conceptions of dignity within the human rights paradigm and within cultural or religious frameworks that dominate the lives of PLWHAs. This further establishes the significance of HIV infection to the construction of subjectivity but also underlines the conflict and plurality, addressed in previous chapters, of the moral frameworks by which respondents regulate their lives. Finally, in the analysis of PLWHAs' claims of membership to multiple, sometimes competing publics, this chapter argues the significant role that appears to be played by the exigencies of HIV infection to PLWHAs' understanding of the idea of citizenship and its attendant obligations, entitlements and rights.

The interviews thus provide an empirical context for which to underline the importance of subjectivity in legal research. They help rationalize and validate the assertions of theorists like Jacques Lacan of the seamless continuity between inner

aspects, like identity and desire, and outer ones like society and law, in the construction of the legal subject. Lacan's theories are briefly outlined towards the end of this chapter and help locate the idea of each PLWHA as a unique legal subject and agent, and to contextualize the multifaceted and sometimes contradictory nature of subjectivity that this research has often revealed.

This thesis is buttressed in the chapter's concluding analysis, which looks at how the varied subjects and subjectivities at the heart of this research, the products of the dynamic and complex environment discussed in previous chapters, also entertain varied notions about their health entitlements. Further, they are shown to have multiple ideas about the rights of the individual and the obligations of the State and other actors.

Ultimately, the chapter underlines the fact that despite its globalization, the human rights paradigm and its norms about the (health) entitlements of the individual are not 'taken-for-granted': for while the human rights enterprise has made strides in promoting its values, major challenges persist, primarily in the grassroots, which are dominated by alternative languages and frameworks by which to conceptualize and articulate entitlement and rights. Here in this key constituency, this research suggests, the multitudes remain unconverted.

I. Rights Awareness

The analysis about PLWHAs' knowledge of rights was greatly aided by the more comprehensive 2006 Haki Index (Chapter 1), which provides a countrywide context about human rights awareness. This research's own inquiry avoided making presumptions about interviewees' knowledge, and started by asking the basic question: had respondents heard of the phrase 'human rights' or its Kiswahili equivalent, *haki za ki-binadamu*. Indeed, the vast majority of respondents said they had. An attempt was made to find any common characteristics among the five who had not, which may be significant to rights awareness. A Zimbabwean human rights awareness study from the early-1990s, for instance, indicated that 'professionals' knew more about rights than any other groups in the survey; however, it suggested that "lack of human rights knowledge [seemed] mainly to be caused by lack of

education than a total absence of education.”¹ Among the five, interviewees 23 and 12 had not attained secondary-level education, with the former, a driver before his illness, leaving primary school after about seven years, while the latter only had three years before she was forced to drop out in 1967 when an illness in the family left her in charge of the household. Interviewee 19 completed two years of high school and was unemployed at the time of the interview; interviewee 38 completed four years of high school of was working as a teacher in a kindergarten; interviewee 49 went had one year of high school education and at the time of the interviews sold second-hand clothes. The information given, therefore, did not suggest any obvious commonalities crucial to human rights awareness.

The Haki Index survey did not break down its findings according to these two important factors, considering instead the gender and living standards of its respondents. These crucial factors will, of course, be referenced here where relevant. In the absence of any obvious patterns, one may speculate about why the five respondents had not heard of the phrase ‘human rights’. The issue of the language in which interviews were conducted is important, as seen in Chapter 2. Some Kiswahili language interviewees appeared better acquainted with the English phrase ‘human rights’ than its Kiswahili equivalent. English is Kenya’s official language and the one by which local and foreign rights experts are most likely to communicate. The language that such professionals chose to express and disperse what William Conklin calls ‘magic terms’, known only to human rights experts², is vital. The apparently greater currency of the English phrase suggests their partiality to this tongue and the exclusivity already inherent in this choice may further substantiate some commentators’ charge that human rights experts have not done enough to cultivate a popular rights movement in Africa, alienating a large percentage of the population and ensuring the discourse remains largely within their circle.

¹ d’Engelbronner-Kolff, Marina, *The Provision of Non-formal Education for Human Rights in Zimbabwe* (Harare: Southern Africa Printing & Publishing House/SAPES Trust, 1998) at 8. The study involved over 800 interviewees, grouped as school pupils, students at institutions of higher learning, professionals (“lawyers, magistrates, teachers, lecturers, doctors, police officers and other government officials”) and adults (“women and men, workers, consumers, religious groups”). They were carefully selected in order to be as representative of the Zimbabwean population as possible. (at 5)

² Conklin, William E., ‘Human Rights, Language and Law: A Survey of Semiotics and Phenomenology,’ *Ottawa Law Review*, Vol. 27, No. 1 (1995-1996), pp. 129-174, at 134-5 and 145

One effect is the poor percolation, knowledge and use of rights terms among the general public, starkly evidenced, perhaps, by the fact that many ethnic African languages- Kenya has dozens- have no equivalent of the phrase 'human rights'.³ As seen in previous chapters, these terms have been useful for PLWHAs seeking to redefine positively their lived experiences and actively, rather than passively, engage in the (re)construction of their identity and subjectivity and the narrative of their illness. Arguably, the suggestion of poor permeation of rights language stands despite the high number of respondents in the Haki Index (77%)⁴ who showed a spontaneous awareness of rights, that is, mentioned without prompting some "aspect of human rights."⁵ This is because the survey's inherent presumption of prior knowledge makes it harder for respondents to correct such a presumption, whether out of embarrassment or deference to the interviewer. Interviewee 33 for this research exemplifies this, although it will be recalled that there the apparent embarrassment came from the respondent's younger interpreter, apparently unwilling to accept the respondent's unfamiliarity with such an apparently popular phrase. This may even account for the significant number of respondents in the Haki Index subsequently unable to offer any definition of the term, discussed presently.

Of course, lack of familiarity with human rights terms or the existence of vernacular equivalents, as will become clear, did not appear to preclude respondents holding ideas about notions such as obligations and entitlements, which will be familiar to human rights scholars. As William A. Edmundson notes, "[t]he presence or absence of a word or concise phrase or locution in another language, with which to translate a word we use is hardly conclusive as to the availability of an idea to speakers of another language."⁶

³ Odinkalu, Chidi Anselm, 'Why More Africans Don't Use Human Rights Language,' *Human Rights Dialogue*, Series 2, No. 1 (1999), Carnegie Council on Ethics and International Affairs, at http://www.cceia.org/resources/publications/dialogue/2_01/articles/602.html, accessed 20/05/09.

⁴ Kenya Human Rights Commission (KHRC), *The 2006 Haki Index: Measuring Public Perceptions on the State of Human Rights in Kenya and the Case of the Devolved Public Funds*, KHRC, 2006, at <http://www.khrc.or.ke/documents/2006%20Haki%20Index.pdf>, accessed 20/05/09); at 20

⁵ *ibid*, at 129

⁶ Edmundson, William A., *An Introduction to Rights*, (Cambridge: Cambridge University Press, 2004), at 5

The high numbers of interviewees for this research who claimed to have heard of the phrase 'human rights,' bore out the Haki Index survey and suggests that the respondents' identity as PLWHAs may have further contributed to the high rates of rights awareness. This is particularly exemplified by the widespread use, without the interviewer's prompting, of terms like 'stigma', 'discrimination' and 'equality', which are firmly part of the human right vocabulary and discourse, discussed later. Arguably, being personally affected by HIV/AIDS not only increases the likelihood of a PLWHA's contact with human rights-related information on these issues, through the media, support groups or advocacy organizations, but it also makes PLWHAs more attuned to rights-related matters. This might explain why interviewee 23, who said he had only discovered he was HIV positive two weeks prior to the interview, may not have heard of the term. He also said he had not initially heard of the government ARV cost-sharing scheme that had been announced about 6 months before, explaining tellingly that:

....my mind was not focussed on issues about HIV. I used to hear that this thing exists but I had never taken a test and been found out to have it. So now is the time that I am listening and paying attention to news about HIV so that I can know what is happening.

It is a view reiterated by another respondent, interviewee 40: although she later conceded she could not name any specific examples of human rights, she said, "When I got this problem with this illness, I started to hear things about rights from the radio and also from the support groups here [at Mbagathi District Hospital]. Like, I met a woman here who then told me about WOFAK so I went there. But I have never been to any human rights organizations to seek help."

The Haki Index appears further to corroborate the linkage between rights awareness and marginality, recording a higher rate of spontaneous awareness of a number of rights among people in Kenya's North-Eastern Province (NEP) in comparison to other provinces. "This," it is suggested, "could be because they are more likely to face violations of them. For example, 90% of the sample in NEP was able to mention, spontaneously, the right to education. The right to nationality or citizenship also stands out in NEP. This can be attributed to the geographical location of the area: it borders Somalia and Ethiopia, and a significant proportion of the population in this

province are ‘perceived’ not to belong to Kenya, rather being seen as refugees from the bordering countries.”⁷

This supports the view in Chapter 6 that voluntary counselling and testing (VCT) sites and medical centres where HIV testing and diagnosis is conducted may be ideally positioned to provide information on, and promote rights related to, HIV/AIDS. National guidelines for HIV testing in Kenya state that part of the minimum services expected in a pre-HIV test session is information on the requirement of consent for HIV tests. Additionally, information on “referral to support, care and treatment” and on the “importance of disclosure to partners and other family members” may be offered.⁸ While these issues are linked to rights and the document stresses respect for the relevant rights, there is no apparent explicit mandate to discuss the client’s rights.

A possible reason may be that healthcare officials conducting the test may themselves be unfamiliar with the human rights involved.⁹ Further, it may be inappropriate to address such issues at this precise stage, particularly when if a patient has just received a positive test result; the immediate medical needs- referral and follow-up care- are likely to be the paramount concern. However, it may be worth availing written information (such as pamphlets and posters) to people undergoing tests or directing them to relevant organizations as part of the support available (although some interviewees rightly questioned the benefits of knowledge about rights which cannot be realized). Indeed, it will be recalled that Leslie London argues that healthcare officials must ensure they do not become tools of the State’s violation of its health rights obligations, suggesting that informing patients of the government’s legislative, financial and administrative failures in providing adequate treatment and preventive services “may help to spur a patient rights advocacy

⁷ KHRC *The 2006 Haki Index: Measuring Public Perceptions on the State of Human Rights in Kenya and the Case of the Devolved Public Funds* (n 4), at 22

⁸ National AIDS and STI Control Programme (NASCO) and Ministry of Health and Sanitation (MoHS), Kenya, *National Guidelines for HIV Testing and Counselling in Kenya* (Nairobi: NASCO, 2008), at http://www.who.int/hiv/topics/vct/policy/KenyaGuidelines_Final2009.pdf, accessed 20/05/09; at 16

⁹ Gostin, Lawrence and Mann, Jonathan, ‘Towards the Development of a Human Rights Impact Assessment for the Formulation and Evaluation of Health Policies,’ *Health and Human Rights: An International Journal*, Vol.1, No.1 (1994) pp.59-81, at 59

movement.”¹⁰ However, she points out the systemic problems that may obstruct the provision of adequate healthcare to patients and warns against situations which foment “fruitless antagonism between the aggrieved rights holder and the disempowered duty bearer without recognizing the structural constraints imposed by a health system poorly geared to respond to a human rights demand.”¹¹ Nevertheless, she argues that rights language can provide a platform on which both parties can build a consensus and challenge the State to be accountable for its obligations to provide adequate healthcare.¹²

a) Sources of Human Rights Information

The media- radio, television, newspapers or magazines- emerged as the main source of information on human rights cited by PLWHAs interviewed for this research. Indeed, *The Daily Nation* quoted polls conducted prior to the August 2010 constitution referendum that identified the media as “the most trusted and reliable source of information on the new constitution”¹³, a significant aspect of which, of course, concerned citizens’ rights. The Haki Index surveyed its respondents’ access to media in the seven days prior to interview: radio access was highest (89%), then television (47%), telephone (40%), newspaper (38%), magazines (15%) and the internet (5%).¹⁴

¹⁰ London, Leslie, ‘What is a Human Rights-Based Approach to Health and Does it Matter?’, *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp.65-80, at 69. Laura Turiano and Lanny Smith provide examples of just such an approach by health rights advocates participating in the ‘Tents of Life’ campaign in Paraguay. The report that, “[i]nside the tents, health facility users are presented with information on the services that should be available by law. Paraguay’s constitution guarantees the right to health and health care, but facilities often lack equipment, fail to provide key services, and are not clean. Furthermore, basic services are supposed to be free, but charges are frequently levied that prevent access.” (Turiano, Laura and Smith, Lanny, ‘The Catalytic Synergy of Health and Human Rights: The People’s Health Movement and the Rights to Health and Health Care Campaign,’ *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 137-147, at 140)

¹¹ London (n 10), at 72

¹² *ibid*, at 73

¹³ *The Daily Nation*, ‘Survey Faults Media Over Referendum Coverage,’ (n 13) 24th August 2010

¹⁴ KHRC, *The 2006 Haki Index: Measuring Public Perceptions on the State of Human Rights in Kenya and the Case of the Devolved Public Funds* (n 4), at 117. However, the usage and social, economic and political significance of some of these media, particularly telephones and the internet, is likely to have risen since the survey, not least due to the increase in mobile phone subscriptions. See, for instance, *The Economist*, ‘How a Luxury Item Became a Tool of Global Development,’ 24th September 2009; McGregor, Sarah, ‘Safaricom of Kenya Money-Transfer Users Rise to 61% in July from a Year Ago,’ *Bloomberg News*, 13th August 2010, at <http://www.bloomberg.com/news/2010-08-13/safaricom-of-kenya-money-transfer-users-rise-to-61-in-july-from-year-ago.html>, accessed 30/08/10

The Vice-President lauded the media's role in enabling the public debate over constitutional reform over the years culminating in the August 2010 referendum, urging them to "moderate the peoples' thinking" during the transitional period.¹⁵ However, the media was also criticized for, among other things, biased and/or sensationalist reporting, misinformation, lack of professionalism and susceptibility to "the political propaganda campaigns peddled by politicians,"¹⁶ suggesting that some of the issues cited in 2004 by Maina Kiai, then head of the Kenya National Commission on Human Rights (KNCHR), have not been addressed. He firmly asserted that media legitimacy in these matters had declined over the years due to their preoccupation with political personalities rather than issues of substance.¹⁷

The media's influence in cultivating human rights consciousness is well illustrated by the example of domestic violence cited by respondents such as interviewees 5, who when asked for a sample of a human right she knew laughed and said, "The famous wife-beating!", citing the media as her source of information. Similarly, in a response in which the interviewee almost appeared to perceive human rights as animate rather than inanimate things (discussed shortly), interviewee 42 said: "[I heard about human rights] from the TV, where someone has been caught and punished for nothing so human rights intervene. Sometimes a wife is beaten by her husband and there's a tussle for the children. Again here the human rights come in."

These responses may be explained by the much-publicized coverage in the local media at the end of 2003 of domestic violence issues and wives' rights within marriage, which followed allegations of assault by an MP's spouse. The wife then sought the help of a women's rights organization, Federation of Women Lawyers of Kenya (Fida Kenya).¹⁸ This was part of a wider debate covered by papers like the popular *The Daily Nation*.¹⁹ Some of the coverage accused the MP of being

¹⁵ *The Daily Nation*, 'VP Lauds Media Role in Constitution Making,' 25th August 2010

¹⁶ *The Daily Nation*, 'Survey Faults Media Over Referendum Coverage,' (n 13)

¹⁷ Interview with Maina Kiai, 26th May 2004

¹⁸ See *The Daily Nation*, 'Of Fred Gumo and his Stone Axe,' 6th November 2003

¹⁹ The Haki Index indicates that "[a]lthough newspaper reading is substantially lower than radio listening and television viewing, a majority of readers (89%) had read *The Nation* in the past seven days." (KHRC *The 2006 Haki Index: Measuring Public Perceptions on the State of Human Rights in Kenya and the Case of the Devolved Public Funds* (n 4), at 118)

“primitive”²⁰; some female MPs called upon his supporter and fellow MP, Mr. Gumo, to resign²¹; others alleged that Fida Kenya itself discriminated against male victims of domestic violence²², while others lauded its efforts and decried the lack of support for victims.²³ Interviewee 47, asked about her source on rights information said, “I’ve only heard about when these women go on hunger-strikes!” Although unable to find any media reports of such an event in the twelve months preceding this interview, such strategies by human rights activists are not unknown in Kenya’s recent political history; it is noteworthy, therefore, that this respondent associated such public acts of protest or defiance with human rights. Further, as these actions are often widely reported in the press, it underlines the importance of media coverage of protests or demonstrations which are explicitly linked to human rights in engendering and crystallizing a national consciousness about the kind of issues that human rights are concerned with. This demonstrates the potency of judicial action coupled with an effective media campaign, which would aid the kind of social mobilization required for a greater and lasting impact. Another respondent, interviewee 48, went on to give this answer when asked to list examples of rights she has heard about: “I keep hearing about them, especially when the story of torture at Nyayo House came out and then also there’s something that happened recently that they had gone to intervene. You remember when [the opposition political party] KANU MPs were stopped from attending a meeting recently... so I have been hearing about it but I haven’t been keen. So mainly through the media.” Indeed, the previous month a local newspaper had carried an article in which “Nyayo House torture survivors... urged local well wishers and the international community to steer clear of retired President Moi’s peace institute. ...[T]he torture survivors said it was an ‘open lie’ for the former president to claim that he never knew of torture at the infamous Nyayo chambers.”²⁴

²⁰ Oywaya, Gathoni, ‘Violence Primitive,’ *The Daily Nation* 7th November 2003.

²¹ *The Daily Nation*, ‘Women MPs demand Gumo’s Resignation,’ 8th November 2003.

²² Mutua, Joseph, ‘Fida Should Say Why it Didn’t Help Battered Man,’ *The Daily Nation*, 11th November 2003.

²³ Oriang’, Lucy, ‘Fida Lawyers Not To Blame, Gumo,’ *The Daily Nation*, 7th November 2003)

²⁴ *The Daily Nation* ‘Snub Moi Foundation, Say Activists,’ 1st April 2004. Further, the interviewee may also be referring to the fundraising meeting by MPs of the opposition KANU political party, disbanded by police on 14th May 2004 amidst protests by the local area MP that he had the right to address his constituents. (See *The Daily Nation*, ‘Police Break up Kenyatta Meeting,’ 15th May 2004)

Educational institutions such as universities were another source of human rights information for PLWHAs. Indeed, one interviewee appeared to rank rights awareness alongside formal education as a signifier of advancement: “I heard about it through education. Like me, I am educated. You have to know your human rights although we’re not being taught. Through counselling, for example, about ARVs, you can know your human rights.” (Interviewee 8, who was attending a computer college at the time of the interview.) It was a view reminiscent of the discussion in Chapter 6, in which some respondents associated biomedical knowledge with modernity and the lack of it with backwardness.

Having recognized the importance of schools as an avenue for transmitting human rights information, the KHRC established a schools outreach programme in 2001.²⁵ In 2002, human rights were introduced into the Kenyan school curriculum, with the KHRC working with teachers- the so-called ‘Friends of KHRC’- to develop the relevant materials.²⁶

Another important source of human rights information for the PLWHAs were conferences and seminars or contact with, or membership of, AIDS support groups, as previous chapters have highlighted. Interviewee 11, asked if she had heard about links between the issues of human rights and HIV/AIDS said, “I really don’t know what I’ve heard but there was a time there was a meeting at Kasarani for women and they were talking about that. But I didn’t really follow it up- I was really ill.” She was referring to a conference, also mentioned by other interviewees, on women and HIV/AIDS held in early 2004, which later was later cited as an example of government resource wastage after it closed abruptly a day earlier than advertised at a cost of Ksh. 30 million (approx. GBP230,000) to the taxpayer. (On informing her about the reported amount spent at the meeting, she said, “I wish they had bought the ARVs instead.”)²⁷ Interviewee 41, who received her free ARVs in the MSF programme at

²⁵ See KHRC website at <http://www.khrc.or.ke/subsubsection.asp?ID=11>, accessed 20/05/09.

²⁶ Nyamu-Musembi, Celestine and Musyoki, Samuel, ‘Kenyan Civil Society Perspectives on Rights, Rights-Based Approaches to Development, and Participation,’ *IDS Working Paper 236* (Institute of Development Studies (IDS): Brighton, Sussex, December, 2004), at 16

²⁷ On the Kasarani debacle, see *The Daily Nation*, ‘Abrupt End to Aids Meeting,’ 23rd February 2004. See also *The Daily Nation*, ‘Uproar Over Kibaki Role at Aids Meet,’ 23rd February 2004. In his article, Muriithi Muriuki reported: “An MP caused an uproar when he sought to know why President Kibaki was allowed to preside over a conference in which Ksh30 million of the taxpayers’ money was spent in

MDH, also said she had heard about human rights from that organization. In fact, so closely did some PLWHAs appear to associate rights with organizations and groups, a number of them, such as interviewee 42, cited earlier (in the paragraph following n 17), seemed to define human rights as the people or groups normally associated with rights, perhaps finding this a more concrete way of capturing a concept that seemed otherwise intangible. For instance, in outlining why she thought HIV/AIDS and human rights interconnected, interviewee 48 appeared to equate rights with the organizations that specialized in them, declaring they were not helping PLWHAs:

But what are they doing for us? I have not heard them speaking out on our behalf....
The human rights [emphasis added] are supposed to stand [up] for PLWHAs where people are being discriminated against, denied jobs, where people can't even get drugs, or get shelter, the very basic things. So I think that's the connection.

Indeed, the work of the International Reproductive Rights Research Action Group (IRRRAG) on reproductive rights illustrates the transformative effects of contact between affected communities and local NGOs. Rosalind Petchesky observes that in many of the countries where IRRRAG ran its project, respondents' connections with local organizations, unions or community groups "seemed to make the difference between an implicit sense of entitlement, expressed mainly through actions, and one that is expressly articulated in terms of rights."²⁸ Interviewee 48 for this research, for example, who spontaneously used advocacy terminology such as 'access' when talking about her health needs and those of other PLWHAs, may well have first acquired them from her regular contact with such groups. She described her role thus: "I'm a volunteer... I'm a public educator, I go for seminars, I educate people and I'm paid." Speaking of the inadequacy with which she felt PLWHAs' needs were being catered for she said, "There's also lack of information in Kenya. I keep saying that knowledge is power because if people knew their rights, they would not be taken for a ride. You heard what is happening at Nyumbani Children's Home, kids being tested without their consent and the tests being taken to other countries."²⁹ Many of

questionable manner. Mr Raphael Wanjala (Budalangi, Narc) said the conference was aimed at enriching some individuals."

²⁸ Petchesky, Rosalind, 'Cross-country Comparisons and Political Visions,' in Petchesky, Rosalind and Judd, Karen (eds.), *Negotiating Reproductive Rights: Women's Perspectives Across Countries and Cultures* (London: Zed Books, 1998), at 309

²⁹ However, she appears to be mistaken as to the children's right of consent; she assumes that they would automatically have it, which is unlikely to be the case especially if they are minors; issues regarding permissions and ethical checks would appear to be a matter for the government and the

interviewee 25's responses, cited in previous chapters (such as Chapter 2, in the paragraph after the text containing n 41; and in Chapter 7, in the quotation that follows note 55) also reflected her awareness of, and involvement with, local NGOs. She highlighted in some of her responses key advocacy issues, such as the plight of AIDS orphans, stigma, the dearth of services in rural areas for PLWHAs and misuse of HIV/AIDS funds. That organizations themselves might come to embody human rights for such an interviewee is therefore perhaps unsurprising: after identifying the right to inheritance as an example of human rights, she was asked how she had heard of it: "I even know their offices! I know Catherine Mumma, I know Maina Kiai³⁰ It's the NSSF Building, 9th floor." Further, she revealed that she had sought and received their help following a dispute related to her HIV status, with the response underlining the role of the media in raising awareness about the work of human rights organizations:

Interviewer: How do you know about them, or is it just a personal interest?

Interviewee 25: No. I had a problem with my in-laws and they were stigmatising me and trying to disinherit me after my husband died. So someone directed me to Human Rights-I went to a lawyer who told me first I should go to them. I went and met Catherine and we really talked. I wanted to know more about my rights.

Interviewer: Was it your first contact with a human rights organization?

Interviewee 25: No. I had been reading about them in the papers, I've been so eager to read about them because I really wanted to...especially after I went public [about my HIV-positive status] and I had been attending seminars. I'd been meeting Catherine in seminars- she'd always been invited in seminars for PLWHAs to talk to us about our rights.

Another instance of identifying organizations with the definition of rights can be seen from interviewee 5, who, it will be recalled, mentioned wife-beating as human rights issue (in the text following note 17, above), and thus may well have had the organization Fida Kenya in mind when she described human rights thus: "These are people who give us a green-light on what our rights as human beings in Africa are. You see, there are people who are very inhuman to others- they do funny things and you don't know that if this guy did this to me, that is inhuman. So, at least, they have been giving us a green-light on our rights as human beings." Interviewee 6 was even more explicit in his association of rights with the organizations that champion them. He declared, "I've heard about human rights, when they are making noise to the

children's home's board of directors, the latter of whom claimed (in the second of the reports above) not to have "consented to any Aids research on children under its care."

³⁰ Both Catherine Mumma and Maina Kiai worked at the Kenya National Commission on Human Rights at the time, with Kiai serving as director.

police. So I know if I were to be arrested, I will call the human rights! If there is any other job they have to do, I'm sorry but that I do not know." I asked him a further question for clarification:

Interviewer: So when you think about human rights, what is the first idea that comes to your mind?

Interviewee 5: It is like I've said- that when I am arrested without fault and taken to a police station, I have to call the human rights people. Because that is the area where I've been hearing them making noise and assisting.

In retrospect, of course, the very fact that his definition was linked to rights organization was telling, as is argued here. Interviewee 40, asked to mention examples of human rights said: "Like WOFAK, aren't they like human rights? I don't know." Interviewee 48, discussed above, also defined human rights by saying, "They are supposed to fight for our rights." When asked to explain who 'they' are she said: "The human rights people." Here again it seems that media publicity helps cement these organizations' identity in the mind of some respondents as human rights made flesh.

It may be that meanings of human rights have become fused with the groups and people that are seen to represent them, and Upendra Baxi points out that, "more often than not, we think of human rights praxis in terms of social movements."³¹ The respondents' comments above may be a further reflection of the dominance of human rights organizations and professionals in the public debate about rights, so that its concepts and ideas become associated with those who are perceived to own the discourse. As such, they might be seen as the outcome of a failure to fully inculcate a more participatory approach to human rights advocacy that focuses on capacity-building for communities, to enable them to conduct these functions themselves. And, as noted by one official for the organization Centre for Governance and Development (CDG), interviewed by Nyamu-Musembi and Musyoki for their study on RBAs, this amplifies the potential for creating dependency on these organizations.³²

b) Conceptions about the Meaning of Rights: A Preliminary Overview

³¹ Baxi, Upendra, 'Voices of Suffering and the Future of Human Rights,' *Transnational Law and Contemporary Problems*, Vol.8, No. 2 (1998), pp.125-169, at 155

³² Nyamu-Musembi and Musyoki (n 25), at 15

Despite the dearth of 'text book' definitions of human rights, as noted in Chapter 1, PLWHAs nevertheless communicated ideas of legal or moral obligations owed to the individual. These were broadly based on two notions familiar to students of human rights: firstly, that certain obligations were owed to them by a range of actors because they (PLWHAs) were *human*; secondly, that the State owed them certain obligations because they were *citizens*. A deeper theoretical analysis of these and a third theme, dignity, to which they are closely allied, will come shortly. For now it is useful to review how interviewees appeared to weave these ideas into their definition and examples of rights, as well as their perceptions about the nexus between HIV/AIDS, health and entitlements.

For some respondents, the concept of human rights and what it means to be a human being was broad, bound up with ideas about needs or wants, and crucially, equality. They defined human rights variously as, "anything about your life, anything that falls under that,"³³ and "something which involves law... What you can demand: literally, the right of somebody."³⁴ Some explicitly cited the government as part of the rights equation, hinting at an underlying antagonism between individual and State: "It means that everyone has their rights and it is for the government to listen to the rights of a person."³⁵ This association of the phrase with the mechanisms of State may alienate many people, who as Petchesky notes,

consistently experience the authorities charged with enforcing rights (police, government officials, hospital and clinic personnel) as oppressive, corrupt and routinely ready to disregard national laws and international principles, or even common decency. As a result, they view formally constituted rights as inapplicable to them, particularly if they are poor and female.³⁶

Indeed, the name of the disgraced former head of the National AIDS Control Council (NACC), Margaret Gachara, came up in a number of interviews: for instance, interviewee 30 was alluding to her when responding to the question of whether the government might be able to provide for healthcare needs: "I don't know. I think human beings are not trustworthy. Like that lady who was put in prison recently who has eaten millions that have been given by donors from abroad."

³³ Interviewee 4

³⁴ Interviewee 3

³⁵ Interviewee 24

³⁶ Petchesky, Rosalind, 'Introduction,' in Petchesky and Judd (eds.) (n 28), at 11

This mistrust of State agents or institutions may also explain the views of interviewee 28, who declared that though it was familiar, the phrase human rights, “means nothing, because I found out about my illness and I depend on myself to keep myself healthy and on praying to God to help me.”³⁷ Another respondent saw rights as a buffer, perhaps against excesses by the State, defining them as, “...what is really yours, or what you are supposed to have... or the type of protection you’re supposed to get, or the security.”³⁸ Yet there is a fascinating paradox in this: the very human rights from which she claims protection from the State also establish and entrench the power of State, declaring it sovereign and with a will as free as that of the subject it brings to life.³⁹

For one respondent, “[human rights] means that for [us] humans there are some rights which are supposed to be given to us.”⁴⁰ Interestingly, her starting point, it seemed, was of lacking rights, then getting them possibly by means of a struggle, thus anticipating Douzinas’s comment that “[g]overnments are the enemy against whom human rights were conceived as a defence.”⁴¹ Yet, as Turiano and Smith emphasize, the concepts of claim-holders and duty-bearers in human rights theory were designed precisely to eradicate the notion of people with an inferior status asking others with a more superior one to grant them things.⁴² Critically, this interviewee appears to have based her claims of entitlement on the fact that she is a human being. Another separated the term ‘human rights’ into its two component words to arrive at an answer: “‘Human’- that means a person, and ‘rights’ is... I think it means the needs of a human being.”⁴³ The issue of needs was emphasized elsewhere: “[Human rights] take care of our needs, don’t they?”⁴⁴, while another respondent stressed the issue of human compassion in her definition: “Human rights is like being concerned about

³⁷ She later revealed that she relied on herself and her family for her health needs and she felt that local government officials could not help her, although NGOs and the government might; however she did not know how.

³⁸ Interviewee 11

³⁹ Douzinas, Costas, *The End of Human Rights: Critical Thought at the Turn of the Century* (Oxford: Hart, 2000), at 101

⁴⁰ Interviewee 10

⁴¹ Douzinas (n 39), at 119

⁴² Turiano and Smith (n 10), at 144

⁴³ Interviewee 40

⁴⁴ Interviewee 47

others....”⁴⁵ However, some commentators advocate a move beyond the notion of compassion, asserting that it is “notoriously unstable and, historically, reliance on it has ill-served the interests of the oppressed” particularly during economic downturns, urging instead the creation of obligations based on something more substantial such as clearly articulated law.⁴⁶

As seen in Chapter 1’s discussion on a conceptualization of rights, several respondents appeared to be influenced by religious norms in the construction of their moral frameworks by linking notions of entitlements and rights with religion, thus echoing ideas by natural law theorists. Interview 16, for instance, integrated within her response an impressive array of examples of rights saying, “Well, it’s basically... like God has commandments, so you don’t break those commandments. We have rights- like, a child within a family has rights, they should have rights to food, medication, they shouldn’t be exposed to child labour- that kind of thing.” As seen in Chapter 1, the references to deism as the moral foundation for human rights may be unfashionable today, and, indeed, by the time the UDHR came into being “secular humanism” this staple of 18th Century legal thinking had been supplanted. However, commentators like Sir Hersch Lauterpacht draw attention to the continued influence of natural law on modern international law⁴⁷, while others like Douzinas problematize the gutting of the moral imagination from the legal jurisprudence of human rights.⁴⁸ Away from the theoretical realm and in the real world, moreover, Michael J. Perry emphasizes that the moral, religious and metaphysical remain intimately connected.⁴⁹ Thus the linkages made by the interviewees’ who compared human rights and religious norms are understandable, especially in a society like Kenya’s where religion and cultural tradition dominate social life and are the primary moral

⁴⁵ Interviewee 2

⁴⁶ Ely Yamin, Alicia, ‘Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health,’ *Health and Human Rights: An International Journal*, Vol. 10, No. 2 (2008), pp. 1-20, at 1

⁴⁷ Marks, Stephen P., ‘From the Single Confused Page to the Decalogue for Six Billion Persons: The Roots of the Universal Declaration of Human Rights in the French Revolution,’ *Human Rights Quarterly*, Vol. 20, No. 3 (1998), pp. 459-514, at 474-5. See also Shestack, Jerome J., ‘The Philosophic Foundations of Human Rights,’ *Human Rights Quarterly*, Vol. 20, No. 3 (1998), pp. 201-234

⁴⁸ Douzinas (n 39), at 373-4

⁴⁹ Perry, Michael, J., ‘Morality and Normativity,’ *Legal Theory*, Vol. 13, No.3-4 (2007), pp 211-255, at 242

languages by which people envision matters of duty and entitlement.⁵⁰ The multitudes who profess these beliefs might view them as the most obvious, perhaps trustworthy, least corruptible standards for moderating human behaviour and relationships, and there is, conceivably, an unarticulated aspiration in these comparisons that even in a country where the State is notorious for violating the rule of law with impunity, manmade norms- and the (State) institutions on which they are founded- may yet attain the unimpeachable standards attributed to religious ones. However, Baxi rightly questions the effectiveness of the moral language of rights to fulfil such aspirations, noting a number of issues already raised by other commentators cited in this research: these include, the limited participatory opportunities for those at the grassroots, the exclusivity of human rights practice and the contestations of power that underlie rights and their social movements. These, he argues, inhibit their “their potential for reflexive ethical action,” and mean that more established normative systems, with their own attendant problems, will remain relevant.⁵¹

For one respondent, ‘human rights’ meant “that every human being should be given his right.”⁵² Another thought perceived them as “the right of human beings, the way a human being deserves to be treated, whoever they may be.”⁵³ Interviewee 21 attached to his definition a proprietary notion of rights and underlined this in an example: “[Rights are what] I deserve. Like this walking stick of mine, I have the right to pick it up from where I have placed it, you see? Because it’s mine.” This strong sense of entitlement was echoed elsewhere: “For me it means that what I am entitled to have I should have and I should not be denied.”⁵⁴ Yet another interviewee pre-empted the unease which became clearer in later questions about the extent to which individuals may make claims against the spectre of the State: for him, the individual did not appear inherently bestowed with human rights; rather “they are the rights that someone should to be given.”⁵⁵

⁵⁰ See Baxi (n 31), at 131

⁵¹ *ibid*, at 140 and 141

⁵² Interviewee 37

⁵³ Interviewee 42

⁵⁴ Interviewee 44

⁵⁵ Interviewee 26

A number of respondents also appeared to link their definitions of rights with the notion that their status as PLWHAs did not negate their claims of entitlement, explicitly mentioning issues like stigma and discrimination in access to social goods and underlining the notion of equality with other human beings. Interviewee 31, for instance averred: “I believe everyone has a right to live, whether you are positive or negative, you have your rights to live and be free in the world,” listing as examples of rights “equal opportunities in employment, health.” For interviewee 46, “Someone who is sick has the right to live like others; if it is going to job, he has to go.” For interviewee 9, human rights were “my rights. For example, I have the right to get free medication...” Meanwhile, interviewee 29 announced that, “‘Human rights’ means that... we can have our own rights so that we can speak up for ourselves; for example, if it is trying to get these drugs, we should not have our path blocked just because we are HIV-positive. You know, even HIV-positive people have their rights.” Interviewee 20 used an example of a right as part of her definition: “It means the way one person might live free of stigma. Like I was stigmatized at my workplace- it is not good to have someone stigmatize you because you’re a PLWHA. It’s good for people to care for PLWHAs and not stigmatize them. Stigma and discrimination are not human rights.”

All the ideas raised by PLWHAs above are reflected in the Haki Index, which categorized the definition of human rights offered by 26% of its respondents (the greatest proportion) as pertaining to things “that a human being is entitled to.” Another 6% of respondents thought of human rights as “human needs and fulfilments,”; 4% defined them as “the things deserved for a better life,”; another 4% related the meaning to “equality between human beings,”; “anything I need is readily available,” (2%); and finally, “the thing you would like to be done to you,” (1%).⁵⁶

The second key idea which PLWHAs seemed to link to human rights and their entitlements was citizenship. It also featured in the Haki Index where the link between marginality and rights awareness was reaffirmed: 31% of respondents in NEP, with its large number of refugees and internally displaced persons,

⁵⁶ KHRC, *The 2006 Haki Index: Measuring Public Perceptions on the State of Human Rights in Kenya and the Case of the Devolved Public Funds* (n 4), at 19

spontaneously listed nationality or citizenship as a right. This was more than twice the next highest figure.⁵⁷ Among the respondents for this research, interviewee 14 said the phrase human rights meant “[J]ust what I feel is my right, my justified right as a citizen,” adding elsewhere that “I think every citizen has a right to healthcare.” Another respondent offered examples of rights he knew and qualified his entitlement to them by his claim to citizenship: “... [R]ight to work, right to move wherever I want, so long as I am a Kenyan citizen.”⁵⁸ Some respondents, like interviewee 18, explicitly based their healthcare claims on the government on their Kenyan citizenship, perceiving the State/citizen, parent/child relationships as analogous:

[T]hat is the responsibility of the government. It should look into that. We are citizens and they cannot just discard us, just like a parent would not discard their own child. They should look into the plight of those who cannot afford to pay for the drugs because it is not their wish to have this disease.

This view has been mentioned elsewhere in Chapter 6 and was echoed by other respondents: “I think after my parents, the other person I expect to help me is my government,” said interviewee 6. “This is another parent of mine, parent [number] two.” It is not unusual given Kenya’s prevailing paternalistic culture but it raises interesting questions about the power of resistance implied by such a notion if and when that protection by “parent number two” mutates into oppression. These issues will be addressed shortly.

For others, the government had a duty to meet the health needs of all its citizens, but particularly if they were poor:

It is [the government’s] responsibility to take care of all its citizens regardless of whether they’re rich or poor. If they can’t take care of themselves, the government should. I don’t have to strive to look after my health or my security. It should be the government which should ensure that all these services are met. (Interviewee 13).

Another respondent, interviewee 25, looked to human rights to equalize the benefits of citizenship: linking HIV/AIDS to human rights she said, “Before this issue of HIV/AIDS became an open secret, people were being sacked from their jobs, being stigmatised, being disinherited. But when human rights come in, regardless of your status, they say you have a right. I think human rights are very helpful to us PLWHAS

⁵⁷ *ibid*, at 21

⁵⁸ Interviewee 26

because we have been treated like 2nd class citizens but when human rights came in, we came to know that we have equal rights.”

c) Examples of Rights

When asked to provide examples of rights, most interviewees revealed an awareness of what human rights text books broadly define as civil and political rights, the so-called ‘negative’ or “first generation or ‘blue’ rights”⁵⁹, which at the inception of the rights movement were imagined to require only the State’s restraint from interfering with the rights of its citizens⁶⁰, and were linked with the liberal ideals of individual freedom.⁶¹ These rights were considered “‘absolute’ and ‘immediate’”⁶² whereas economic, social and cultural (ESC), “second generation or ‘red’” rights⁶³ were “programmatically, to be realized gradually, and therefore not a matter of rights.”⁶⁴ As noted elsewhere, the examples cited by PLWHAs were particularly concerned with issues of stigma and discrimination and equality. Non-discrimination is central to the health rights laid out in the WHO Constitution and is re-emphasized in numerous human rights instruments, including the Convention on the Elimination of All Forms of Racial Discrimination (CERD, Article 5(e)(iv)), and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW, Article 11(1)(f)).⁶⁵ Interviewee 18, for instance, felt it was “the right of every human being to be treated equally,” and said she had heard it from the Kenyan president. The Haki Index reinforces the view that respondents’ identity as PLWHAs influenced awareness of certain rights: it notes with dismay the low ranking accorded to the “right against discrimination for people living with HIV/AIDS regardless of the campaigns that have

⁵⁹ Douzinas (n 39), at 115

⁶⁰ Steiner, Henry J. and Alston, Philip, *International Human Rights in Context: Law, Politics, Morals* (2nd Edition, Oxford: Oxford University Press, 2000) at 181

⁶¹ Douzinas (n 39), at 115

⁶² Eide, Asbjørn, ‘Economic, Social and Cultural Rights as Human Rights,’ in Eide, Asbjørn; Krause, Catarina and Rosas, Allan (eds.), *Economic, Social, and Cultural Rights: A Textbook* (2nd Revised Ed., Dordrecht; Boston: Martinus Nijhoff Publishers, 2001), at 10

⁶³ Douzinas (n 39), at 115

⁶⁴ Eide, ‘Economic, Social and Cultural Rights as Human Rights,’ (n 62), at 10. For a summary of the history of ESC rights and the right to health in particular, see Kirby, Michael, ‘The Rights to Health Fifty Years On: Still Sceptical?’, *Health and Human Rights: An International Journal*, Vol.4, No. 1(1999), pp. 6-25

⁶⁵ Leary, Virginia, ‘The Right to Health in International Human Rights Law,’ *Health and Human Rights: An International Journal*, Vol.1, No. 1, 24-56, at 33

been carried out in the country on this issue.”⁶⁶ When they are asked to rank the list of rights provided, only 1% of the Haki survey respondents thought this right as the first, second or third most-important.⁶⁷

There were other examples of human rights from the respondents of this research: some linked them with “torture, when people are arrested, such basic things.”⁶⁸ Indeed, protection from torture was mentioned spontaneously by 7% of the Haki Index respondents. Allegations of this violation were widely reported in the media- to be sure, interviewee 39 above explicitly cited it as his source- particularly during the latter days and aftermath of the Moi regime.⁶⁹ Interviewee 11 meanwhile associated rights with issues around child abuse and women’s rights.

Some respondents’ catalogue of rights consisted almost entirely of ESC rights: “The right to education, right to healthcare, right to clothing, right to eat!”⁷⁰ Others included a right to inheritance⁷¹; free medication⁷²; and rights for the disabled.⁷³ Interviewee 29 stressed that she had rights pertaining to sexual interactions with her husband:

For example, it is a woman’s right to insist that her husband uses a condom. If he doesn’t want to then he should leave me alone. Some of them refuse and threaten to beat up their wives or chase them away from the home. A lot of women I speak to complain about this. This is not right and there should be a law to stop this so that women can be protected.

Interviewee 41, meanwhile, had heard of “the right to get treatment” after attending a human rights workshop. Her response and that of interviewee 13 are particularly interesting: as will be seen later, rarely did interviewees spontaneously mention an

⁶⁶ KHRC, *The 2006 Haki Index: Measuring Public Perceptions on the State of Human Rights in Kenya and the Case of the Devolved Public Funds* (n 4), at 25

⁶⁷ *Ibid*, at 24

⁶⁸ Interviewee 39

⁶⁹ See, for instance, proceedings by victims of the Moi regime’s demanding compensation for alleged torture. (*The Daily Nation*, ‘Date Set for Ruling in Nyayo Torture Case,’ 5th November 2009.)

⁷⁰ Interviewee 13; see also interviewee 16, mentioned elsewhere. Interviewee 34’s list is near-identical and concerns, “free education, free medication, people without food.”

⁷¹ Interviewee 2

⁷² Interviewee 9

⁷³ Interviewee 10 linked rights to the needs of the disabled: “...The other day I heard that handicapped people also wanted the government to look upon them and enlighten them on this HIV problem.” She may have been referring to reports in the news on lobbying by organizations for the audio- and visually-impaired for services that cater to their special needs (See, for example, *The Daily Nation*, ‘Inside a VCT Centre for the Deaf,’ 7th April 2004)

actual right to health or healthcare as examples, although when questioned about the links between health and rights nearly half would later claim to have heard of such a right.

ESC rights were widely regarded as 'positive' rights obliging affirmative action from the State.⁷⁴ It is perhaps unhelpful to sustain the Cold War-inspired dichotomy of civil and political versus ESC rights⁷⁵, especially given the emphasis on the indivisibility of rights.⁷⁶ Many commentators acknowledge the dominance of this classification but denounce such categories as superficial and indiscrete.⁷⁷ Indeed, health is one the areas where both these species of rights heavily intersect.⁷⁸ The interviewees were unaware of, or made no such distinctions, listing a range of needs and requirements such as water, sanitation and shelter, all health determinants that straddle these categories. Nevertheless, this dichotomy serves a purpose in the analysis of interviewees' responses, because it suggests that issues often associated with the first category receive wider media coverage, the interviewees' primary source of rights information. Because, and perhaps as a result of this they attract the most attention from campaigners and activists. Indeed, Kiai suggested that lack of understanding about ECS rights by local and international media may have led them to overlook or underplay this dimension during their reporting of certain events and campaigns, thus denying these rights much-needed publicity.

⁷⁴ Steiner and Alston (n 60), at 181

⁷⁵ Petchesky, Rosalind P., 'Rights and Needs: Rethinking the Connections in Debates over Reproductive and Sexual Rights,' *Health and Human Rights: An International Journal*, Vol. 4 No. 2 (2000), pp.17-29, at 20

⁷⁶ See for instance Office of the United Nations High Commissioner for Human Rights (OHCHR), *Vienna Declaration and Programme of Action*, Adopted by the World Conference on Human Rights in Vienna on 25th June 1993, at <http://www2.ohchr.org/english/law/pdf/vienna.pdf>, accessed 14/03/09; Art. 5.

⁷⁷ Steiner and Alston (n 60), at 136. See also Heywood, Mark and Altman, Dennis, 'Confronting AIDS: Human Rights, Law, and Social Transformation,' *Health and Human Rights: An International Journal*, Vol.5, No.1 (2000), pp.149-179, at 169; Feria Tinta, Monica, 'Justiciability of Economic, Social and Cultural Rights in the Inter-American System of Protection of Human Rights: Beyond Traditional Paradigm and Notions,' *Human Rights Quarterly*, Vol.29, No. 2 (2007), pp.431-459; Nickel, James, 'Rethinking Indivisibility: Towards A Theory of Supporting Relations Between Human Rights,' *Human Rights Quarterly*, Vol. 30, No.4 (2008), pp. 984-1001

⁷⁸ Mhloyi, Marvellous, 'Health and Human Rights: An International Crusade,' *Health and Human Rights: An International Journal*, Vol.1, No.2 (1995), pp. 125-127, at 125. However, commentators like Halabi, have been keen to warn against the oversimplification of such a notion, pointing out, in relation to the link between the right to participation as a political right and as an aspect of the right to health, an example from Indonesia: here the decentralization of political authority as a means for boosting political participation has not resulted in improved health outcomes, or indeed the political participation of the marginalized. (See Halabi, Sam Foster, 'Participation and the Right to Health: Lessons From Indonesia,' *Health and Human Rights: An International Journal*, Vol. 11, No. 1 (2009), pp. 49-59)

In Kenya the imbalance may also be a consequence of the much publicized political turmoil of the early 1990s, and even today reports of the ongoing debate about possible war crimes committed during the post-election violence of 2007/8 and the role of the International Criminal Court will be similarly influential in further informing people about these issues.⁷⁹ Yet the fact that these events occur against the background of a long and unbroken history of socio-economic problems has arguably failed to promote ESC rights awareness in the same way, although the Haki Index suggests things may be changing.⁸⁰ In his interview with this author, Kiai, who co-founded and headed the KHRC during the turbulent early 1990s, argued that it was unfair to categorize the organization's work as purely focused on civil and political rights and insisted that the organization could gain little legitimacy by adopting such an approach. He noted the cross-cutting elements of their early programme, citing their campaigns on land rights for those disenfranchised by the ethnic clashes of that period and famine relief (in association with the Catholic Church) in drought-stricken northern Kenya. But he also admitted early capacity deficiencies, noting that with civil and political rights issues being its main competence, the organization, inevitably, tended to "do what they [knew] best."⁸¹

It should indeed be a cause for concern for human rights organizations that despite clearly articulating many ESC-related needs, few respondents were aware that most are covered by rights guaranteed under international law.⁸² Few national human

⁷⁹These have received wide coverage in a range of media, including the electronic. See reports from *The Daily Nation* such as: 'Kenya Post-Poll Case Set for ICC,' 5th November 2009, the online version of which gives readers an opportunity to comment publicly on the articles and the news. See also Chapter 2, note 4.

⁸⁰The 2006 survey revealed that there was a lower spontaneous awareness of all civil and political rights, bar freedom of worship, than in the previous year. By contrast, there was a generally higher number of spontaneous awareness amongst respondents of socio-economic rights in 2006 than in the previous year. When the survey respondents were asked to prioritize a number of rights read out to them, at least 3 of the top 5 may be strictly classified as socio-economic ones, with the right to life topping the list, then education, food, security and "good health." (KHRC, *The 2006 Haki Index: Measuring Public Perceptions on the State of Human Rights in Kenya and the Case of the Devolved Public Funds* (n 4), at 25)

⁸¹ Interview with Maina Kiai, 26th May 2004

⁸² This does not mean that PLWHAs do not want to civil and political rights but suggest that their most immediate needs are of socio-economic nature. Paul Farmer makes a similar observation citing his work over a decade ago with a group called Partners in Health which motivated a rethink in approach: "...[A]lthough those we served ardently desired civil and political rights, they spoke more often of social and economic rights." (Farmer, Paul, 'Challenging Orthodoxies: The Road Ahead for Health and Human Rights,' *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp.5-19, at 5)

rights institutions, for instance, are involved in ESC rights work, even fewer on health⁸³, and CSOs have generally have been accused of a reluctance to develop strategies to promote ESC rights.⁸⁴ One reason for this may be that the most influential human rights organizations which might spearhead the fight are based in, and rely on funding from, the wealthier global North⁸⁵, where the agenda may prioritize civil and political over ESC rights.⁸⁶ Some commentators highlight a geopolitical divide in the emphasis and promotion of ESC rights, with a Northern emphasis on civil and political rights while the poorer South stresses the importance of ESC ones.⁸⁷ Per this critique, the globalization of the human rights enterprise and CSO activism on its behalf has not translated to a similarly geopolitically transcendent agenda. Further, the integration of ESC rights has been criticised by some as diluting the UDHR and “considerably [reducing] the impact of Western ideals by securing approval for some fundamental postulates of the Marxist ideology”, and condemned as “a letter to Santa Claus”.⁸⁸ But the idea that developed countries denigrate ESC rights has been dismissed elsewhere as a myth.⁸⁹ It is pointed out that the original drafters from these countries recognized that the UDHR needed to address the socio-economic deprivations which had significantly contributed to the rise of totalitarian regimes in the interwar period.⁹⁰ Nevertheless, the philosophical debates persists about the validity of ESC and other categories of rights⁹¹, namely, the “third generation or ‘green’ rights” that guarantee self-determination, group and (recently)

⁸³ Ely Yamin, ‘Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health,’ (n 46), at 5

⁸⁴ Heywood and Altman (n 77), at 168

⁸⁵ Odinkalu (n 3).

⁸⁶ Paul Farmer accuses a wide range of stakeholders of shying away from the difficult topic of resource redistribution which is a crucial component in addressing socio-economic problems, from NGOs to human rights organizations and university researchers. (Farmer (n 82), at 10)

⁸⁷ See for instance Douzinas, *op. cit.*, at 124. See also Nyamu-Musembi, Celestine and Cornwall, Andrea, ‘What is the ‘Rights-Based Approach’ All About? Perspectives from International Development Agencies,’ *IDS Working Paper 234* (Institute of Development Studies (IDS): Brighton, Sussex, November, 2004), at 9

⁸⁸ The first description is Antonio Cassese’s, the second by the former US president Ronald Reagan administration’s representative to the UN. Both are quoted in Douzinas (n 39), at 123

⁸⁹ See Whelan, Daniel J. and Donnelly, Jack, ‘The West, Economic and Social Rights and the Global Human Rights Regime: Setting the Record Straight,’ *Human Rights Quarterly*, Vol.29, No.4 (2007), pp. 908-949

⁹⁰ Eide (n 62), at 16

⁹¹ See Odinkalu’s rejection of this position in Odinkalu, Chidi Anselm, ‘Implementing Economic, Social and Cultural Rights Under the African Charter on Human and Peoples’ Rights,’ in Evans, Malcolm and Murray, Rachel (eds.), *The African Charter on Human and Peoples’ Rights: The System in Practice, 1986-2000* (Cambridge: Cambridge University Press, 2002) 181-2

environmental rights⁹², leading to questions about the slippage from needs to rights characteristic of post-War period and the possible ‘overproduction’ of rights.⁹³ The right to development, too, has proved contentious⁹⁴, even as others argue that it might provide the appropriate framework in which to address the multiple aspects of health.⁹⁵ Kenneth Roth sidesteps the philosophical quandaries about whether ESC rights are rights at all and hangs the legitimacy of his (Human Rights Watch) and similar organizations’ work on the hook of positive law.⁹⁶ And, as Steiner and Alston underline, rights are dynamic, their content expanding or contracting over time.⁹⁷ This is reflected in the increased advocacy that ESC rights now attracts from organizations like Amnesty International, whose work has previously focused on the promotion of civil and political rights.⁹⁸ Rubenstein argues that at a minimum such groups should use their credibility to find innovative ways to promote the acceptance of ESC issues such as healthcare as matters of right.⁹⁹

d) Perceptions about Links Between HIV, Health and Human Rights

Most interviewees had heard of, or appeared to see a connection between HIV/AIDS and human rights. Interviewee 17 observed simply: “Because even though I’m HIV-positive, I’m still a human being, so I also have my rights. I think that’s the link.” It is hard not to hear in this echoes of Seckinelgin’s observation on the globalization of HIV/AIDS activism “spilling over national borders”, quoted in Chapter 7 (quote preceding note 20). For many, this nexus was founded on concerns about stigma and discrimination, one of the primary reasons behind the WHO’s integration of human

⁹² Douzinas (n 39), at 115

⁹³ See, for instance, Baxi (n 31), at 139-141

⁹⁴ See Noam Chomsky’s quote (reproduced in Douzinas (n 39), at 115) of the US Ambassador Morris Abrams in his address to the UN Commission on Human Rights, who referred to this right as “‘a dangerous incitement’ and ‘little more than an empty vessel into which vague hopes and inchoate expectations can be poured.’” See also Nyamu-Musembi and Cornwall (n 87), at 8-9

⁹⁵ Meier, Benjamin Mason and Fox, Ashley M., ‘Development as Health: Employing the Collective Right to Development to Achieve the Goals of the Individual Right to Health,’ *Human Rights Quarterly*, Vol. 30, No. 2 (2008), pp.259-355

⁹⁶ Roth, Kenneth, ‘Defending Economic Social and Cultural Rights: Practical Issues Faced by an International Human Rights Organization,’ *Human Rights Quarterly*, Vol. 26, No.1 (2004), pp. 63-73, at 64

⁹⁷ Steiner and Alston (n 60), at 181

⁹⁸ Rubenstein, Leonard S., ‘How International Human Rights Organizations Can Advance Economic, Social, and Cultural Rights: A Response to Kenneth Roth,’ *Human Rights Quarterly*, Vol. 26, No.4 (2004), pp.845-865, at 846. See also Ely Yamin, Alicia, ‘Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care,’ *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 45-63, at 52

⁹⁹ Rubenstein (n 98), at 847

rights into its original Global Strategy.¹⁰⁰ For interviewee 3, the connection lay in the fact that anyone could contract HIV and so suffer discrimination. He said:

Like me, I'm HIV-positive. That doesn't mean I should be denied unemployment because I'm [HIV-] positive. I should not be discarded from the community because I'm HIV-positive. I should not be discriminated against. I have the right to be respected, to be offered help because of my being HIV-positive, because even I myself would not mean to be HIV-positive. It's accidental and it's a disease. It can happen to anybody. So if someone is still negative, don't think that there are some specific people who are supposed to be positive and there's a group who are supposed to be negative. So the human rights still have to be maintained.

Other respondents highlighted the issue of stigma at home or in the local community: Interviewees 20 and 5 are an example here, but they had different experiences to share. The former reported a positive experience after revealing her sero-status to her children: "I think PLWHAs are just like anyone else and so it's not good to stigmatize or discriminate against them. ... I'm a mother of 3. My children know my status and love me still and call me mother." However, interviewee 5's was less so and she was weary of the how the children of known PLWHAs might suffer. She said:

HIV and human rights... are connected, because like this idea of stigma and discrimination: you see, the human rights people want every human to have his rights, without discrimination and without stigma. And you find that most of us who are positive what usually happens, like may be if you're sharing a toilet in the plot, people start saying, 'you'll give us this disease', 'you'll infect us'- sometimes they don't even want to see your children- they discriminate. You see such like things. You see if they had kids, they were playing together and now they say, 'don't go and play with so-and-so; you'll be infected'. So there's a lot of stigma and discrimination. And you see I think those are some of the things that the human rights is against so they have to be connected so that they teach people that you're supposed to stay like this, whether you're infected or you're not infected.

Several also raised concerns about employment discrimination or prejudice in the workplace. Linking HIV/AIDS to human rights, interviewee 21 said: "They should not discriminate, for example, that if you have the virus you cannot get employment for the job that you able to do. Or if people are in a meeting, you are put separately from them, or when it comes to eating during celebrations, you are put separately from

¹⁰⁰ Tarantola, Daniel, 'The Shifting HIV/AIDS Paradigm: Twenty Years and Counting,' *Health and Human Rights: An International Journal*, Vol.5, No. 1 (2000), pp.1-6, at 1-2. Interviewee 1 said: "I haven't heard [about the link between HIV/AIDS and human rights], but there's discrimination, there's stigma.... It's really affecting humans so it's related."

other people.” Links were also made between HIV and rights in relation to the care of AIDS orphans.¹⁰¹

But one respondent, despite her unease about discrimination and ill-treatment of PLWHAs, confessed that she did not concern herself much with human rights issues, perhaps because of her declared scepticism about the usefulness of purely nominal rights which could not be realized:

Somehow I don't really bother [about rights] but sometimes I have heard things like, [PLWHAs]are denied jobs, sometimes they are fired, I don't know if it's still happening- this kind of discrimination everywhere. Like the other time some kids were being discriminated in a school and I felt very pained. Now there's this insurance thing- there's discrimination. It's like once you are HIV-positive your life is cut out and at the same time they are telling us to live positively and move on. So where do we belong? That's what I have heard about human rights and AIDS. So I think there's a relationship. With the scourge of AIDS, there's that relationship that the AIDS victims are being denied some of their rights and they really have to fight.” (Interviewee 14)¹⁰²

Discriminatory practices by medical insurers and the banking industry were also highlighted elsewhere. Interviewee 16, for instance, raised both these matters: of the latter she said:

Well, when we go for post-test therapy- like this weekend- we were arguing about the HIV people who want to get a loan from the bank who are told they can't take so much money because they don't know if you're going to die before you pay off the amount of money. So that's discrimination. And in any case, who says those who are negative have a guarantee that they won't be hit by a bus immediately after they're given the money, you know? I have accepted my status and I am planning to go into high-schools and educate people who are HIV negative about this so they remain negative. I don't want them to be in my shoes because these shoes are very tight!

¹⁰¹ For instance, interviewee 41 said: “I am ill, and I would like for my children to be looked after even when I am not here; isn't that the relationship [between HIV/AIDS and human rights]?”

¹⁰² The reference to discrimination against schoolchildren likely relates to a story that broke in early January 2004, in which some schools in Nairobi were alleged to have denied some HIV-positive and other orphans from Nyumbani Children's Home places, ostensibly for spurious, bureaucratic reasons such as a lack of birth certificates, etc. This matter was later settled out of court after stringent public denials from the schools and education boards. (See *The Daily Nation*, 'End Bias Against Children,' 8th January 2004). Her reference to discrimination in the insurance industry is also likely to be linked to reports about insurance companies refusing to provide medical insurance to PLWHAs (see *The Daily Nation*, 'Insurers Told to Give Cover to Aids Patients,' 23rd June 2003). Some of the companies threatened to abandon their life insurance policies in response to government plans that would require insurers to provide unconditional life and medical insurance to PLWHAs (see *The Daily Nation*, 'Aids Clause in Draft Bill Tests Insurance Industry Unity,' 18th May 2004.) It is now illegal for insurers and health service providers to discriminate against HIV sufferers. See Sec. 19 ('Access to Healthcare Services') of the HIV and AIDS Prevention and Control Act 2006, Kenya Law Reports, 'Laws of Kenya,' at www.kenyalaw.org, accessed 12/12/10. One of the envisioned changes in the National Hospital Insurance Fund (NHIF) scheme includes doing away with the requirement of medical check-ups for the insured, which have proved a barrier for PLWHAs. (See *The Daily Nation*, 'What Health Scheme Means to the Excluded,' 21st August 2010)

For interviewee 47, the benefits of a right to healthcare involved equal treatment for PLWHAs by health insurance firms. She complained: “[T]hese medical cover companies, like AAR, they never cover us....The practical benefit would be like letting people like these medical cover firms know we’re all human beings and just like other diseases like diabetes, we also need cover. We also need proper treatment.”

But for interviewee 13, for whom HIV/AIDS and human rights were “inseparable”, there was a deeper link: exemplifying the connections discussed in Chapters 6 and 7 between rights language, subjectivity and participation, he asserted: “Human rights give us the right to speak, it offers us a platform to express ourselves.” Another respondent had other linkages in mind, too, referring to the protection of women from their sexually-promiscuous partners: “You know, like us women, we can be faithful, but men are not. So that is our right: men should be responsible.” (Interviewee 9). This view was echoed by another respondent, whose denotation of women as “very, very, very, very innocent” and men as sexually-errant was quoted in Chapter 3 (in the last of the sequence of quotations before note 99), but whose response was also interesting because she appeared to suggest that the pertinence of human rights to AIDS stemmed from the magnitude of the epidemic rather than being inherently linked to it: “The way it has hit the country so hard, there should be some human right on this. But the problem is that there are some people whom if they hear you are HIV-positive you’re just someone who was a loose person, and it is not that way.” (Interviewee 10).

Stigmatization of PLWHAs based on presumptions of immorality provided the link between HIV/AIDS and rights for one respondent, quoted in Chapter 6. As noted, there was some irony in her comments because, having been raped, she had spoken of not “getting the disease rightfully.”¹⁰³

For another, interviewee 2, the nexus lay in the principles of human compassion and solidarity: “[T]o me, people should care about each other. Because when God created us, we’re brothers and sisters. Your needs are my needs. So, if I have a problem I think it shouldn’t only be my own problem- it should go to the society, the

¹⁰³ Interviewee 11

government and so on.” In a similar vein, interviewee 18 felt that human rights meant that Kenyans, like nationals of other countries, should have access to life-saving medicines: “For example, we used to hear that there were ARVs out there in other countries and now we have them here in this country- we can access them. That is the right of a human being.”

As seen in Chapter 1, most respondents had not heard of or thought of a link between health and human rights, with only a handful claiming to have heard of a right to healthcare. It will be recalled that of these, a number were sceptical about the government’s efforts towards realizing this right and stressed the worthlessness of a formal right to healthcare that could not be realized.

Another issue to emerge, which further elucidates the foundations of notions of entitlement, was that of socio-economic goods as a privilege and entitlement of taxpayers.¹⁰⁴ Others identified poor governance- or poor management by government- as the obstacle to enjoying that privilege. This posits a particular idea of the State-citizen relationship, the entitlement to healthcare provision from the State in exchange for the citizen’s fulfilment of her duty to pay taxes; in this scenario, the tax system underwrites a kind of social contract between the parties and thus establishes a tangible, explicit reciprocal relationship. Yet the nagging notion persists of the individual as more consumer than rights-holder. This is due, not least, to the implication that this relationship is predicated on the individual’s capacity to access the health market either through the government health insurance fund (restricted to employees) or through private means (restricted to those with private resources). Either way, many Kenyans would be, and are, excluded from such citizenship. Indeed, the distinction in status between a consumer and rights-holder has not always been clear, with even the frameworks and policy articulations of organizations and agencies claiming to champion rights-based approaches to health betraying the easy slippage from rights language to markets language.¹⁰⁵ It recalls Baxi’s dreaded

¹⁰⁴ Pointing out the obvious disadvantage to the poor implied by this view, Paul Farmer asserts, “But imposing user fees and selling therapy for AIDS did not work in Africa. It was not until diagnosis and care were made rights rather than commodities that people living with AIDS and in poverty had any hope of help.” (Farmer (n 82), at 7)

¹⁰⁵ Turiano and Smith, for instance, provide by way of example a reproductive health programme detailed by UNFPA on their website. They note that, “[d]espite the mention of human rights and

scenario of an emergent market-friendly human rights paradigm in which the interests of global capital predominate and the exclusion of the poor and marginalized from access to basic needs is rationalized and normalized in the name of “progress” or “development”.¹⁰⁶

The intersection of access to information issues with health and rights was also raised by a few respondents, as already seen in the previous chapter. Interviewee 18, for instance, reaffirming that now-familiar rural/urban delineation, thought the link between health and human rights involved tackling misconceptions about HIV/AIDS in rural areas: “I have heard about these things. Firstly, this rubbish in the villages is one of the things that is responsible for spreading diseases. If you’re already sick, your illness is doubled by this rubbish. The government should look into this, and after the welfare of people in villages.” This crucial point recalls the *Committee for Economic, Social and Cultural Rights (CESCR) General Comment 14 on The Right to the Highest Attainable Standard of Health (Art. 12)*.¹⁰⁷ It emphasizes the centrality of access to information to the right to health, along with non-discrimination, physical accessibility, acceptability and quality of health goods and services. Individuals have the right to seek, receive and impart this information.¹⁰⁸ Yet guaranteeing this right is an empty gesture if people lack the agency that would allow them to utilize information to actualize their rights.¹⁰⁹

government obligations, claims and duties are replaced in this UNFPA program by supply and demand. The concept of participation is not framed by the role of a claim holder who is entitled to certain conditions, but by the role of a consumer of services whose participation is through their ability to ‘articulate what they need and expect’ and provide ‘input’ and ‘feedback.’ In this model, a program would empower service users by telling them what they should demand, as if people are too dumb to know that they need quality health care and have not been demanding it all along.... Supply and demand make no sense in a human rights-based approach to health except to evade its most powerful elements.... There can be no real demand in economic terms if an individual does not have the money to purchase necessary or desired goods or services. Although the poorest may want health services, all their wanting does not create much actual demand unless they give up some other necessity, or the government steps in with public funds to buy services for them.” (Turiano and Smith (n 10), at 144-5)

¹⁰⁶ See Baxi (n 31), at 166

¹⁰⁷ Committee for Economic, Social and Cultural Rights (CESCR), *CECSR General Comment No. 14 on The Right to the Highest Attainable Standard of Health*, Adopted by the 22nd CESCR on 11 August 2000, at <http://www.unhcr.org/refworld/pdfid/4538838d0.pdf>, accessed 08/05/09; Art. 12, Para. 12(b).

¹⁰⁸ See also Hunt, Paul and Backman, Gunilla, ‘Health Systems and the Right to the Highest Attainable Standard of Health,’ *Health and Human Rights: An International Journal*, Vol.10, No.2 (2008), pp. 81-92, at 83

¹⁰⁹ Ely Yamin, Alicia, ‘Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,’ *Health and Human Rights: An International Journal*, Vol.11, No.1 (2009), pp.5-21, at 10

Finally, with the issue of access to ARVs established as a central concern, many respondents alluded to links between rights and healthcare in the context of the Kenyan government's ability to provide treatment for PLWHAs. Although one respondent acknowledged that some people may require assistance to pay for healthcare services, she nevertheless believed that government could not as yet afford the cost and thus people should be prepared to pay: "I have heard [about the right to healthcare] but this is the thing: about these ARVs, we must pay something. Now, a lot of people go empty-handed. How will you be helped, and yet our government is new? It has nothing. So if you're asked to pay a certain amount, pay it. The day that the government gets richer it will lower the prices." (Interviewee 18). This belief came up again elsewhere: "[I]t's not easy, as an African country, especially Kenya... we're still a developing country. They're trying, but I know it's not easy to reach out to meet needs for everybody; it's not easy, because we're also over-populated." (Interviewee 2). But it was also rejected outright by a number of respondents, like interviewee 34 who said: "[The government] can because it has the right machinery. I think saying we're a poor country is a poor excuse. We can't be poor when we are able to do some other things yet when it comes to healthcare they say they can't."

Perceiving a limitation in resources for healthcare provision, some interviewees inevitably saw the prioritization of PLWHAs and the least well-off as a vital aspect of health and human rights concerns: "Myself and those who are ill, but the poor should honestly be put first. At least those who can afford to buy the medicine can be put aside for a while but those who cannot afford should be prioritised." (Interviewee 35) Interviewee 30 also thought PLWHAs should be the primary beneficiaries of the right to healthcare although he did not trust authorities to meet those needs. But others sought to be more inclusive, suggesting beneficiaries of a right to healthcare beyond the PLWHAs' circle.¹¹⁰

Prioritization is unavoidable and some commentators contend that government use of resources to actualize first the rights of the most affected in society should not be

¹¹⁰ An example of these was interviewee 41 who, as quoted in Chapter 2, asserted: "You know if you're ill you must get treatment, whatever illness it is. Even if it's malaria."

automatically criticized by human rights organizations as arbitrary.¹¹¹ Even then, the demand is most likely to outstrip supply, and in a society such as Kenya's, where the perception of public sector corruption is high¹¹², those at the back of the queue may view this as a replication of the patterns of bias they sense in general public life.¹¹³

II. Emerging Themes:

a) Being Human

A number of issues can be seen from the above responses: firstly, in attempting to define 'human rights' many interviewees also sought to define what it means to *be human*, thus revealing how their particular subjectivities were constituted. Many attached certain qualities such as inherent worth, value or dignity (discussed presently) to 'humanness', which entitles them to a particular kind of treatment. Such ideas, which elevate the status of the human being above that of other creatures and organisms, are a fundamental facet of the cultural and religious normative structures within which most PLWHAs will have lived, and it is arguably these paradigms which (most) inspired these responses. But these notions are also cornerstones of modern human rights, with various rights instruments restating the human being's special status. The landmark UDHR, for instance, attributes many qualities to the human being¹¹⁴, and although it owes much to the 1789 French Declaration of the Rights of

¹¹¹ Rubenstein (n 98), at 861. Kenneth Roth in his article defines 'arbitrary' as a lack of "sincere effort to deploy resources progressively to realize ESC rights." (Roth (n 96), at 69)

¹¹² Kenya fared badly in Transparency International's 2009 Corruption Perception Index, scoring it 2.2 out of 10. It came in 32nd out of 47 countries in the sub-Saharan African region. See http://www.transparency.org/policy_research/surveys_indices/cpi/2009/regional_highlights, accessed 22/11/09.

¹¹³ See Peris Sean Jones account of such perceptions in Zambia, in Jones, Peris Sean, 'On a Never-Ending Waiting List: Toward Equitable Access to Anti-Retroviral Treatment? Experiences from Zambia,' *Health and Human Rights: An International Journal*, Vol. 8, No. 2 (2005), pp.77-102, at 87. Jones writes, "Many Zambians have the strong impression that people who are 'better off' are the ones getting access, whereas 'ordinary' Zambians are put on apparently never-ending waiting lists. The perception that ARVs cannot be accessed by the 'average man on the street' but rather only by civil servants is prevalent: 'If I was an average man on the street somewhere along Cairo Road [a busy street in downtown Lusaka] then I would not appreciate this [that is, prioritizing civil servants for ARV treatment].'"

¹¹⁴ For instance, it states in Article 1 that "[a]ll human beings are born free and equal in dignity and rights," and "endowed with reason and conscience and should act towards one another in a spirit of brotherhood." (United Nations (UN), *Universal Declaration of Human Rights*, 1948, at <http://www.un.org/en/documents/udhr/>, accessed 20/05/09.)

Man and Citizen, it opts for the vaguer 'human' rather than the former's more precise 'man', for reasons discussed presently.¹¹⁵

What it means to be 'human' or a 'person' and therefore to be a subject of (human rights) law bears more scrutiny, for the concept has been accorded various cultural and political interpretations, some of which, as seen in Chapter 3, exclude or marginalize groups such as women (the majority of interviewees) and PLWHAs.¹¹⁶ These manifold ideas pose various other theoretical challenges, like the idea of universal standards in a setting where the central figure presupposed by the rights dynamic can be many things and have many different, sometimes irreconcilable political claims, all seeking acknowledgement and resolution within a common system of human rights. Winfried Brugger, acknowledging this tension, tries to reconcile it through a conceptual discussion of the 'image of the person' applied by the German Federal Constitutional Court.¹¹⁷ For him reference to an "image" humanizes the concept of human rights and provides a holistic perspective of the human rights enterprise.¹¹⁸ But as Brugger himself concedes it also entails the creation of a cipher imbued with a society's highest ideals; any attempt to make these the compulsory goals of universal human rights would hinder their general acceptance.¹¹⁹

This already hints at concerns about the exclusion of certain values considered undesirable or insignificant, which would inevitably mean that even within specific cultures some individuals may be deemed as falling outside the image of the human person. Those traditionally regarded as failing to embody society's most valued ideals, for example women, would find themselves excluded from having their claims represented and accorded the exalted status of human rights: in effect, they would not be considered to fit the 'image of the person'. So, too, other marginalised categories such PLWHAs and sexual minorities.

¹¹⁵ Douzinas (n 39), at 85-6. See also Marks (n 47)

¹¹⁶ Baxi (n 31), at 134

¹¹⁷ Brugger, Winfried, 'Image of the Person in the Human Rights Concept,' *Human Rights Quarterly*, Vol. 18, No. 3 (1996) pp. 594-611, at 595

¹¹⁸ *ibid*, at 595

¹¹⁹ *ibid*, at 596. This is arguably a view shared by Edmund Burke, for whom, "human nature is socially determined and each society creates its own type of person." (Douzinas (n 39), at 154)

Brugger eventually arrives at a formula which he argues is a common denominator of the universal ideals to which the human rights project aspires for the human being: a “self-determinate, meaningful, and responsible way of leading one’s life”.¹²⁰ This formula, he argues, identifies some fundamental elements of human existence, a “universal core” that might transcend the cultural differences of the disparate addressees of human rights and takes into account the human being’s existence both as an individual and as part of a society.¹²¹

The discussion about the qualities of the human being predates the attempts of Brugger and others, of course. The ‘man’ at the heart of the French Declaration, for example, was widely criticized by thinkers of both the political right and left: for Burke on the right, this ‘man’ imbued with all manner of privileges was so abstract as to be a metaphysical apparition without practical meaning. Douzinas quotes Burke’s incisive question that is especially pertinent to this research: “What is the use of discussing a man’s abstract right to food or medicine? The question is upon the method of procuring and administering them. In that deliberation I shall always advise to call in the aid of the farmer and the physician, rather than the professor of metaphysics.”¹²² Burke appears to place the practicability of the aspirations of the human rights project at the heart of its legitimacy; he rightfully questions the value of articulating a privilege, however high an ideal it may embody, that might not be realized. Similar doubts are echoed by some respondents for this research: Asked if she thought there was a practical benefit to having a right to healthcare interviewee 29, for instance, laughed and said, “Well, it is all very well to inform me that I have a right, but you have to tell me what I can do with this right!” To the same question, interviewee 39 responded, “If you just told me [I have a right to healthcare] and then you don’t give, then there’s no help. If you give me the healthcare then I will benefit.”

For Marx on the left, the problem is that ‘man’ is not abstract, after all, but rather too specific to be universal; for he is actually a white, propertied, bourgeois male whose property rights the human rights enterprise is engineered to protect.¹²³ Exclusion, as

¹²⁰ Brugger (n 117), at 611

¹²¹ *ibid*, at 600

¹²² Douzinas (n 39), at 98

¹²³ *ibid*, at 100

Baxi asserts, is a predominant feature of the concept of human rights at this point in its narrative.¹²⁴ The idea of privileges claimed for all but which only a chosen few are able to take full advantage of is once again echoed by interviewee 3, who, as he left his interview, declared that human rights were a luxury for rich people alone and few could afford to have lawyers to defend their rights.

The interviewees cited above allude to the gulf between the conceptual 'human' of human rights theory and text, endowed with various rights, and the real human of their everyday experiences, whose circumstances and environment prevent the realization of these rights. Essentially, the basis of PLWHA advocates' claims is that they, too, fit the image of the human person endowed by various instruments with special privileges. In some of the responses that dealt specifically with the right to healthcare, respondents may even be suggesting that they, more than other people, best represented that image. For instance, asked who should benefit from the right to healthcare, interviewee 44 replied, "Those who cannot afford to pay." When interviewee 30 was asked if he had heard it claimed that there was a right to healthcare, he answered with a question: "For those with HIV?"

Interviewer: No, that everyone has a right.

Interviewee 30: How can that be? How is it possible for everyone to get health care? I don't think it is. Those with HIV are the ones with problems because they're the ones with an incurable illness and who will need treatment for the rest of their lives.

Perhaps they perceived rights as designed especially for those with grievances or those most in need and therefore saw such people- among whom they self-identified- as the main, maybe the sole- intended beneficiaries of these privileges. They seemed to be asserting the primacy of their (health) claims over those of the general public. This is significant: as a discussion already seen in Chapter 6 made clear, questions persist about the prioritization of HIV/AIDS in countries with manifold health problems, some of which claim more lives than this illness. In a country with insufficient resource allocation for health this is a politically combusive issue worsened by the stigma surrounding HIV/AIDS. The right to health, as with all other rights, is exposed as a locus for struggle but not a substitute for it.¹²⁵

¹²⁴ Baxi (n 31), at 134

¹²⁵ Hunt and Backman (n 108), at 90

Women's struggle for recognition as human beings with equal rights, too, the topic of much writing, is also relevant to the analysis here, not least because it provides vital insights into a group's efforts to reconstruct, claim or affirm their subjectivity. The rollback of women's rights in Afghanistan under the Taleban, for instance, prompts Arvonne Fraser to map the development of women's rights down the centuries and the process by which they became equal subjects of the law.¹²⁶ Highlighting the importance of education, of recording the women's struggle, and of the contribution, too, of male leaders she provides the perfect analytical context which is effectively about the unmaking of women's subjectivity under the Taleban.¹²⁷ Recalling issues raised in Chapter 3, she describes how women have been systematically demeaned as individuals and their contribution to society denied recognition, and observes "the great irony... that women have been charged with- and have often found security in- maintaining customs and tradition, thus, institutionalizing the discrimination against them through the education and socialization of children."¹²⁸

Yet it may be a measure of the extent to which the female interviewees for this research automatically constituted themselves as human beings, if only in the simplest sense, that there seemed to be no doubts about this aspect of their identity although it was not raised explicitly in the questionnaire. This may suggest that despite the conceptual challenges articulated by Burke and Marx many groups and individuals do nevertheless see their images reflected in the ideals of human rights. Even more likely is that their cultural and/or religious frames of reference superficially obscure the subtleties of such questions: for as several interviewees illustrated, many of the significant hardships they encountered were directly or indirectly linked to their identity as women, which their additional identity as PLWHAs seemed to compound. Each interviewee's identity and subjectivity is further contoured by ethnicity, class, age and so on. What seems to emerge is the heterogeneity of subjectivity even among respondents united by an iconic illness, as

¹²⁶ Fraser, Arvonne S., 'Becoming Human: The Origins and Developments of Women's Human Rights,' *Human Rights Quarterly*, Vol. 21, No. 4 (1999) pp. 853-906

¹²⁷ *ibid*, at 854

¹²⁸ *ibid*, at 855

the plurality of views about entitlements and duty-bearers appears to indicate. These will be reviewed at the end of the chapter.

b) Having Dignity, Taking Dignity

The second issue revealed by the responses was that many interviewees attached a sense of dignity to humanness and saw this as an essential aspect of their subjectivity. Their notions of this concept, a mainstay of human rights¹²⁹, were sometimes complex but this is typical of a concept that is nowhere defined in any of the major national and international instruments that cite it, and whose precise core content is still unclear.¹³⁰ Yet rights claims not yet crystallized into law can sometimes be legitimately founded on ethical rather than legal obligations where there is a solid basis in human dignity.¹³¹ Schachter argues that the relationship between human rights and human dignity is philosophical rather than historical.¹³² Recalling Kant, for whom human dignity was elevated to a “noumenal realm,”¹³³ he suggests that respect for every person’s intrinsic dignity might mean that she should be treated as an end in herself and not a means.¹³⁴ For Kant the onus was on society to recognize the dignity of others.¹³⁵ But, as will be seen presently, in reality this does not happen automatically, with society often choosing whether to accord or deny an individual her dignity based on her conformity with its most valued ideals. An implication of this, he argues, is the supreme- though not absolute- importance that should be accorded to individual choice, and that all things social, political and legal should be organized to facilitate this; on a political level, this would mean curbing government’s

¹²⁹ The UDHR declares in its preamble that “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world...” (UN, Universal Declaration of Human Rights (n 114)). The new Kenya constitution declares in Art.28 that, “Every person has inherent dignity and the right to have that dignity respected and protected.” (Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010*, 2010, Kenya Law Reports (www.kenyalaw.org), accessed 10/12/13. (Published by the National Council for Law Reporting, with the Authority of the Attorney General)

¹³⁰ Schachter, Oscar, ‘Human Dignity as a Normative Concept,’ *The American Journal of International Law*, Vol.77, No.4 (1983), pp 848-854, at 853. See also Shestack (n 50), at 216. But Eleni Coundouriotis (Coundouriotis, Eleni, ‘The Dignity of the Unfittest: Victims’ Stories in South Africa,’ *Human Rights Quarterly*, Vol. 28, No.4 (2006), pp. 842-867) argues that the lack of analysis of the concept of dignity in human rights discourse, where it is consigned either to the beginning or the end of the rights narrative, means it is marginalized in discussions about the actual process of human rights (at 843).

¹³¹ Nyamu-Musembi and Cornwall (n 87), at 3

¹³² Schachter (n 130), at 849 and 851

¹³³ Conklin (n 2),, at 133

¹³⁴ Schachter (n 130), at 849. See also Ely Yamin, ‘Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care,’ (n 98), at 46

¹³⁵ Coundouriotis (n 130), at 844

sometimes coercive involvement in matters that fundamentally belong in the private sphere.¹³⁶ This touches on several pertinent issues for PLWHAs, who find themselves at the heart of a public health crisis, as they interact with the State: they include the debate about involuntary testing, disclosure of HIV test results to sexual partners, and their right, especially for women, to choose if, when and how to have sexual intercourse.

But the bifurcated state theory is also relevant here: a basis may exist upon which to challenge the national State, the locus of civil power, should it violate human rights norms such as respect for individual dignity¹³⁷, not least because it alone is the recognised duty-bearer in the international human rights dynamic. However, it is harder to contest the deprivation of individual dignity in a customary sphere which prioritizes other norms, privileges group solidarity over individual entitlement, and applies different interpretations of dignity. It is therefore imperative to unpack this concept in the cultural context within which most respondents will likely have been referencing it as a basis for their entitlement claims.

Commentators like Makau Mutua contend that dignity is a concept intrinsic to societies worldwide including African ones¹³⁸, although Rhoda Howard and Jack Donnelly argue that just because a society's norms historically recognize human dignity does not necessarily mean it possesses a human rights culture.¹³⁹ The analysis here is concerned with the constitution of subjectivities and the development of notions about duties and entitlements and thus less interested in the Mutua/Howard-Donnelly debate about the Eurocentricity or not of human rights.¹⁴⁰ Howard and

¹³⁶ Schachter (n 130), at 849-50

¹³⁷ Indeed, commentators such as Mariana Chilton argue that dignity should be viewed as a right in itself, and not simply as being about reaffirming the self-worth of the individual. (Chilton, Mariana, 'Developing a Measure of Dignity for Stress-related Health Outcomes,' *Health and Human Rights: An International Journal*, Vol.9, No.2 (2006), at 216)

¹³⁸ Mutua, Makau, *Human Rights: A Political and Cultural Critique*, (Philadelphia: University of Pennsylvania, 2002), at 81. See also Freedman, Lynn P., 'Reflections on Emerging Frameworks of Health and Human Rights,' *Health and Human Rights: An International Journal*, Vol. 1, No.4, 315-348, at 337. Freedman argues that the basic values at the root of human rights " - human dignity and social justice- ...have historical and contemporary roots in cultures throughout the world,"

¹³⁹ Howard, Rhoda E. and Donnelly, Jack, 'Human Dignity, Human Rights and Political Regimes,' *The American Political Science Review*, Vol. 80, No. 3 (1986), pp. 801-817, at 801

¹⁴⁰ See Makau Mutua's summary of this debate in Mutua (n 138), at 79-81. It will be recalled, too, that Baxi persuasively points out the limitations of the notion of human rights as exclusively rooted in the West, suggesting that a covert agenda that underlies its perpetuation. (Baxi (n 31), at 148)

Donnelly's definition of dignity captures its social function and would be familiar to Kenyans, particularly- but not exclusively- those in the customary domain. They explain that "[c]onceptions of human dignity, in their social and political aspects, express particular understandings of the inner (moral) nature and worth of the human person and his or her proper (political) relations with society," while human rights are "equal and inalienable" and owed to individuals simply by virtue of their being human.¹⁴¹ Dignity is bestowed upon an individual by her community to reflect her position within it, or is earned over time by adherents of the community's values, whatever their restrictions.¹⁴² But if reserved only for those deemed 'respectable' it becomes a mechanism for the reinforcement of the status quo and the marginalization of those regarded as deviant. This is the 'real' world, the opposite of that of theorists like Kant, whose ideal 'Kingdom of Ends' is populated by rational, autonomous individuals who regard each other and are regarded as ends in themselves.¹⁴³ Even Schachter acknowledges that the individual is more than just an atomized figure: she is also part of a community whose links may be weakened in the assertion of individual will and choice; the notion of human dignity must account for the individual's freedom as well as her obligations.¹⁴⁴

This idea of dignity as socially bestowed will be familiar to PLWHAs, for whom it has significant implications, facing as they do immense challenges with stigma and discrimination. Indeed, interviewees often spoke of a public perception that their illness resulted from sexual deviance. As noted in earlier chapters, this discouraged many from disclosing their HIV status for fear of rejection or ostracism, with some even displaying personal or group self-stigmatization. That they seemed to adjudge themselves or others guilty of violating their communities' norms and so rightfully bereft of any claims to dignity, appears to reinforce the suggestion here that their overarching conception of dignity was founded in the moral universe and language of culture, not rights.

¹⁴¹ Howard and Donnelly (n 139), at 802

¹⁴² Howard, Rhoda E., 'Dignity, Community, and Human Rights,' in An-Na'im, Abdullahi Ahmed, *Human Rights in Cross-cultural Perspectives: A Quest for Consensus* (Philadelphia : University of Pennsylvania Press, 1992)

¹⁴³ Conklin (n 2), at 133

¹⁴⁴ Schachter (n 130), at 851

Take interviewees 5 and 30, noted also in Chapter 3 (in the first two quotes of the sequence before note 99): the former asserted a claim on the government for health entitlements, distinguishing herself, a married, sexually-faithful but nevertheless HIV-infected woman from others who may be infected but lacking these other qualities:

It's the government's duty because [AIDS] is a natural disaster. It's not the way people put it that those who are infected are harlots, prostitutes and so on. It's not like that. Some of us, since we were born, maybe you have only had 2 boyfriends, maybe even one, in all your life. Some of us, since you got married, you settled, but this thing just got into your house.

The latter, too, stressed her constant sexual fidelity to her husband and expressed bitterness at aspersions regarding her chastity when it was he who had infected her. She said that fear of being suspected of immorality, of being one of "these ... prostitutes who carry out their business in secret," discouraged her going public with her illness, as healthcare officials advised. Both respondents (and others elsewhere) were at pains to separate themselves from other women who violated society's marital and sexual codes, based on cultural or religious norms they appeared to accept and defend. In doing so they were claiming as part of their identity membership- citizenship- to a community, imaginary or experiential, which professes, if not practices, these values; they felt bound by a moral obligation towards this 'primordial public'.¹⁴⁵ They condemned these 'others' as 'prostitutes,' not worthy of dignity or respect, even while acknowledging that they themselves might be (mistakenly) victimized as such because of their illness. In their view, PLWHAs like them who became infected through no fault of their own were worthy of dignity; others who became infected through their own risky, transgressive behaviour, and who further may have contributed to the spread of the virus to the innocent ones (recall interviewee 10's comments about 'very innocent' women) by tempting their unfaithful husbands, were not.

Self-stigmatization also seems to corroborate Howard's view of dignity as objectively attained. Yet within it, too, lies clear proof of the subjective dimension of dignity, which supports the dynamic definition adopted by Mann, who was so influential in laying out many of the key ideas in the health, rights and HIV discourse. He concluded

¹⁴⁵ Ekeh, Peter P., 'Colonialism and the Two Publics in Africa: A Theoretical Statement,' *Comparative Studies in Society and History*, Vol. 17, No.1 (1975), pp. 91-112, at 106.

that dignity seems to have two fluid elements: “[O]ne internal (how I see myself) and the other external (how others see me). The common denominator is the fact of being seen and the perceived nature, or quality of this interaction.”¹⁴⁶ This is reiterated by Chilton, whose definition acknowledges both these objective and subjective elements, adding that they are “socially and politically mediated.”¹⁴⁷ Indeed, many of the same self-stigmatizing respondents simultaneously appeared to have internalized advocacy messages that challenge such attitudes and stigma and discrimination. Their answers reflected a strong sense about dignity as intrinsically adhering to all them as humans and not negated by their illness or the circumstances in which they supposedly became infected. Further, they did not wait to be given dignity but asserted their claim to it even if those around them appeared to deny it to them; they claimed it “‘in advance’ of the fight”.¹⁴⁸

It is argued here that such contradictions are manifestations of the tensions between deep-rooted cultural frameworks and the new human rights one within which respondents were attempting to understand and perhaps reconcile norms such as dignity. When expressed as part of advocacy messages about stigma and discrimination, words which several PLWHAs employed, the denial of dignity because of respondents’ sero-status is itself classified as wrong, transgressive. The new language of rights gives form to the PLWHAs’ new subjectivities. In the terms of Lacanian psychoanalysis, discussed later, the subject retreats into a linguistic system that helps give voice to her desires and facilitates her progress through the legal (and, indeed, other) discourse.¹⁴⁹ Language virtually brings a new world into being, creates an alternative reality, “[producing] existence by producing the collectively recognized, and thus realized, representation of existence.”¹⁵⁰ The injection of human rights language into the HIV/AIDS discourse gives PLWHAs a new moral universe with a new moral language and a new set of norms by which to operate. According to these

¹⁴⁶ Mann, Jonathan, ‘Dignity and Health: The UDHR’s Revolutionary First Article,’ *Health and Human Rights: An International Journal*, Vol.3, No.2 (1998), pp. 31-38, at 32

¹⁴⁷ Chilton (n 137), at 215

¹⁴⁸ Coundouriotis (n 130), at 848

¹⁴⁹ Stacy, Helen, ‘Lacan’s Split Subjects: Raced and Gendered Transformations,’ *Legal Studies Forum*, Vol. 20, No. 2 (1996), pp. 277-294, at 288

¹⁵⁰ Hastrup, Kirsten referencing Pierre Bourdieu in, ‘Representing the Common Good: The Limits of Legal Language,’ in Wilson, Richard Ashby and Mitchell, Jon P. (eds.), *Human Rights in Global Perspective: Anthropological Studies of Rights, Claims and Entitlements* (London: Routledge, 2003), at 20

norms, they are not undesirable sexual deviants and/or social outcasts, unworthy of dignity, but human beings living within particular circumstances and dealing with particular challenges, which they are entitled to have recognized. A human rights framework challenges a definition of dignity that is purely objective and externally acquired: it demands the recognition of its subjective element and the contested self-assertion of dignity by marginalized groups like women, sexual minorities, and now PLWHAs.

This highlights the complexity surrounding dignity: in a human rights context, perhaps in any context, it is in claiming it that it is realized¹⁵¹; yet even this action anticipates a role for the 'other': for in staking her claim, the PLWHA's actualization of dignity may still rely on those to whom she reveals her sero-status as she makes that claim. She must emerge from the private into the public arena where competing, often conflicting conceptions of dignity may reign (witness the Gugu Dlamini murder, discussed in Chapter 6)¹⁵², to reclaim this aspect of her individual, multi-faceted identity. Writing about South Africa's apartheid victims and the telling of their stories in that country's Truth and Reconciliation Commission hearings, Coundouriotis pertinently notes that, "[w]hen the victim's response [such as accepting the opportunity to testify at the hearings] is the issue, then the burden of actualizing dignity falls on the audience to that response. Testimony, in particular, seems to leave the victims vulnerable. Retaining some control over the meaning of one's testimony seems crucial."¹⁵³

The refusal to recognize her- to "see" her- or seeing her only as part of a group, violates her dignity under human rights.¹⁵⁴ The challenges highlighted here, of exposure and rejection (indeed, many PLWHAs object to the idea of making their sero-status a mark of their identity¹⁵⁵), are relevant to PLWHAs' decisions about which moral framework or language to prioritize as they attempt to imagine, express and defend their claims to dignity, where and when. This seems to give credence to

¹⁵¹ See Feinberg, Joel, 'The Nature and Value of Human Rights,' *Journal of Value Inquiry*, Vol. 4, No. 4 (1970), pp. 243-260

¹⁵² Heywood and Altman (n 77), at 158

¹⁵³ Coundouriotis (n 130), at 866

¹⁵⁴ Mann (n 146), at 33. Mann also notes two other kinds of dignity violation: the infringement of personal space and humiliation.

¹⁵⁵ Heywood and Altman (n 77), at 158

the conclusions of commentators like Alan Gewirth that dignity is thus 'empirical' and cannot be equally possessed by all.¹⁵⁶ For those like the PWLHAs who must oscillate between multiple spaces with varying norms perhaps the more appropriate qualification is: not everywhere and not always.

This casts doubt on the cohesive capacity of human rights norms. To be sure, the human rights paradigm, in creating rights and responsibilities for the individual, presupposes the existence of others.¹⁵⁷ As Douzinas puts it, "a right is a particular way of being in common. A demand for recognition of an aspect of the claimant's identity couched in rights terms is always addressed at another and is validated through the other's acknowledgement."¹⁵⁸ But at the heart of this Hegelian idea of legal recognition is the reciprocal acknowledgment of the rights of other members of the community, an affirmation of the autonomy of each individual member and the respect due them.¹⁵⁹ Community is the context as well as the consequence of legal recognition.¹⁶⁰ But the responses above exemplify, beyond the logic and rhetoric of rights, the ongoing contestations in practice about the content of its core principles and whether the agreed rights will be owed to all equally, all the time. They suggest a strategic approach to the adoption of human rights norms rather than a wholesale one. The long-standing frameworks and values which legitimize discriminatory behaviour and which the new normative system of rights promises to expunge often prove durable.¹⁶¹ Thus the contours and nature of a burgeoning community of rights is undecided. This implies, then, that even within the special sub-community of PLWHAs, arguably more sensitized to certain human rights issues, it may be premature to talk without condition of a community bound together by human rights. Its success may depend on how well it fits in with the existing supra-communities to which Kenyans belong. These, particularly the ethnic or customary, are founded on

¹⁵⁶ Gewirth's views are summarized in Coundouriotis, (n 130), at 845

¹⁵⁷ Douzinas (n 39), at 287

¹⁵⁸ *ibid*

¹⁵⁹ *ibid*, at 286. See also Brugger, who includes in his formula of the image of the person a component on reciprocity: according to this element, persons must recognize the rights and freedoms they claim for themselves in others. Brugger links this element to the notion of dignity in human rights claims: "This means that no one may pretend to stand above other human beings, because all persons as persons have the same dignity and worth." (Brugger (n 117), at 604). See also de Negri Filho, Armando, 'A Human Rights Approach to Quality of Life and Health: Applications to Public Health Programming,' *Health and Human Rights: An International Journal*, Vol.10, No.1 (2008), pp. 93-101, at 98

¹⁶⁰ Douzinas (n 39), at 287

¹⁶¹ Baxi (n 31), at 143-4

systems and norms that are more established in this environment than those of human rights.

To be sure, members of any such new human rights-based community may nevertheless feel compelled to retain the seemingly contradictory views featured above in order to maintain membership in other spheres. IRRRAG's findings on the AIDS-linked issues of sexual and reproductive rights provide some insights: for the PLWHAs' responses may be seen as exemplifying the "accommodation-resistance nexus" that Petchesky and the IRRRAG team observed in their fieldwork.¹⁶² She notes that women seldom adopted strategies of outright compliance with, or outright resistance to, the prevailing norms. Instead, their approaches were more nuanced, aimed at achieving a level of sexual and reproductive autonomy without threatening their position in the community.¹⁶³ It underscores an instrumental approach to the adoption of human rights norms and the continuing importance of cohesion within the community, still the primary framework within which people have their lived experiences.¹⁶⁴

c) (Multiple) Citizenship

This multiplicity of identities and subjectivities raises a third issue: citizenship. By basing entitlement claims on national citizenship, the interviewees who did so reflected a perceived relationship with the State and an awareness of the political rights that issue from this affiliation, which enhances their legal identity as human beings.¹⁶⁵ This consciousness may be located in the same relatively fresh landscape as the human rights system. It forms part of the ongoing conversation between the State and the individual, as does the State's reaffirmation of the individual's humanity, for, as Douzinas argues, it is less the case that humans have rights and more that rights make human.¹⁶⁶ Becoming a legal subject elevates the individual from the universal 'man' of the French Declaration into a citizen of the State and a

¹⁶² Petchesky, 'Introduction,' (n 36), at 17

¹⁶³ *ibid*

¹⁶⁴ Ghai, Yash, in Twining, William (ed.), *Human Rights, Southern Voices: Francis Deng, Abdullahi An-Na'im, Yash Ghai and Upendra Baxi*, (Cambridge, UK ; New York : Cambridge University Press, 2009), at 150

¹⁶⁵ Douzinas (n 39), at 105

¹⁶⁶ *ibid*, at 372

person of substance; her subjection to the law, unlike the alien, makes her law's subject.¹⁶⁷

But citizenship for many Africans is a more complicated experience and so respondents' reference to it reasserts the overarching importance of the postcolonial citizen-subject theories of Mamdani, Ekeh, Ndegwa and others, which spotlight, too, the long-standing but ever-present alternative publics to which PLWHAs belong and also simultaneously claim citizenship. In this sense, even this third basis for PLWHAs' claims to healthcare and other entitlements is not impervious to notions whose frame of reference is external to human rights.

Said Adejumobi makes the point that the African nation-state is a collection of nationalities and that citizenship and multiple identities are complementary; loyalty to the latter need not negate the former but if the privileges and benefits of citizenship exist in name only pluralism may be seen as competing, challenging or threatening to the State.¹⁶⁸ The exception may be in States which are dominated by members of one's community.¹⁶⁹ This idea of citizenship, these commentators assert, is far removed from the essentially Western notion of a singular political community¹⁷⁰, although as Halisi, Kaiser and Ndegwa remind us, citizenship is a perpetually fluid concept forever being shaped and redefined by new conditions.¹⁷¹ Early, European meanings of citizenship have evolved, they add, so that today they encompass ideas pertinent to nation-building such as social equality.¹⁷² Indeed, there new attempts to reframe citizenship as more participatory, 'practiced' rather than 'a given', partly reclaiming the space that separates citizen from State.¹⁷³

¹⁶⁷ *ibid*, at 106

¹⁶⁸ Adejumobi, Said, 'Citizenship, Rights, and the Problem of Conflicts and Civil Wars in Africa,' *Human Rights Quarterly*, Vol. 23, No.1 (2001), pp. 148-170, at 155-6

¹⁶⁹ See Ndegwa, Stephen N., 'Citizenship and Ethnicity: An Examination of Two Transition Moments in Kenyan Politics,' *American Political Science Review*, Vol. 91, No.3 (1997), pp. 599-617, at 602

¹⁷⁰ *ibid*, at 600

¹⁷¹ Halisi, C.R.D.; Kaiser, Paul, J.; and Ndegwa, Stephen J., 'Rethinking Citizenship in Africa: Guest Editors' Introduction: The Multiple Meanings of Citizenship- Rights, Identity, and Social Justice in Africa,' *Africa Today*, Vol. 45, No.3/4 (1998), pp. 337-350, at 340.

¹⁷² See *ibid*, at 341

¹⁷³ See Ely Yamin 'Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,' (n 109), at 15

And PLWHAs' notions of citizenship were often linked to this, centring on issues of nationality and national community, and attached to ideas like equal treatment of all nationals. To be sure, citizenship was among the salient issues during the national constitutional debate and an entire section of the new instrument is devoted to outlining the rights and privileges of the citizen.¹⁷⁴ For many respondents their identity as Kenyan citizens was an important aspect of their subjectivity and by overtly claiming membership of the wider national political community they were distinguishing themselves from non-citizens, whose claims to privileges such as healthcare they were, consciously or otherwise, therefore rejecting. Though this appears at odds with the idea of equality which some PLWHAs simultaneously raised, the human rights enterprise often appears to be a conspiracy between the State and the citizen to exclude 'the other'- the alien.¹⁷⁵ As Douzinas notes, they "are subjected to the law but they are not law's subjects."¹⁷⁶ And yet some commentators challenge the notion a monolith rights-possessing African citizenry in cahoots with a State from which it may claim equal privileges while the acceptably-excluded alien looks on enviously. Adejumobi, reiterating arguments raised in Chapter 4, asserts that "[t]he construction and nature of the state in Africa which is rooted in the colonial pedigree, tend toward the institutionalization of ethnic entitlements, rights, and privileges, which create differentiated and unequal status of citizenship."¹⁷⁷ Indeed, many interviewees mentioned several examples of perceived State inefficiency and selective dispersal of public resources: Interviewee 3, for instance, said he knew the government could afford to meet its obligations under the right to healthcare "if they use their funds well. If we forget about the political side of things they can afford it if they are properly governed." Interviewee 29 concurred: "If they plan well, the government can afford to help. But you hear all the time, 'the money was eaten by so-and-so', 'it was eaten by Goldenberg [a multi-million dollar fraud, committed in

¹⁷⁴ See Chapter 3 of the new constitution of Kenya, 2010, which state in Art 12(1)(a) that 12. (1) Every citizen is entitled to "the rights, privileges and benefits of citizenship, subject to the limits provided or permitted by this Constitution..." (Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010* (n 129))

¹⁷⁵ Douzinas (n 39), at 103

¹⁷⁶ *ibid*, at 104. But, note, too, that, as Ely Yamin points out, proponents of the afore-mentioned participatory notion of citizenship see it equally as a social and legal concept, designed to include non-citizens, to regulate and facilitate their interaction with State where they live and the nature of claims they can make from it. (See Ely Yamin, 'Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,' (n 109), at 15

¹⁷⁷ Adejumobi (n 168), at 148

the 1990s but criminal charges for which were only brought in 2006, with senior members of the ruling elite implicated¹⁷⁸]. Then you hear someone is getting paid [Ksh.] 2 or 3 million in salary, then there will be nothing left for other projects like treating people. There should be a law to ensure the money goes where it is meant to go- to those who are ill.”; “[The government] can help if it wants but people are short-sighted. There are those who feel that they are there to satisfy themselves and it will take the government a long time to give a hand to those in need.”(Interviewee 45)

This breeds and compounds a sense of moral illegitimacy about the very entity around which a national community is intended to cohere, impeding social integration and, ultimately, the enhancement of a shared sense of citizenship.¹⁷⁹ A diminished sense of belonging to such a community thus becomes yet another aspect of many PLWHAs’ subjectivities.

One forum where members of that community might seek redress for the violations of State, and so reaffirm their relationship to it, is in a court of law. And much has been made about the possibility of holding States accountable for their obligations under the ICESCR or national legislation through judicial activism, now a distinct possibility under the new Kenyan constitution. Roth, for instance, argues that litigation or adoption of legislation that would make ESC rights justiciable would also promote these rights¹⁸⁰, and health is one of the key areas where this strategy is being tested. In South America litigation is increasingly used to secure State accountability for its health rights obligations.¹⁸¹ States and private health providers there face increasing challenges from organizations (in public interest cases) and

¹⁷⁸ See BBC, ‘Q&A: Kenya’s Goldenberg Affair,’ BBC Online, 15th March 2006, at <http://news.bbc.co.uk/1/hi/business/4808618.stm>, accessed 07/07/13.

¹⁷⁹ Adejumobi (n 168), at 162

¹⁸⁰ Roth (n 96), at 66

¹⁸¹ See Gloppen, Siri, ‘Litigation as a Strategy to Hold Governments Accountable for Implementing the Right to Health,’ *Health and Human Rights: An International Journal*, Vol.10. No. 2 (2008), pp.21-36; also Ely Yamin (‘Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health,’ (n 46), at 12. See also Baxi (n 31), at 161) on the Indian example which exemplifies the possibilities of transforming courts, previously vehicles for State repression, into vehicles for achieving social justice.

private individuals.¹⁸² The recognition of the role of extra-State actors in the fulfilment or violation of individuals' health rights is crucial, as reviewed in the previous chapter. As Nahid Toubia writes,

The human rights field operates in such a way as to protect the individual from the vicissitudes of power that impact his or her life. In the field of health, this power may be the state; international policies and programs; multinational and local drug companies; the medical establishment; and finally, the family and community.¹⁸³

It challenges the rigid focus on States as primary duty-bearers as conceived under international law, suggesting that this perspective does not reflect power relations today, as the effect of the policies and actions of donors, Northern NGOs and multilateral organizations like the World Bank on national health systems, discussed in Chapter 7, have shown.¹⁸⁴ Some have even argued that this multiplicity of responsible actors, which makes the identity of ESC rights violators more uncertain (some have even blamed the victims themselves¹⁸⁵), is partly responsible for the obscurity of ESC rights in comparison to civil and political ones. The HIV/AIDS crisis has especially exposed the limited capacity of States like Kenya in the provision of social goods and services for its own citizens, further weakening the ties that bind the individual to it. Yet the greater involvement of other actors does not displace the obligations of government, whose responsibility it remains to provide adequate health systems nationwide.¹⁸⁶

Kenya's new constitution, with its robust Bill of Rights, aims to incorporate into domestic law an aspect of Art. 2(1) ICESCR.¹⁸⁷ More importantly, it aims to provide a

¹⁸²Victor Abramovich and Laura Pautassi give an account of this development in Argentina, in Abramovich, Victor and Pautassi, Laura, 'Judicial Activism in the Argentine Health System: Recent Trends,' *Health and Human Rights: An International Journal*, Vol.10, No. 2 (2008), pp. 53-65, at 54

¹⁸³ Toubia, Nahid F., 'Health and Human Rights: Where Do We Go From Here?', *Health and Human Rights: An International Journal*, Vol. 1 No. 2 (1995), pp. 136-141, at 138

¹⁸⁴ See Ely Yamin, 'Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care,' (n 98), at 54

¹⁸⁵ Leckie, Scott, 'Another Step Towards Indivisibility: Identifying the Key Features of Violations of Economic, Social and Cultural Rights,' *Human Rights Quarterly*, Vol.20, No.1 (1998), pp. 81-124, at 82

¹⁸⁶ London (n 10), at 68

¹⁸⁷ This requires States to undertake steps to realize ECS rights through "all appropriate means, including particularly the adoption of legislative measures." (Office of the United Nations High Commissioner for Human Rights (OHCHR), 'International Covenant on Economic, Social and Cultural Rights (ICESCR), 1966, at <http://www2.ohchr.org/english/law/cescr.htm>, accessed 14/03/09). Further, individual petitions will be allowed should the Optional Protocol to the ICESCR be adopted. See Ely Yamin, 'Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health,' (n 46), at 5. As of 20th November 2009, the Optional Protocol of the ICESCR, adopted on the 10th December 2008, had only 30 signatories, of which Kenya was not one (UN,

legal framework that not only (nominally) guarantees a right to “the highest attainable standard of health” but also includes enforcement mechanisms through which, say, individuals can bring claims of violations before courts or tribunals.¹⁸⁸ The contribution of this development to the fulfilment of ESC rights is arguable: there are plausible arguments that instituting a normative framework founded on international legal instruments encourages different perceptions not only by States but other actors such as development agencies.¹⁸⁹ Further, enabling legislation and court actions explicitly compel States to meet their human rights obligations under international and domestic law and provide a direct route for individuals to challenge State violations.¹⁹⁰ Moreover, litigation itself can provide an effective platform for raising awareness and mass mobilization on issues like HIV/AIDS and rights where the process is linked with media coverage and public campaigns. However, care must be taken in the formulation of legislation so that its results do not prove counterproductive, actually entrenching rather than alleviating human rights violations against PLWHAs: for instance, Sec. 26 of Kenya’s 2006 Sexual Offences Act looks to use the criminal law ostensibly to curb the intentional HIV infection.¹⁹¹ Campaigners argue that this could have negative effects for the treatment and prevention efforts, such as, among other things, disproportionately targeting marginalized groups such as sex-workers, drug-users and men who have sex with men; discouraging from HIV testing individuals who might look to negate the basis of the criminal offence which is founded on knowledge of one’s sero-status; moreover,

‘Status: Chapter IV Human Rights: International Covenant on Economic Social and Cultural Rights (ICESCR)’, United Nations Treaty Collection (UNTC), 2012, at http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-3&chapter=4&lang=en, accessed 16/05/09). Art. 2 allows submission on behalf of individuals or group of individuals (See UN, Optional Protocol to the International Covenant on Economic, Social and Cultural Rights, 2008, at http://treaties.un.org/doc/Publication/CTC/Ch_IV_3_a.pdf, accessed 02/05/10; at 2.)

¹⁸⁸ Art.22 on the Enforcement of the Bill of Rights says that “Every person has the right to institute court proceedings claiming that a right or fundamental freedom in the Bill of Rights has been denied, violated or infringed, or is threatened. (2) In addition to a person acting in their own interest, court proceedings under clause (1) may be instituted by (a) a person acting on behalf of another person who cannot act in their own name; (b) a person acting as a member of, or in the interest of, a group or class of persons; (c) a person acting in the public interest; or (d) an association acting in the interest of one or more of its members. (Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010* (n 129))

¹⁸⁹ Nyamu-Musembi and Cornwall (n 87), at 4

¹⁹⁰ Gloppen (n 181), at 24

¹⁹¹ Kenya Law Reports, ‘Laws of Kenya’ (n 102). See United Nations Development Programme (UNDP)/UNAIDS, *Policy Brief: Criminalization of HIV Transmission*, (n 191) http://data.unaids.org/pub/BaseDocument/2008/20080731_jc1513_policy_criminalization_en.pdf, August 2008, accessed 8/05/09; at 1 and 3. Further, it is not clear what treatment and care opportunities are envisaged for those who might be convicted of such offences.

such laws could also punish those who may not have disclosed their status because of the prejudice and even possibility of violence that PLWHAs face.¹⁹² The legal tussle between the South African government and pharmaceutical companies is a good example of this.¹⁹³ Indeed, it has been noted that litigation has often been a political rather than a legal tool.¹⁹⁴ Closer to home, the examples of rights provided by interviewees, inspired by well-publicized court cases such as the domestic abuse suit brought against an MP, underline the promotional potential of such processes.

But there are valid criticisms, too: that as legal processes benefit those most likely to use them, which does not often include the poor and marginalized, they succeed largely in reproducing existing inequalities¹⁹⁵; further, it has been contended that favourable court decisions which affirm an individual's health rights claims may strengthen the rights of some who are thus doubly rewarded for having the wherewithal to access the legal system¹⁹⁶, but weaken the collective right to health by undermining long-term national health policy-setting. The effect of an additional workload on an overworked legal system is also questioned, as might be the judiciary's competence in dealing with tricky technical and politically-charged issues such as the government's allocation of resources.¹⁹⁷

A proactive judiciary willing to engage with difficult public health policy issues seems crucial to the success of the litigation strategy.¹⁹⁸ Yet South Africa's Constitutional Court, for instance, has been criticized for deference to the executive and legislative: Karin Lehmann argues this may be seen, first, in its silence over whether individual applicants have a prima facie right to the socio-economic good in question (the court looks instead at the vague issue of whether the relevant policy is reasonable), and,

¹⁹² See UNDP/UNAIDS, *Policy Brief: Criminalization of HIV Transmission*, (n 191), at 1 and 3) Further, it is not clear what treatment and care opportunities are envisaged for those who might be convicted of such offences.

¹⁹³ London (n 10), at 67

¹⁹⁴ Ghai (n 164), at 149

¹⁹⁵ Nyamu-Musembi and Cornwall (n 87), at 4. See also Motta Ferraz, Octavio Liuz, 'The Right to Health in the Courts of Brazil: Worsening Health Inequities?' *Health and Human Rights: An International Journal*, Vol. 11, No 2 (2009), pp. 33-45. He argues that there are signs that this is indeed what is happening in Brazil, one of the South American countries where judicial action for the violation of the right to healthcare has taken off.

¹⁹⁶ See *ibid*

¹⁹⁷ Gloppen (n 181), at 24

¹⁹⁸ Abramovich and Pautassi (n 182), at 54

secondly, in failing to assert a monitoring role, thus appearing to trust the government to amend its policies where ordered to.¹⁹⁹ These arguments are reminiscent of a point highlighted Kiai, one that is worth remembering even in the light of Kenya's improved Bill of Rights: referring in 2004 to the unprecedented, quasi-judicial powers, constitutionally guaranteed, of his own organization, the KNCHR, he cautioned that it was far better that such powers were not exercised than that they were abused or exercised badly, thus creating poor precedent.²⁰⁰ The issue is particularly pertinent in an area of law still in its infancy and where decisions in one jurisdiction are likely to influence those in another.

Lehmann also doubts whether jurisprudentially the decisions of South Africa's Constitutional Court really protect the individual's rights, questioning the utilitarian principles at the heart of their key decisions.²⁰¹ She notes the utilitarian ideals articulated in a famous decision in which the claimant was denied his dialysis treatment after the expense of prolonging his life was weighed against, and ultimately defeated by, other broader health choices.²⁰² She highlights, too, that in another case, this time a successful claim brought by the organization TAC, the individual rights of the pregnant women denied Nevirapine (which helps prevent mother-to-child transmission of HIV) and that of their children happened to coincide with utilitarian interests of preventing the spread of HIV to the general public; as such the government was ordered to make the medicine available, amongst other

¹⁹⁹ Lehmann, Karin, 'In Defense of the Constitutional Court: Litigating Socio-Economic Rights and the Myth of the Minimum Core,' *American University International Law Review*, Vol. 22, No.1 (2006-2007), pp. 163-198, at 178

²⁰⁰ Interview with Maina Kiai, 26th May 2004.

²⁰¹ As noted in the Introduction, the new Kenyan constitution requires the State to "take legislative, policy and other measures, including the setting of standards, to achieve the progressive realisation of the [socio-economic] rights guaranteed under Article 43." (Art.21(2). Art.20(5) asserts that, "In applying any right under Article 43, if the State claims that it does not have the resources to implement the right, a court, tribunal or other authority shall be guided by the following principles- (a) it is the responsibility of the State to show that the resources are not available; (b) in allocating resources, the State shall give priority to ensuring the widest possible enjoyment of the right or fundamental freedom having regard to prevailing circumstances, including the vulnerability of particular groups or individuals; and (c) the court, tribunal or other authority may not interfere with a decision by a State organ concerning the allocation of available resources, solely on the basis that it would have reached a different conclusion." (Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010* (n 129), at 20)

²⁰² Lehmann (n 199), at 169. The case is *Soobramoney v Minister of Health, Kwazulu-Natal* 1998 (1) SA 765 (CC) (S. Afr.)

orders.²⁰³ This is an important point, for these decisions appear blind to the individual at the heart of these claims for socio-economic goods, for whom “pain, illness, and death are individual events.”²⁰⁴

And even with robust legislation and an effective, proactive judicial process, the realization of socio-economic rights may remain a mirage: London notes that the community at the heart of the landmark South African *Grootboom* case, for instance, which established socio-economic rights (in this case regarding housing) as justiciable under that constitution, still awaited the remedy that drove them to court in the first place; nor has the decision altered housing policy in any fundamental way.²⁰⁵ Litigation, unless its decisions are implemented and herald wholesale changes in health systems and policies, may only be a limited way of asserting health rights.²⁰⁶ Justiciability, after all, as Ghai rightly points out, is a last resort, deployed when all else fails, and so the role of courts in ensuring States meet their ESC obligations may lie in settling the question of the core entitlements of these rights.²⁰⁷ And as Charles Ngwena points out, if fundamental problems remain, as they do in South Africa despite its constitutional and judicial pioneering, of “disease and trauma, extreme disparities in income, and general poverty,” the adoption of a new legislative instrument may do little to alleviate the real socio-economic problems of most.²⁰⁸ With it goes another opportunity for the State to prove its effectiveness and legitimacy and foster a sense of equal citizenship and membership to a national community, and through this specific arm of its machinery engage in a positive exercise of nation-building. But in Kenya the idea of courts as avenues for redressing rights violations has long been fraught with problems, dogged for decades, like the other arms of State, by accusations of lack of impartiality and corruption.²⁰⁹

²⁰³ *ibid*, at 176. The case is *Minister of Health & Others v Treatment Action Campaign & Others* 2002 (5) SA 721 (CC) (S. Aft..

²⁰⁴ Alleyne, George A.O., ‘Health and Human Rights: The Equity Issue,’ *Health and Human Rights: An International Journal*, Vol.2, No.3 (1997), pp. 65-70, at 69

²⁰⁵ London (n 10), at 67

²⁰⁶ Gloppen (n 181), at t 22

²⁰⁷ Ghai (n 164), at 154

²⁰⁸ Ngwena, Charles, ‘The Recognition of Access to Health Care as a Human Right in South Africa: Is It Enough?’ *Health and Human Rights: An International Journal*, Vol.5, No.1 (2008), pp. 26-44, at 36

²⁰⁹ See, for instance, Sally Falk Moore’s account of the infamous S.M. Otieno case of the late 1980s, in which the highest courts in the land were widely seen to be doing then-president Moi’s government’s bidding in the decision regarding burial rights, which pitched the widow- an outspoken critic of the government- against her in-laws. (Falk Moore, Sally, ‘Systematic Judicial and Extra-Judicial Injustice:

The use of legal processes to address socio-economic rights may also hold other problems for the individual who can access its mechanism, inherent in the language applied by the law: she may find inadequate the existing confines of the language by which she is bound to express the fullness of her grievances. As Conklin writes, “in terms of the words of human rights enactments, the [claimant’s] circumstances are transformed into a network of terms which sanitize the pain which citizens incur during the events leading to the prosecution of a human rights violation.”²¹⁰ The language employed by experts takes in the individual’s pain and suffering and regurgitates it, “re-presenting [it] through signifiers which experts alone can ‘know.’”²¹¹ This results in the further isolation of the victims. Conklin argues that legal language, in hock to ‘reason’, drains the victim’s claims of all colour and texture: by neatly packaging her grievances, it conceals her particular experience and the depth and complexity of her suffering, and the underlying processes by which she has become disenfranchised. Unless her claims can be presented in such a language, she has no claims because the “written texts of statutes, regulations, and judges’ ‘reasons for judgement’ are believed to constitute the closest approximation to the will and voice of authority.”²¹² Language and the meaning of language therefore become yet another hurdle to claiming socio-economic goods: the victim’s reality is only validated once it has been transformed, through language, into the law(yer)’s reality.²¹³

For Ndegwa, all these are elements of the vibrant debate that has been taking place in Kenya since the late transformative 1990s, particularly in the urban-based civic realm where competing visions of citizenship rights were being articulated. One

Preparations for Future Accountability,’ in Werbner, Richard (ed.), *Memory and the Postcolony: African Anthropology and the Critique of Power* (London; New York: Zed Books, 1998). The Harmonized Draft Constitution of Kenya included a proposal- criticised by members of the judiciary- that would suspend all current sitting High Court and Court of Appeal judges, their readmission subject to their passing corruption checks. They complain that there are better ways to reform the judiciary, which poorly resourced and woefully understaffed. For instance, Kenya, with a population of 40 million has only 70 judges; Canada has 2,000 judges to cater for a similar population, while Ghana’s 22 million people have 83 judges. (*The Daily Nation*, ‘Judges Want Sacking Clause Cut out Draft,’ 22nd November 2009.

²¹⁰ Conklin (n 2), at 133

²¹¹ *ibid*, at 137. See also Odinkalu, who writes, “Instead of being the currency of a social justice or conscience-driven movement, “human rights” has increasingly become the specialized language of a select professional cadre with its own rites of passage and methods of certification.” (Odinkalu, ‘Why More Africans Don’t Use Human Rights Language,’ (n 3))

²¹² Conklin (n 2), at 141

²¹³ *ibid*, at 154

faction sought “to retain only minimal citizen’s right (i.e. subject status)”²¹⁴; the other, led especially by NGOs who since 1997 had embarked on a nationwide campaign for constitutional change, posited that individuals had certain intrinsic rights which were not gifts to be dispensed and withdrawn by the State on a whim.²¹⁴ Many interviewees for this research clearly appeared to espouse either idea but there was sometimes evidence of contradiction where an interviewee simultaneously affirmed a belief in her entitlement as a human being or citizen, while apparently basing any expectations of their fulfilment not on a rightful obligation on the State but on its magnanimous intervention. Reflecting the power dynamics between themselves and the State, many respondents felt that it should not or cannot be compelled to fulfil its obligations: Interviewee 9, for example, when asked whether the government should they be made to help PLWHAs meet their health needs said, “No, they shouldn’t be forced but it is their job.” Interviewee 19, asked if the government could help meet her healthcare needs said: “Yes they can. Like these drugs we are taking for free, isn’t that the government’s work? And if they want they can ensure this continues.” Further questions were deemed useful:

Interviewer: But the free drugs you’re getting are from MSF. I don’t know whether the government has had a role in it.

Interviewee 19: Well, if they wanted to get involved they could do it-nothing is beyond their abilities.

Interviewer: Ok. But should they be compelled?

Interviewee 19: Well, they should be approached and spoken to gently! (Laughs.)

Interviewer: So they shouldn’t be ‘compelled’?

Interviewee 19: No, they shouldn’t.

One even called for divine intervention as far as State action is concerned: “The government can and should help, and we’re still praying for the government, especially the Ministry of Health, to continue fighting hard so that they can continue reducing the price of these drugs because even [with] the Ksh 1,500 there are people who are still paying Ksh 3,500 for them. We’re lucky we get them for Ksh 1,500 here. So we hope the government continues fighting for us.” (Interviewee 10)

Another, while cognisant of how the State could help, did not feel entitled to demand its assistance because, she said, it had not been responsible for getting her infected:

If they know my problem, then maybe they can help. But even with the reduction of the prices of ARVs, isn’t that help that they have offered? So, I see that they can.” But

²¹⁴ Ndegwa, Stephen, ‘Citizenship Amid Economic and Political Change in Kenya,’ *Africa Today*, Vol. 45, No. 3/4 (1998), pp 351-368, at 361

when asked if they should be compelled to she said, “What if they are compelled and then refuse? I think they should help of their own accord. Can you force someone to help you yet they didn’t send you out there to go and get the virus?! But they do help. The reduced ARV prices are a huge help. (Interviewee 40)

Although far more respondents were uncomfortable with, or uncertain of, the notion of compelling the government to act, there were those for whom even the more precise Kiswahili question about compelling the government to act was not too stern a proposition. Interviewee 18, for instance, was adamant: “Even the government should get in the middle of this [crisis]. Because it is the head. They should look after me in every way if I am struggling, for example in giving money for the drugs.... Yes, they should be compelled to help the citizen.” The trend, however, indicated perceptions of disempowerment: many respondents appeared resigned about the conduct of the State and felt unable to effect change in its behaviour despite the implied automatic privileges of citizenship. And according to Ekeh, it can only encourage further alienation of the individual from the State and her retreat to that other public: the customary or primordial. As noted elsewhere, many interviewees revealed claims of membership, however transcendental or lapsed, to sub-national, rural communities, although a considerable number were likely to be urban migrants, resident in a sphere where notions of membership to a wider national community have more traction.²¹⁵ Alluding to a community and place with phrases like ‘back home’, respondents claimed certain entitlements based on membership to age-old ethnic, land-based societies.²¹⁶ They claimed assistance with their healthcare needs, psychological comfort, indeed, communion and fraternity.

The experiences of residents of the Kibera informal settlement in Nairobi, among whom numbered some interviewees for this research, provides useful insights into the lengths urbanites often go to in order to preserve their primordial ties in the ethnic sphere, and the struggles of establishing and sustaining new ones in the urban environment. Sarah Jenkins observes that many residents continue to travel back to their rural villages for cultural events, and even after death bodies are often

²¹⁵ See also Ndegwa, ‘Citizenship and Ethnicity: An Examination of Two Transition Moments in Kenyan Politics,’ (n 169), at 603, on how these bonds are maintained by migrant populations with their kin in the rural areas.

²¹⁶ Mamdani, Mahmood, *Citizen and Subject: Contemporary Africa and the Legacy of Late Colonialism*, Princeton, NJ: Princeton University Press, 1996) (1996), at 292

repatriated back to these villages for burial, for “no matter how long you have lived outside the land of your ancestors, it remains the place where you belong.”²¹⁷ She notes that this practice of repatriation went on despite the dangers posed by the post-election violence of 2007, in which Kibera was a major flashpoint.²¹⁸

Yet these urban migrants also actively seek ways to gain a foothold in their new environment in order to claim citizenship in it and in the wider national public. Paradoxically, burial again provides an opportunity: Jenkins writes of members of the Luo ethnic group in Kibera, whose claims of entitlement to the land here the Kenyan government has consistently denied, burying their dead within the informal settlement, for “[i]n the absence of title deeds the practice of burying the dead within Kibera is frequently invoked to substantiate claims of belonging.”²¹⁹

There is intense competition for limited resources in these marginalized spaces and multiple intractable socio-economic challenges such as inadequate- yet expensive- shelter.²²⁰ The ethnic enclaves that have developed here thrive in defiance of the multi-ethnic urban setting.²²¹ The notion that access to favours or benefits may be contingent on ethnic identity creates hostility and bitterness that only galvanize kinship and filial ties to the family, clan and ethnic group.²²² As such, it neatly and perfectly exemplifies the citizen-subject tensions Mamdani and others describe, and provides a theatre upon which their sometimes violent manifestations are played out. This is what happened in 2007/8. As one Kibera resident informed a BBC reporter in the violent aftermath of the 2007 national elections, “unless President Kibaki [the Gikuyu incumbent whose contested re-election had sparked the violence] and Mr Odinga [his Luo rival for the presidency] can solve their differences, the ethnic tensions are here to stay. ‘In some parts of Kibera and Nairobi, you have to be sure of

²¹⁷ Jenkins, Sarah, ‘Ethnicity, Violence, and the Immigrant-Guest Metaphor in Kenya,’ *African Affairs*, 111/445 (2012), pp. 576-596, at 580

²¹⁸ See Mwakagu, Noel, ‘Kibera Residents Wary of Ethnic Politics,’ BBC News Online, 15th January 2008, at <http://news.bbc.co.uk/1/hi/world/africa/7190263.stm>, accessed 20/09/13

²¹⁹ Jenkins (n 217), at 581

²²⁰ Marx, Benjamin; Stoker, Thomas M.; and Suri, Tavneet, ‘There is No Free House: Ethnic Patronage and Property Rights in a Kenyan Slum,’ Working Paper, available on Massachusetts Institute of Technology (MIT) website at <http://mitsloan.mit.edu/newsroom/2013-tavneet-suri.php>, accessed 03/02/14, at 3

²²¹ Jenkins (n 217), at 582

²²² Marx, *et al* (n 220), at 3

the crowd you are talking to, to avoid being on the wrong side of the ethnic divide.’”²²³

Adejumobi might have been writing about Kenya and not Nigeria when he highlighted the role of ethnic rather than national citizenship identity in political life, and the extent to which it determines access to social and economic benefits, all of which undermine the notion of equal citizenship.²²⁴ Indeed, Ekeh might conclude that some respondents’ despondent feelings about State inaction exposed the underlying lack of the moral imperative which he asserts might otherwise bind individuals more effectively to the civic public.²²⁵ The postcolonial State, he argues, despite the few interviewees who imputed to it the esteemed parental status, is at fault for failing to nurture the trust of the individual. Many Africans generously tend their links with the primordial public even though they might extract little economic benefit from it.²²⁶ But the privileges they draw from citizenship in the primordial public should not simply be reduced to economic terms, which fail to capture the vital, though intangible “identity or psychological security” they also extract.²²⁷ They feel a moral duty to contribute to and maintain their primordial publics but de-emphasize obligations over rights with the civic public, to whom they do not feel morally bound and from whom they look only for material gain.²²⁸

The utility of these multiple citizenship claims to PLWHAs is obvious: as discussions throughout this research have shown, their experience has often been one of stigmatization and rejection- ejection- from various levels of community. Any new avenues for association and community thus present considerable advantages, despite the fact that they may be founded on excluding others, who might equally deserve assistance, simply because they do not share a particular ethnic identity. It is precisely this exclusion that was alleged by a number of respondents during the Mbagathi District Hospital group session I attended: they claimed to have been denied membership to some local HIV/AIDS NGOs and support groups because they

²²³ Mwakagu, ‘Kibera Residents Wary of Ethnic Politics,’ (n 218)

²²⁴ Adejumobi (n 168), at 161

²²⁵ Ekeh (n 145), at 92

²²⁶ *ibid*, at 108

²²⁷ *ibid*, at 107. See also Ghai (n 164), at 141

²²⁸ Ekeh (n 145), at 107

and the organizations' key leadership were not co-ethnics. A couple of organizations were mentioned and matched to their favoured ethnic group, with widespread concurrence by session participants.²²⁹

And Ndegwa points to another underlying danger: the rights that can be claimed in the customary or primordial sphere are narrowly defined. Comparing national and ethnic citizenship he asserts, "[I]n the ethnic community, citizenship can be best characterized as illiberal and republican. Whereas liberalism is centred on the individual, ethnic groups are centred on the community, and a person cannot claim rights that would jeopardize group claims."²³⁰ This tension revealed itself often in the interviews and was evident, for instance, in the responses where PLWHAs claimed dignity for themselves while appearing to deny it to those counterparts they considered in violation of prevailing sexual norms. There may also be more sinister consequences where unequal national citizenship rights lure the individual closer to her sub-national identity group, which, when coupled with the high-stakes, zero-sum game of Kenyan presidential elections, can result in the kind explosive violence of late 2007/early 2008.²³¹ For while ethnicity, as Ghai observes, may offer a platform for challenging State oppression, it also "dulls the consciousness of rights... [Whereas] human rights seek to bring groups within a broader unity, emphasizing our common humanity, ethnicity fragments." Indeed infringing the rights of others seems to be condoned and may in fact be welcomed.²³²

²²⁹ Evan S. Lieberman posits a fascinating hypothesis that in ethnically-fragmented countries where the State is dominated by a particular ethnic group, its ruling elite may actually underplay the need for AIDS treatment (unlike other public goods) for its own group "because it would require a highly public claim that the ethnic group is afflicted with the stigmatized problem." (in Lieberman, Evan S., 'Ethnic Politics, and Risk, and Policy-Making: A Cross-National Statistical Analysis of Government Responses to HIV/AIDS,' *Comparative Political Studies*, Vol. 40, No. 12 (2007), pp.1407-1432, at 1414

²³⁰ Ndegwa, 'Citizenship and Ethnicity: An Examination of Two Transition Moments in Kenyan Politics,' (n 169), at 603

²³¹ Adejumbi (n 168), at 156. For Kenya's election violence see Commission of Inquiry into Post-Election Violence (CIPEV), *Republic of Kenya Report of the Commission of Inquiry into Post-Election Violence*, 2008, at

http://www.kenyalaw.org/Downloads/Reports/Commission_of_Inquiry_into_Post_Election_Violence.pdf, accessed 10/03/10; Ashforth, Adam, 'Ethnic Violence and the Prospects for Democracy in the Aftermath of the 2007 Kenyan Elections,' *Public Culture*, Vol. 21, No.1 (2009), pp. 9-19. See also Klopp, Jacqueline, "'Ethnic Clashes" and Winning Elections: The Case of Kenya's Electoral Despotism,' *Canadian Journal of African Studies*, Vol. 35, No. 2 (2001), pp. 473-517.

²³² Ghai (n 164), at 141

Yet alongside the examples of the apparent mistrust of the government, there was still evidence of acceptance of the State's presence if not legitimacy, not least in the presumption, manifest in all responses, of at least some relationship with it, and even a readiness by some respondents to explicitly knit themselves closer to it. As noted, some even went as far as comparing it to a protector or parent, perhaps only to strengthen their claims to its benefits, perhaps trusting it as a "neutral [arbiter] of injury" and overlooking its capacity to inflict it.²³³ In appearing to base their health and other socio-economic entitlements on their Kenyan citizenship, such respondents were arguably actively entrenching a role for the State in their own identity.²³⁴ They showed a consciousness of modern individual-State relations, through which this entity accords a civil identity to its nationals, binding them to it.²³⁵ This in itself is interesting: for as Ndegwa points out, in Kenya, as in many postcolonial African countries, the State alone defined and then conferred citizenship rights rather than the population negotiating, through a struggle, the parameters of such privileges.²³⁶ But the attitudes expressed by a number of respondents above suggested a willingness to articulate thoughts on the nature of citizenship and how its benefits should be apportioned. It appears to provide grounds for the earlier-noted emphasis on the social, inclusive, and participatory aspects of a recast concept of citizenship: as Ely Yamin asserts, for its proponents, "such notions 'suggest a more active notion of citizenship- one that recognizes the agency of citizens as 'makers and shapers' rather than as 'users and choosers' of policies, programs, or interventions.'"²³⁷ It also supports the point raised in the previous chapter, of an increasingly politically assertive electorate readier to probe and influence its relationship with the State, no doubt inspired by greater civil society activism.

This, however, has coincided in Kenya with an increased failure by the State to meet its socio-economic duties.²³⁸ Civil society organizations (CSOs), especially in the age of globalization, continue to contest the monopoly of professional politicians to

²³³ Baxi (n 31), at 145

²³⁴ Halisi, Kaiser and Ndegwa (n 171), at 340

²³⁵ Marks (n 47), at 474

²³⁶ Ndegwa, 'Citizenship Amid Economic and Political Change in Kenya,' (n 214), at 352

²³⁷ Ely Yamin, 'Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,' (n 109), at 15

²³⁸ Ndegwa, 'Citizenship Amid Economic and Political Change in Kenya,' (n 214), at 351

represent citizens in the public sphere.²³⁹ This phenomenon is exemplified by the rapid increase of PLWHA rights advocacy groups and health NGOs, the latter of whom it will be recalled were perceived by some interviewees as more equitable than, and preferable to, the government in the provision of their other medical needs. Such groups have thus become hugely influential in the way PLWHAs and other Kenyans view their relationship with State and how they constitute themselves as subjects, playing a vital role in the effort to transcend the merely formal rights of citizenship that nationality accords them and raise them to fully-fledged rights-holding citizens. The trend towards using judicial action to enforce socio-economic rights offers further avenues of influence for CSOs. Petchesky cites the *amicus curiae* or 'friend of the court' intervention (now also provided for in Kenya's new constitution²⁴⁰) by the TAC in the lawsuit filed by pharmaceutical companies against the South African government as an example of successful campaigning which targets both the court and wider public opinion.²⁴¹

Alice Miller's analysis of the challenges facing victims of violence against women in their citizenship claims also offers useful parallels for PLWHAs. She writes of the evolutionary journey that the narrowly-defined victims of sexual harm have to make from "suffering [female] bodies in need of protection by the law and the state [to] bodies and minds in need not only of protection, but participation and equality."²⁴² Such a construction, embedded by human rights organizations themselves, ultimately diverts attention away from the national and transnational systems that create the conditions for the violation of these rights. Further, this evolution is inhibited by the cementing of a paradigm which casts the victim ideally as a chaste, reticent woman. Only if she conforms to this image is she recognized as a human person who is law's subject and can rightfully claim its protection.²⁴³ Meanwhile, trafficked women, sex-workers and others whose sexualities are deemed questionable find less protection, if

²³⁹ *ibid*, at 363. See also Halisi, Kaiser and Ndegwa (n 171), at 341

²⁴⁰ See Art. 22(2)(b), (c) and (d), quoted earlier (in note 188). (Republic of Kenya, *Laws of Kenya: The Constitution of Kenya, 2010* (n 129))

²⁴¹ Petchesky, Rosalind P., *Global Prescriptions: Gendering Health and Human Rights* (London; New York: Zed Books, 2003), at 88. See also, Gloppen, *op. cit.*, at 28, for the role that *amicus curiae* might play in a successful litigation.

²⁴² Miller, Alice M., 'Sexuality, Violence Against Women, and Human Rights: Women Make Demands and Ladies Get Protection,' *Health and Human Rights: An International Journal*, Vol.7, No. 2 (2004), pp. 16-47, at 27

²⁴³ *ibid*, at 29

any, under the law, as they do not fit the accepted image of a rape victim.²⁴⁴ This is especially the case if they display any sexual agency. When advocates move their campaign beyond the focus on sexual harm against sympathetic victims and into other areas such as sexual health or equality, they find themselves silenced and attacked as lesbians or prostitutes.²⁴⁵

There are insights for PLWHAs' advocacy campaigns here: they, too, have travelled – and continue to travel- a considerable distance to be recognized as full rights-holders. Miller's meaning of 'distance' is adopted here, of "barriers placed (sometimes in law) by social stereotypes around gender, sexuality, age, race or ethnicity, for example."²⁴⁶ From the earlier popular images of PLWHAs as gay, promiscuous men or helpless, body-wasted Africans in remote villages, one can see the challenges PLWHAs have faced down the decades to establish themselves as human beings, let alone citizens. The State has routinely regarded these groups with hostility and/or indifference. These images discourage the notion that these groups, too, have equal and valid claims to the law's protection from discrimination, and to health and other social and economic goods; that their lifestyles, choices or circumstances are to be recognized and accepted, not pitied or ignored at best, criticized or punished at worst. Popular perceptions of moral transgression and lack of innocence associated with sexual agency come into play, despite the irony that it is precisely a lack of agency that makes women, in particular, vulnerable to HIV infection. Further, PLWHAs are afflicted by an illness which in its final stages physically transforms them in a manner even more removed from many people's notion of what a human person looks like, prompting several PLWHAs to withdraw from public life.

The continued recognition of PLWHAs' rights claims owes much to the vigorous efforts by local and global advocacy groups to challenge such stereotypes and to represent the image of the PLWHA as everyman/woman: for even more socially sympathetic victims such as heterosexuals, and particularly heterosexual men, nationals of developed countries, members of higher socio-economic classes, children and so on can be afflicted. Hence the promotion of high profile HIV sufferers and calls

²⁴⁴ *ibid*, at 34

²⁴⁵ *ibid*, at 37

²⁴⁶ *ibid*, at 30

for politicians and other well-known personalities to take HIV tests and publicize their results.²⁴⁷ If they can be infected, the message goes, so can we all; if they can be the image of a PLWHA, so can we.

Yet even as the rights of PLWHAs become more widely recognized there is still resistance even within the PLWHA community itself, as evinced by those earlier-noted interviews, to the claims of tricky subjects of the law such as drug users, men who have sex with men and sex-workers. It is another reminder that the journey to becoming a rights-holder is not equal for all within the PLWHA body itself and that here, too, multiple sub-strata of identities exist. It also suggests that a psychoanalytical discussion of law, seen shortly, may be a useful tool for examining how the law might deal with the complex and varied notions of self that the interviewees revealed.

The decision to go public is an important process in the PLWHA's claim for citizenship and may be seen even in the simple decision to be interviewed and have one's experiences recorded. Miller re-emphasizes this, writing of the campaigning strategies of breaking the silence and intimate story-telling that were used to draw attention to women's right to protection against sexual harm.²⁴⁸ They raise the profile of this human rights violation and explode myths on issues like marital rape and normalization of rape in war.²⁴⁹ These strategies have benefitted PLWHA rights campaigns and the interview process itself may be seen as a modest extension of this: in revealing her sero-positive status, circumstances of infection and claims for assistance on family, friends or the State, the interviewee is asserting her humanity and asking the interviewer to recognize her claims.

In speaking for herself, the PLWHA stakes her claim in the public sphere and further asserts her citizenship though the process might be, as it often is in reality, periodic and in degrees. For as Fraser notes with specific reference to the women's struggle-

²⁴⁷ See reports of some Kenyan MPs publicly submitting to HIV tests (*The Daily Nation*, 'MPs Have to Lead Fight Against Aids,' 9th April 2007); see also then-Senator Barack Obama taking an HIV test during a visit to his visit to Kenya (*The Daily Nation*, 'Obama to Take HIV test at Father's Home,' 23rd August 2006) and reports of Tanzania's president Kikwete and his wife taking an HIV test in public (*The Daily Nation*, 'Kikwete and Wife Take Aids Test,' 17th July 2007)

²⁴⁸ Miller (n 242), at 25

²⁴⁹ *ibid*

and this is especially relevant to the female respondents of this research- this allows a woman to publicly narrate her own experiences unmediated by men and is critical to asserting her identity as an individual human being.²⁵⁰ The same applies to all the PLWHAs, including those interviewees who spoke but chose to retain their anonymity: their tentative steps onto the public arena should be seen in the light of their understandable need for privacy and the sometimes disastrous consequences that have accompanied disclosure of HIV status, and their choice by no means devalues their claims for individual recognition. Such exposure gives the PLWHA an identity or presence in a sphere through which she can negotiate with the State and each interviewee arguably claims a right to this very space whenever she references the State and articulates the experiences of her interaction with it. But staking a claim in the public sphere makes her much more than just a subject on the national arena, for as Buergenthal points out, the individual is now recognized as a subject of international law in her own right to the extent that she is the rights-bearer of international human rights law.²⁵¹

III. Psychoanalysis, Subjectivities, and Notions of Entitlement

Throughout this research, the plurality PLWHAs' senses of self have been manifest despite their shared identity-defining illness and (likely) Kenyan nationality. These varying subjectivities fundamentally influences how they interact with each other and with those who play a role in helping or hindering their efforts to meet their health needs, from family and community members to State and extra-State entities. PLWHAs' perceptions about their place within this complex social, economic and political grid and their notions about its system of entitlements and obligations moulds the choices and strategies they adopt to meet their health needs. Subjectivity therefore becomes central to a debate on entitlements to health and the realization of health rights, and the theory of psychoanalysis, which is particularly concerned with subjectivity, is thus a worthwhile lens through which to further analyze the concept.

²⁵⁰ Fraser (n 126), at 860

²⁵¹ Buergenthal, Thomas, 'The Normative and Institutional Evolution of International Human Rights,' *Human Rights Quarterly*, Vol.19, No.4 (1997), pp. 703-723, at 708

Psychoanalysis draws on the work of philosophers like Jacques Lacan, whose reputedly dense writings I make no attempt to discuss directly here.²⁵² But his theories anticipate the multiple aspects of the Kenyan legal subject as revealed by the interviews: Lacan's subject has "no inside (e.g., psyche) and outside (e.g., culture)... so everything - identities, desire, language, society, law - seems to be involved in the constitution of the subject."²⁵³ The interviews reveal subjects whose identities are sometimes diametrically opposed to the legal subject as conceived in various human rights instruments, which see her as a "conscious, sovereign individual subject- the conventional liberal subject."²⁵⁴ Psychoanalysis adopts a more robust perspective, proposing instead that a subject's unconscious life is instrumental and shapes her according to her view of herself and those around her.²⁵⁵ The subject is not a predefined or complete entity but "reflectively and intersubjectively constituted."²⁵⁶

Psychoanalysis therefore poses a fascinating conundrum for the law: the law does not- perhaps cannot- presuppose the subject as a moving target, a changeable creature, or it must alter its precepts. Instead legal theorists attempt to pin down a singular subject who encompasses the 'essential self,' an exercise which still preoccupies some today, as seen in Brugger's attempts to bridge the universalist-versus-cultural relativist divide. This abstract creation may provide the preferred template that "allows theorists to discuss liberty, property, and rights in the aspirational mode of liberalism with no connection to what those concepts mean in real people's lives."²⁵⁷ Yet there is no such thing as an 'essential self'.²⁵⁸ The reality instead is of "multiple and contradictory selves," an idea perhaps well illustrated by the dignity-claiming interviewees who rebuked other PLWHAs as prostitutes, and

²⁵² Lacan's writing has been criticized for taking "the art of obfuscation to new height, making straightforward ideas unnecessarily opaque and complex," and the suggestion made that "he could have used a good freshman writing course." (Richard E. Redding, reviewing Caudill, David S., *Lacan and the Subject of Law: Toward a Psychoanalytic Critical Legal Theory* (Atlantic Highlands, N.J.: Humanities Press, 1997), in 'Does Law Need an Analyst? Prospects for Lacanian Psychoanalysis in Law,' *Washington and Lee Law Review*, Vol. 54, No. 3, (1997), pp. 1119-1146, at 1122 and 1123

²⁵³ Caudill (n 252), at 73.

²⁵⁴ Schlag, Pierre, 'The Problem of the Subject,' *Texas Law Review*, Vol. 69, No. 6 (1990-1991), pp. 1627-1743, at 1730

²⁵⁵ Stacy (n 149), at 277

²⁵⁶ Douzinas (n 39), at 323

²⁵⁷ Matsuda, Mari J., 'When the First Quail Calls: Multiple Consciousness as Jurisprudential Method: A Talk Presented at the Yale Law School Conference on Women of Color and the Law, April 16 1988,' *Women's Rights Law Reporter*, Vol. 11 (1989), pp.7-10, 9

²⁵⁸ Stacy (n 149), at 286

indeed of no self at all at the outset.²⁵⁹ But when the law speaks- through, for example, human rights instruments- who does it speak for and to whom is it addressed? Or rather, which notion of the subject and political interests does it represent?

Some feminist theorists argue that women's unique role as child-bearers and as primary child-rearers means that their selves are fundamentally different from the male.²⁶⁰ For them the presumption appears to be of a single notion of self that is bifurcated only at the point of sex but that is otherwise the same for all women, as all men, regardless of their other identities of race, class or sexuality.²⁶¹ But critics of this notion of essentialism contend that the presumption that all women prioritize the gender aspect of their subjectivity as opposed to, say, their race, betrays a preference for recognizing the experiences of white over black women.²⁶² This is a particular argument among postcolonial feminist theorists, who critique the usurpation of the right of women in less geopolitically dominant environments even to define their experiences. Ratna Kapur, for instance, problematizes the notion of a 'global sisterhood' as an expression and extension of the hegemonic status quo by means of the universalization of women's experiences.²⁶³ Yet others might suggest any of the identities mentioned above, and more, as the most central to their notion of self. These are important issues here because they not only help illuminate the hidden values and preferences of the law but also provide a context for some of the seemingly contradictory values revealed in some respondents' answers. It should not be automatically assumed they are necessarily blind to these contradictions- claiming dignity while denying it to others, for example, the capacity to be the oppressors as well as the oppressed.²⁶⁴ The responses may be a confident assertion of their multiple identities and a claim of their right to a split selfhood.²⁶⁵

²⁵⁹ Harris, Angela P., 'Race and Essentialism in Feminist Legal Theory,' *Stanford Law Review*, Vol. 42 (1989-1990), pp.581-616, at 609 and 584. See also Ely Yamin 'Suffering and Powerlessness: The Significance of Promoting Participation in Rights-Based Approaches to Health,' (n 109), at 14

²⁶⁰ Harris (n 259), at 602

²⁶¹ *ibid*, at 603

²⁶² *ibid*

²⁶³ Kapur, Ratna, *Erotic Justice: Law and the New Politics of Postcolonialism* (London: GlassHouse, 2005), at 4.

²⁶⁴ Harris (n 259), at 609

²⁶⁵ Stacy (n 149), at 286

Understanding the complexity and multiple consciousness of the individual at the heart of the human rights project may facilitate a re-evaluation of her aspirations and expectations with regards to her health needs, and provide insights into how she internalizes and strategically prioritizes certain human rights norms for adaptation at the grassroots level. For while legal theory flattens the individual's identity into an abstract shape, offering no accommodation for the irregular contours of her subjectivity, a psychoanalytical perspective may help health and human rights policy-makers and advocates reclaim her and provide perspectives that may help bridge the gap between possessing rights in theory and realizing them. Psychoanalytical theory illuminates the coexisting and sometimes contradictory interests that are represented in the health entitlements claims made or not made by PLWHAs. And because subjectivities are fluid, influenced, as seen, by such factors as contact with CSOs, human rights and development advocacy strategists will be more successful if they abandon entirely the convenient notion of a ready-made, self-aware, autonomous subject and focus on how to shape the subjectivities of their audience and help nurture a sense of entitlement to health. This would help to better engender a human rights culture that has roots in the local communities in which it operates and which can flourish long after the activists have gone. As Petchesky notes, "political action can be effective only if [those affected] believe in and own their rights."²⁶⁶

IV. Shaping Notions of Entitlement, Rooting Human Rights

As a result of the varying subjectivities and normative paradigms which ground claims to health entitlements, a range of perceived duty-bearers emerged among the PLWHAs, as well as rationales for thus locating these obligations. They are responses that rights campaigners and others would do well to take note of: the majority, such as interviewee 25, expressed certain entitlement claims from more than one actor:

I think everyone must take part with HIV. Like now I have gone public so it has become a responsibility of all my family, now that I have disclosed [my seropositive status]. Whenever I have a problem, they take responsibility. It becomes a problem when you've not told them because they won't know whether you're sick. But personally I think it's my responsibility and also the government must also chip in to assist us especially on ARVs. Like now I've come all the way from Murang'a to here. If they were available in Murang'a, it could be cheaper. But now you have to take transport to come here for treatment and that is quite expensive.

²⁶⁶ Petchesky, 'Introduction,' (n 36), at 5-6

Only about a quarter perceived the government as the exclusive or primary duty-bearer, as human rights frameworks dictate and advocates would have them understand. As well as the respondents reviewed in Chapter 5 who argued that the government's main responsibility was to provide them with employment to facilitate their self-sufficiency interviewee 3 noted: "Like the ARVs nowadays: the government is supposed to give these because I hear that there are some donors giving out money....Yes, it's the government [that should provide] because donors have come out to help- at least we read in the papers that such and such a country has given this towards this project and so on, and nothing has been done." Petchesky rightly argues that a sense of entitlement to rights may be easier to form and claims less difficult to express where more remote figures or decision-making authorities are concerned; it is much harder against actors closer to home (such as the sexually unfaithful partners mentioned in some interviews who refused to use condoms, or relations reluctant to assist in meeting the healthcare needs of PLWHAs they deem undeserving) although this is the site of many human rights violations.²⁶⁷ One respondent, interviewee 14, pointed out the government's vested interest in preserving PLWHAs' health to avoid exacerbating other problems with socio-economic implications like the large orphan population: "Well, I still feel that because this is a life-long thing, the government should do more than it has done because parting with this money every month [for ARVs] and we're family people who have to take care of these children, it's a bit difficult...[W]e just bank on the government because relatives are never there most of the times... [A]t the end of the day, if I die, the government has the burden of taking care of the orphans and so on. It will be a burden on the society so if they can make the drugs more affordable to everyone, so that we can live and help in nation-building it will ease the government's burden." For another, the government had a duty to assist the many affected poor: "I think because this is a situation that is affecting so many people and many of those affected happen to be living below the poverty line so I think the government should try and do something with the diet, the medication, so many people cannot afford these medicines." (Interviewee 31)

Perhaps Petchesky's observation merely reaffirms the primacy of alternative frames of reference in the location and articulation of entitlements and obligations, for other

²⁶⁷ Petchesky, 'Introduction,' (n 36), at 11

interviewees made claims against those with whom they had blood or marriage ties; for many of them, the possibility of rejection was a constant and present concern. Interviewee 20, for example, volunteered 'family' should have been included in my questionnaire's list of actors who might assist PLWHAs, but added, "[F]or me, no one has helped me pay for my daughter's school fees. Most of them stigmatize people." The particular responsibility of male spouses to meet their wives' healthcare needs was highlighted by several female interviewees, which is unsurprising in the context of the social and cultural structures outlined in Chapter 3. Interviewee 43, for instance, said, "It's my husband's duty because if he had a good job, he would be the one providing for me, but he does not." Meanwhile, for interviewee 7 the situation was clear: "I am married and I have no job, so it is my husband's duty to provide for me." Lack of a husband meant the absence of the principle automatic duty-bearer for one respondent, interviewee 40: "It's my duty [to meet my health needs]. Who else will do it? I'm not married, the child I have is not employed, so who else? But God loves me and I get along, and the stronger I get the money strength I have to do my small business."

Other interviewees' claims on their sexual partners were based on their beliefs that they were responsible for infecting them:

It's my husband's if possible, because I am a married person. He was supposed to be responsible but he is irresponsible in providing for me so the in-laws are doing it... [It is his responsibility] because we're together. When I came from my home I was not having that disease. I gave birth the first time and the kid was ok- it did not have that disease. We got it because this is someone who is a drunkard, out of carelessness." (Interviewee 8)

It should be the one who gave me this disease- he should be responsible for providing for my needs. But he left his work and it is as if he now wants me to take care of him as well. And with the children there, too, you see, it becomes a burden. [He should provide] because he gave me the illness. To be honest in my whole life, I have never slept around. He is the only man I knew. So it is very painful. I thought he would go on with his work so that we can look after our children. But he didn't. (Interviewee 9)

For interviewee 18, her husband was still responsible even in death: "It should have been my husband's duty were he alive but I he isn't, and I have children... [B]ecause this is his household. I couldn't have taken our problems anywhere else." For another, interviewee 35, the task was shared between her husband and NGOs, with the latter

shouldering the greater obligation. Her comments will be recalled from Chapter 2 (in the text immediately following note 31) , as she thought I was an NGO representative:

It's the responsibility of people like you! So I am very glad that I met you! You can help me! You and my husband combined can help me! Because I think that these organizations especially, more than even my husband, are the ones with the ability to help me. My husband can then help a little.

Interviewee 41 exemplified the aforementioned notion of ever changing subjectivities, illustrating how HIV had altered her perceived role within the family dynamic, and, arguably, crucially, her perspective on entitlement claims: "I think it's my duty and also my husband's for each of us to take care of our needs... because we must both try and do something to survive. This is not a time to say that the husband should work while the wife stays at home. Everyone must make a contribution." For interviewee 33, the responsibility reverted to her children, as it traditionally would: "[It's] my daughter's [responsibility]!" she replied, "because she herself brought her husband and we all agreed that she would look after me."

A few respondents even saw religious institutions and officials as having an obligation to assist particularly with their psychosocial needs, as seen in Chapter 6, despite the fears explored there of condemnation and rejection for perceived sexual trespasses and doubts about confidentiality:

They can help by using the money they collect in their churches to alleviate the needs of some of their congregation, even if it's just 5 or 10 people, because every church has its own PLWHAs. For example if you are a Catholic, your church should help you- but I should not put the Catholic Church down, they have really helped. But the problem is that the moment you volunteer information that you're a PLWHA, the gossip starts. So many people just keep quiet and die in silence in their homes. (Interviewee 37)

Even church leaders. They should pray for people, give them hope. With God, everything is possible. I know. I didn't even have drugs, I was just left there, sick, with no food. Someone has run away from you, you have a child, you're sleeping hungry, waking up hungry, you have no money. But I know through God, everything is possible for me- that's why I'm alive now. (Interviewee 8)

But interestingly the majority of respondents saw the obligation to maintain their health burden as wholly or primarily their own, which may have been inspired by different ideas from the varied norms and moral frames of reference. On the one hand, attributing the obligation to oneself may be influenced by a sense, articulated

by some, of the injustice of shifting the onerous task of providing for PLWHAs onto others who may be unable to bear it:

I think it is my own because no one else is able to help me. [A]ll the others in my family have their own responsibilities and only small means just like myself, and they have their own families. You know, when a parent gives birth to you they feel they must help you, even if it's by something small such as buying you a bar of soap or *leso* [wrapper]. And with an illness like this, if you tell your parents about it, it will kill them even before their time is due. (Interviewee 30)

Interviewee 6, though mentioning the role played by NGOs, opined: "It is mostly my duty to provide for myself...to make sure I'm living, eating, sleeping... I think it is nobody's responsibility. ...When it comes to assistance I cannot blame anybody, even my parents I don't have to blame them, or my brothers and sisters. It is none of their responsibility." After all, it is important to remember that perceived duty-bearers are often also rights-bearers whose own rights are not being fulfilled. There may also have been considerations of a human rights-related notion of personal dignity, for "at the core of human dignity lies the ability to be an affective agent in guiding the course of one's own life."²⁶⁸ Moreover, recalling Mann's first and second type of dignity violation- refusal to 'see' the individual and her subsumption into a group identity- PLWHAs who declared that they should provide for their own needs (whether or not they in fact could) may have been contesting the refusal to see them as (potentially) productive individuals and any notion that homogenizes and characterizes them all as helpless victims unable to work, reliant on- or sponging off- the charity of family, friends, society and government. This is evident from the many respondents who desired only that the government create economic conditions which would enable them to find work to meet their own needs. The opinions of interviewee 16, who identified herself as the main duty-bearer for meeting her health needs because she alone had assumed the risks of infection (sexual intercourse while a student), have been mentioned in other chapters. They are echoed by interviewee 35, who while dismissing the idea of compelling the government to assist and regarding its commitments as charitable appeared to be influenced in her limited sense of entitlement to make claims from the government because of the mode of infection: "Yes, [the government] can help by meeting and talking about this issue and if there is some money left over they can use to do something useful [but] how can you

²⁶⁸ Freedman (n 138), at 324

compel the government as if it is the one that gave you this illness! It should be by their own free will.”

But it was the need for self-sufficiency, undoubtedly encouraged by the lack of State welfare provisions, that may have prompted many to identify themselves as the main duty-bearers in the provision for their health needs. Some notions of self-reliance were linked to customary as well as modern ideas about adult or parental responsibilities. For interviewee 14, “It is my duty because I am an adult and so need to provide for myself.”; for interviewee 10, “It is just me. If I don’t and I have my children to look after, it is me who will go down. I must struggle the much I can.”; likewise, interviewee 42 said: “It is my responsibility... because I should be the one looking after myself and my child just like my mother did for me. And but for my health, I would, too.”

Others notions of duty-bearing were bound up with traditional cultural and religious perceptions of gender roles, with some male respondents illustrating how these frameworks and norms continued to shape individual subjectivity and consequently notions of duty and entitlement amidst increasingly-weakened traditional social bonds and systems of obligations. Interviewee 24 felt:

It’s my duty...[b]ecause... when you rely on someone else all the time you don’t enjoy it. But if you have your own money, you like it better because you’re in control. You don’t have to go to someone and say, ‘I don’t have any meat’ - you find some might even get angry. And that anger is not good for your health.

Interviewee 32 said it was his responsibility because he was “supposed” to take care of himself. Outside help, even from family was also a last resort for interviewees 44 and 39: the former said, “I can explain it to someone and ask for help but at the end of the day, the responsibility is mine. If I had a job and I was healthy, I would be able to provide for myself.” The latter asserted, “It should be myself, but because I can’t afford, that’s why my immediate family helps. ...[I]f I was working, I would be doing it by myself. I would not go seeking help from others. Also I think the government should try giving free ARVs.”

Finally, these responses may be influenced by the empowerment paradigm in the development and health promotion sectors. Its emphasis on self-sufficiency and ‘self-

determination', as espoused by some key development organizations in Kenya may be pragmatic given the State's shortcomings in providing socio-economic goods but it raises questions about its position on holding the State accountable for what are often failures to fulfil its human rights obligations.²⁶⁹ The success of the empowerment model might also be seen as an aspect of Baxi's bleak market-led human rights paradigm, with its credo that "in the absence of economic development, human rights have no future at all."²⁷⁰ Yet individual economic empowerment and the fulfilment of State human rights obligations are, of course, not mutually exclusive. Indeed the role of the individual in meeting her socio-economic needs through her own resources has been anticipated in such documents as the UN General Assembly Declaration on the Right to Development²⁷¹, the source of such ferocious opposition from donor countries, as seen in the introductory chapter.²⁷²

Where, then, does all this leave the human rights project? Its paradigm arguably resembles the biomedical one described in Chapter 6: the official 'right' framework for addressing socio-economic and other problems for those who aspire to, and (self-) identify with, 'modernity'. And while few would question its underlying values—equity, equality, dignity of the human being, and so on—, not only do many experience the significant gaps between the lofty ideals of its texts and rhetoric and the daily struggles of reality, but they have other belief systems, values and vocabularies by which to conceive and articulate grievances, entitlements and rights.

Human rights theorists and practitioners make certain presumptions about people's perceptions: about their relationships primarily with the State, their duties and

²⁶⁹ Nyamu-Musembi and Musyoki note of CARE's interpretation of rights-based approaches in its work: "Like Oxfam, CARE Kenya does not programme its work around rights campaigns. Rather, CARE Kenya seeks to integrate a rights framework into its existing Household Livelihood Security approach through its *Nuru* strategy, thus defining its work as being about achieving the minimum conditions for living with dignity. The integration of livelihood security and rights means, according to one official, that their work becomes oriented toward enabling the right to self-determination at the personal and household level – in the sense of enabling people to make decisions on their own well-being, through securing the resources that make that possible." (Nyamu-Musembi and Musyoki (n 25), at 8.)

²⁷⁰ Baxi (n 31), at 166

²⁷¹ In Art. 2(1) and (2). (UN, General Assembly (GA) Resolution 41/128, *Declaration on the Right to Development*, 4th December 1986, at <http://www.un.org/documents/ga/res/41/a41r128.htm>, accessed 27/04/09.)

²⁷² Eide (n 62), at 23.

entitlements and their notions about the nature and value of human rights norms. Yet discrepancies, frequently noted in this research, often exist between identifying (socio-economic/health) needs and conceptualizing them as entitlements, and, yet further, human rights. There are also some gaps in the envisaged assignation of responsibility for the fulfilment of these officially-recognized human rights.

Some of these discrepancies may indeed be bridged by education about, or popularization of, the human rights project and its values, whose importance has been widely noted here. As Halabi asserts, "Citizens armed with knowledge of human rights are better equipped to demand action from [government] and hold it accountable."²⁷³ But this is only part of the story, for deeper issues relating to the backgrounds, moral frames of reference and lived experiences of the PLWHAs apply. These appear to mould their perceptions of themselves as individuals and their places in the social, economic, cultural and political grid. Their subjectivities also seem to be significant to defining their understanding of concepts such as humanness, dignity, citizenship, and their ideas of entitlement.

Yet it should be remembered that subjectivities are constructed, and can therefore be deconstructed and reconstructed, and herein lies the (crowded) space in which human rights can- and must- compete for attention, along with the other value systems and moral languages of cultural tradition and religion, and the market.

And there is every reason to believe that they can be successful: Kenyans are, indeed, increasingly more familiar with the human rights enterprise and its goals. The interviews also suggest a broad absorption of, and willingness to, accept certain fundamental human rights notions and norms although this process was sometimes contradictory, often uneven and largely strategic. Values were often incorporated into a PLWHA's subjectivity, personal moral language and outlook when they enabled her to (re)construct a more positive sense of self, or facilitated or improved her claims to privileges from the State and other actors. Indeed, this is a positive

²⁷³Halabi (n 78), at 55. See also London, who highlights, also in reference to health rights, "[p]ilot studies in the Western Cape province of South Africa highlight the importance of building learning networks around health and human rights to provide information to those most marginalized to effect the changes needed to reduce their vulnerability." (London (n 10), at 73)

development, suggesting an agency that is often denied laypeople in the human rights discourse. Her stake in the human rights agenda can thus be better understood in this light, and it is erroneous, unrealistic and unhelpful to assume that she will endorse any such agenda and its values wholesale without any critical consideration of its benefits to her, irrespective of whether she manifests such an analysis actively or passively, privately or publicly.

For proponents and advocates of human rights to look beyond the above-mentioned presumptions and understand how individual and collective notions of entitlements and rights are constructed, they must start by putting these very laypeople and their varied subjectivities at the heart of the human rights project. Nyamu-Musembi and Musyoki noted an encouraging- though embryonic- recognition of this in 2004 by the governance organization, CGD, which was working in Kenya at the time:

The notion that a rights-based approach is about telling people about rights is mistaken. It's more effective to start from letting people identify and analyse their problems and then come up with their solutions. It's about figuring out who is responsible for what. Sometimes they realise that they themselves are responsible for some of the things [. . .] The important thing is to facilitate people's own understanding of their entitlements; helping to remove what constrains their potential. It's about facilitating a discovery of the root causes, and then facilitating the search for solutions. The biggest challenge is to avoid creating another type of dependency, where people begin to view you as the 'rights giver' since you are the one telling them about their rights.²⁷⁴

Ultimately, if the human rights framework, its norms and their practice are to be rooted at the grassroots and their ideals transformed into reality, communities must be accepted as participants in the shaping and development of the agenda and in the effort to actualize it. They must feel to those expected to practice and promote it on the ground as inherent and internalized, in the apt allusion by the WOFAK official, like religion.²⁷⁵ They must not feel like a set of detached, alien notions parachuted in by people or organizations with little or no perceived history, familiarity or long-term interest in the local communities expected to espouse them and the individuals expected to live them.

²⁷⁴ Nyamu-Musembi and Musyoki (n 25), at 15

²⁷⁵ Informal exploratory discussion with WOFAK Program Officer, 22nd March 2004

Conclusion

HIV infection has profound health implications for PLWHAs. But it also arguably impacts on their subjectivities, notions about their location in the wider socio-economic grid, and consequently their perceptions about their health entitlements and rights. This research laid out in detail the events, processes and actors that converge to produce these subjectivities, with PLWHAs' responses providing empirical evidence for the analysis. Further, the research established the fundamental role of HIV infection in the construction of PLWHAs' subjectivities. As was stressed in the introduction, only by outlining the exterior landscape, the site on which individuals' prevailing moral frames of reference are formed and subjectivities produced, can one hope to illuminate the often unseen hinterland in which the individual, per Hicks¹, first encounters the law. And only by adding flesh to the individual 'human' of human rights and understanding how she synthesizes her lived experiences with its norms can one hope to understand how she imagines her entitlements, human rights in general and a right to health in particular.

In Chapter 1, the ideas and arguments which frame this research were outlined. And as this chapter explained, before any analysis of laypeople's conceptions of health entitlements and a human right to health can begin, a researcher must contend with the contestations that surround the key terms of reference among the experts themselves. The definition of 'health' for the purposes of human rights, for instance, inspires much debate. The Introduction showed that the term is sometimes used to refer to the wellbeing of the corporeal body only, whereas other definitions encompass mental wellbeing, too. Yet other definitions apply a broader conceptualization of health beyond the prevailing preoccupation with the individual's biological wellbeing. Such definitions emphasize the social environment in which her health is produced. Indeed, Chapter 1 highlighted biomedicine's role in the formation of subjectivities of patients like the PLWHAs. Its underlying ethos promotes the idea of the patient as a rational, autonomous agent in the production of her own health.

¹ Hicks, Stephen, 'Law and Being in Law as Way of Being,' in Panou, S.; Bozonis, G.; Georgas, D.; and Trappe, P., (eds.), *Human Being and the Cultural Values: 12th World Congress, Athens, 1985* (Stuttgart: F. Steiner Verlag Weisbaden, 1988)

However, in places like Kenya, this obscures the structural obstacles and limited choices individuals experience in reality. Meanwhile, as the introduction also highlighted, the concept and content of human rights are also much contested, with a number of the ideas associated with them- such as humanness, dignity and citizenship- being variously defined. These contestations were echoed in the PLWHAs' responses about the meaning of health and human rights explored in Chapter 1, thus establishing the template for this research.

Disputes of meaning and ideas recurred in Chapter 2. This was an analysis of the methodological approach of this research, which also illustrated how interviewing a subject who suffers from a socially stigmatizing illness affects the interaction between respondent and interviewer, and thus the strategies used to obtain information and the nature of that information. Crucially, too, the chapter explored the challenges of communicating in, and translating to, different languages and contexts key human rights terms whose definitions are alterable, nuances liable to blunting. This exemplified a fundamental argument in this research: those who engage with and internalize terms like entitlement, duty and rights inevitably give them meanings in accordance with their own contexts and normative frameworks. Further, they reflect one's perception of location within a wider socio-economic matrix and the relationships and balances of power between the actors in this matrix. These are the complex dynamics which produce and are reflected in individual subjectivity, and which make the interpretation of these concepts bespoke. And it is the key thesis in this research that HIV/AIDS adds yet another layer to those dynamics and is a vital component of the subjectivity of PLWHAs, playing a principle role in how they interpret human rights concepts and norms. It was a fact that the detailed analysis of the 49 interviews at the heart of this research consistently highlighted.

In Chapter 3 the task began of systematically mapping the broader social, cultural, economic and political landscape that has produced PLWHAs' subjectivities in Kenya. It argued that this process must necessarily begin as far back as the pre-colony, and by pinpointing three key themes which determined the distribution of power in Kenya during this era, the chapter was able to illustrate the continuities that appear to mould many interviewees' responses about their entitlements to health and rights.

The analyses of systems of land ownership, kinship and patriarchy and the bonds of privileges and duties which regulated them revealed how power was organized in pre-colonial Kenya and the ancient roots of some contemporary notions of entitlements. More than that, the chapter contextualized the normative frameworks within which many interviewees for this research lived. These frameworks nurtured their customs and norms about individual autonomy, social responsibility, gender, sex, as so on, all of which shaped interviewees' understanding about the stigma surrounding HIV/AIDS and their own contentious identity as PLWHAs. As the chapter showed, these deep-rooted paradigms are not easily supplanted by newer ones like human rights, and it falls on individuals like the interviewees for this research to reconcile or accommodate the inevitable conflicts between models that would promote community cohesion and obligations and those which privilege individual autonomy and rights.

Chapter 4 explored how the colonial experience transformed local power structures, making race the definitive determinant of legal and political identity. It is a theme which ensured parallels between the colonial and the AIDS narratives, as the chapter showed, shaping the debate on attitudes about African sexuality, the power imbalance between donor and recipient nations, the legal and/or moral the obligations of the former and the rights of the latter in relation to affordable AIDS treatments. This chapter also analyzed the development under colonialism of the State as a separate locus of power from the customary and charted the construction of the African legal subject, a distinct entity from the settler citizen. While the former resided in, and drew her entitlements from her membership of, the customary, the latter was a fully-fledged citizen with rights from the State, which protected her from its excesses. This bifurcation, as Mamdani and others argue, transcended the deracialization that came with independence. This chapter located and grounded the importance of Mamdani's bifurcated State theory in this research, using the PLWHAs' interviews to exemplify the citizen-subject duality. For while many interviewees revealed a sense of belonging to a wider national public with the State at its heart, they also expressed membership to a more exclusive customary-based ethnic public, with its emphasis on community cohesion. Yet their responses also problematized this dual allegiance and the challenges of internalizing conflicting normative

paradigms, as exemplified by the contrasting attitudes in the civic and customary spheres towards AIDS and PLWHAs. The chapter revealed mixed perceptions about the role and legitimacy of the State, with interviewees' responses interrogating its status as a unifying, inclusive, alternative sphere of power to the customary domain, despite the latter's rigid limitations on individual autonomy. All of these elements, it was underlined, arguably contributed to the construction of PLWHAs' subjectivities and notions about entitlement to health and rights as accruing from the State.

Chapter 5, the first of the empirical chapters, was an illustration of just how these very notions are the products of the aggregated factors discussed in preceding chapters. The interviewees' responses not only underlined the importance of, and challenges to, realizing nutritional and income needs, but they also revealed how PLWHAs assign the duty to meet these health needs. This chapter especially emphasized the role played by HIV infection in the construction of PLWHAs' subjectivities, revealing how some interviewees' magnified sense of their identity as PLWHAs seemed to shape their ideas of their health entitlements. It suggested that some PLWHAs interpreted the real or imagined infringement of prevailing sexual norms as justifiably disempowering contraveners to privileges such as healthcare assistance, which may otherwise be guaranteed by the networks of entitlements and obligations which bound traditional socio-economic matrices. However, some interviews suggested that these bonds are significantly diluted today and that infection with a stigmatizing illness weakens them even further. This was exemplified by the numerous responses from PLWHAs which prioritized financial self-sufficiency over the sometimes unreliable promises of assistance from their traditional social networks. And yet, as Chapter 5 illustrated, the possibility of economic autonomy and actualization of socio-economic rights was still often determined by the systems of land tenure, kinship and patriarchy discussed in previous chapters, which continued to define the nature of entitlements, limiting those of marginalized groups like women.

Chapter 6 further galvanized the thesis that HIV infection appears pivotal to the construction of PLWHAs' subjectivities and thus their notions about their health entitlements and rights. By analyzing interviewees' self-identified psychosocial and

medical needs, the chapter was able to look more closely at how the stigma surrounding AIDS, the dearth of conventional psychosocial therapies, and inaccessibility of treatment compounds stigma and breeds self-stigma in sufferers. Rigid customary and religious norms about sexual behaviour, which produce and perpetuate the stigmatization of PLWHAs, isolate sufferers from what are usually their only avenues for psychosocial care: the social and religious networks on which many rely for moral and emotional support. The idealization of sexual submissiveness in women was shown to be particularly pernicious, often imposing a double penalty on female PLWHAs who, like several interviewees for this research, become infected as a result of conferring the unrestricted sexual access to (promiscuous) husbands that these very norms dictate. As this chapter revealed, the cumulative negative self-image may have resulted in narrowed perceptions in some PLWHAs about their range of health entitlements, especially costly ones like medical care. Several interviewees testified that hidden expenses make such care unattainable despite greater availability of subsidized or even free ARVs. Consequently, PLWHAs may opt for, or be compelled to supplement modern biomedical therapies with, contentious traditional therapies. As this chapter contended, this is a different dimension to a familiar conflict highlighted by this research: that between normative frameworks. Biomedicine is often accused of conceptualizing patients like PLWHAs as unfettered autonomous beings, much like the subjects of the human rights paradigm. For traditional medicine, meanwhile, the patient is more than just a body alienated from the socio-economic context which produces her health. It seeks to treat the whole person, physical as well as spiritual. Yet, as this chapter argued, the biomedical-versus-traditional therapies debate also highlighted the pivotal accommodation identified in this research: the citizen-subject duality.

The perception by some PLWHAs of increasingly unreliable claims against traditional social or kinship networks was juxtaposed in Chapter 6 with the accentuated importance of other actors in delivery of healthcare. These were the Kenyan State, NGOs and donors, in reference to whom many interviewees were shown to have formed various notions of entitlement. Their crucial role in the delivery of ART for PLWHAs was examined in detail in Chapter 7. This research found largely favourable views about NGOs and donors, as PLWHAs compared their performance in the

delivery of healthcare with that of the State. The contrasting negative reviews of the Kenyan State not only testified to the expectations of healthcare assistance that many PLWHAs now espoused to it but also suggested doubts about its legitimacy. It was argued in this chapter that donors and NGOs, the most visible embodiments of the civil society phenomenon, were now so ensconced in the fields of health and development that they were redefining the concepts of the State and the citizen-subject. The chapter was careful to put their actual reach into perspective, noting that civil society's reach in Africa was uneven: familiar in the civic sphere, that is, urban centres, but rare in seat of the customary sphere, the rural areas where most Kenyans live. The PLWHA interviews again provided empirical examples of these arguments which were raised by Mamdani and others. Nevertheless, the chapter showed that NGOs as a part of a broadly defined civil society had opened up new arenas for public participation for marginalized groups like the PLWHA community. But the chapter also spotlighted some of the more contentious aspects of civil society/donor involvement: it raised concerns that NGOs may sometimes reproduce and entrench the same patterns of inequality and marginalization that they sought to challenge. It also problematized their financial dependence on, and ultimate accountability to, their often overseas-based donors, which limits local recipients' agency. Finally, the chapter highlighted arguments that NGOs and donors' involvement in the delivery of health may undermine State sovereignty and legitimacy. As this research explained, this has complex implications for the balance of power and influence in the bifurcated State, where the State's reach may extend to the national public in the civic sphere but is already more muted among the ethnic public in the customary.

Finally, Chapter 8 expounded on the human rights concepts and theories raised throughout the research and located them in the foundations of interviewees' claims to health entitlements, and their attribution of obligation to fulfil these entitlements. It analyzed the PLWHAs' human rights awareness, comparing a number of emerging issues, such as their particular familiarity with what are categorized as civil and political rights, with findings from more general surveys conducted by the Kenya Human Rights Commission. Crucially, this research also highlighted differences that may be accounted for by the PLWHAs' particular identity. Once again, this chapter

developed the thesis about the role HIV infection may be playing in moulding PLWHAs' subjectivities and thus their conceptualization of entitlements and rights. In particular, it illustrated how three fundamental human rights ideas which emerged from the interviews, namely, humanness, dignity and citizenship, were often interpreted by the respondents through an HIV/AIDS lens. Moreover, this chapter exemplified the contradictions inherent in PLWHAs' attempts to understand and define these concepts from conflicting perspectives: that of human rights, as popularized by PLWHA rights campaigners, and that of the religion and/or culture that dominates their lived experiences. This research argued that while the former defined humanness, dignity and citizenship inclusively, which appealed to the often-marginalized PLWHAs, the latter paradigm often defined these terms to exclude those like PLWHAs who were suspected of violating its norms and undermining social cohesion. By exploring such contradictions, the research was able to provide a context against which to investigate theories that link psychoanalysis and the law. This discussion interwove Jacques Lacan's concept of the seamlessness of the internal and external aspects which constitute the subject of law with the empirical example of PLWHAs' complex subjectivities and their influence on their imaginations of law and human rights. And although the interviewees for this research were selected on the basis of one crucial common factor, infection with HIV, Chapter 8 underscored how the other factors discussed throughout this research may also play a role in producing PLWHAs' subjectivities and coloured individual understanding of health entitlements and rights. For it outlined the range of actors to whom the PLWHAs attributed the duty to meet their health needs, each a reflection of the individual's aggregated subjectivity and her conception of her place in the wider socio-economic grid. As the chapter concluded, subjectivity remained dynamic and malleable. But while the modern human rights paradigm may yet supplant or at least provide a credible viable alternative to the predominant exclusive moral frameworks, it cannot yet claim to provide the reflexive frame of reference or vocabulary by which laypeople imagine themselves, their grievances and their entitlements.

Human rights advocates would do well to acknowledge this. For although the human rights paradigm has been increasingly mainstreamed in the latter part of the 20th Century, there is often a disconnect between the way human rights experts and

laypeople conceptualize and articulate claims to entitlements like health. This challenges the efficacy of the human rights framework itself to address these concerns. Indeed, William Conklin has highlighted the counterproductive effect of using a medium that is hidden from, or unknown to, those in whose aid it is apparently deployed, decrying the fate of “the pained individual ... overwhelmed by the distant language of experts.”² Yet the PLWHAs’ interviews analyzed throughout this research offer glimpses of the opportunities and possibilities for popularizing the human rights project and promoting its framework to complement or even supersede alternative cultural or religious paradigms. For PLWHAs’ belief systems were seen to be elastic, dynamic, fluctuating between the socio-cultural spaces they inhabit. This allowed them to make strategic choices about when and where to espouse and enact certain norms, despite the inherent contradictions this sometimes entailed, in order to facilitate their complex existence in often hostile environments and to maximize the potential (health) benefits of membership to various communities and sub-communities.

As this research illuminated, the human rights framework holds certain attractions for marginalized groups like PLWHAs, for it has in its key concepts the power to highlight the suffering of individuals and provide alternative narratives for their lived experiences. Further, its dynamic language may help them (re)create positive identities for themselves that empower them to re-conceive their entitlements and rights. These often exceed the limited privileges afforded by traditional customary systems and by providing individuals with the tools to re-imagine their subjectivities, the international human rights paradigm enables them to renegotiate their broader relationships and to make claims against actors beyond their own narrow ethnic and national publics. Indeed, embracing it promises membership to a powerful globalized community, both real and ideational, which can mobilize the language of rights, the lingua franca of any modern powerbroker with claims to legitimacy, to address concerns like the lack of access to ART for the poor. The overwhelming, though as yet incomplete, success of this latter campaign has become a blueprint for how to deploy

² Conklin, William E.; ‘Human Rights, Language and Law: A Survey of Semiotics and Phenomenology,’ *Ottawa Law Review*, Vol. 27, No. 1 (1995-1996), pp. 129-174, at 137.

rights to alleviate specific socio-economic problems while highlighting the breadth and interconnectedness of the issues which underpin them.

But the human rights framework is not perfect and it is assailed by a range of theoretical and practical problems. To highlight just a couple, its preoccupation with a generic, ideal individual can sometimes appear to de-emphasize the highly variable social and structural settings within which she experiences the fulfilment or violation of her rights. Moreover, while its soaring rhetoric may inspire, it can also be a weakness. In poor countries like Kenya, where the realization of its promises seems ever more distant its ideals can appear hollow and feed perceptions about the bankruptcy of the project. This is especially the case as the promotion of the human rights model occurs contemporaneously with the reluctance by some of its most vocal proponents to address the long-standing asymmetries that define local and global power relations and determine the actualization- or not- of rights.

And yet its potency is undeniable: its rhetoric, language and values encouraged many of the PLWHAs interviewed for this research to publically acknowledge their illness and relate their experiences of living with HIV/AIDS. This allowed them to claim a space in the public arena which many had often been denied, and provided them with a platform from which they could challenge stigma, discrimination and inadequate healthcare services. Further, their individual and collective voices have been influential in popularizing certain human rights terms and issues which relate specifically to the epidemic but are linked to public health more generally. As Upendra Baxi and others have highlighted, despite the many valid criticisms of the human rights enterprise, it has an immense potential to give greater visibility to victims of human rights violations and, when properly applied, a rights-based framework can help illuminate the underlying causes and patterns of their suffering. It is therefore eminently worthwhile to engage with the challenges of rooting its ideas and norms among laypeople.

To be sure, there appears to be a wide grassroots awareness of certain human rights-related concepts and norms: as this research showed, many respondents seemed to espouse the notion of human dignity and equality, even though they might have

come to them from different moral frames of references. The Haki Index also attested to the broad awareness over the last few years of human rights issues in general. Contemporary events in Kenya like general elections, constitutional referenda and the recent post-election violence enquiry have provided opportunities and platforms to inform the public and engage them in debates about the aims of the human rights project, and to popularize its language and values. But there remains a considerable discrepancy between the eloquence with which the interviewees represented their health needs and their awareness of any legal claims to entitlements to which they might be connected. This missing link is crucial to the organization of the kind of mass movements and campaigns that groups like TAC in South Africa have so successfully orchestrated.

Human rights organizations and experts will be instrumental in bridging this gap if the full potential of Kenya's new Constitution, with its enforceable Bill of Rights, is to be harnessed. And yet some commentators have remarked on their lack of leadership and insufficient engagement with laypeople. Their failure to mobilize the grassroots means that human rights largely remain their preserve. It is a charge arguably borne out in this research by the predominance of alternative frames of reference in the PLWHAs' conceptualization and expression of their health and other entitlement claims, almost seven decades after the UDHR, nearly five after the ICESCR and close to a quarter of a century since the epochal early-1990s which heralded a human rights revival.

In order to be best positioned to cultivate the human rights paradigm into the privileged frame of reference for conceptualizing and articulating suffering, its agents will have to discard what often seems little more than a superficial interest in understanding its audience. They must recognize and respect laypeople's self-identified concerns and priorities, the social relations and events that shape their diverse subjectivities and how on this basis they formulate their particular ideas about rights. Some of these ideas may be challenging, perhaps even odious to conventional human rights norms but that is no reason to exclude them from the debate. Indeed the intrinsic promise in the process of constituting subjectivities and belief systems lies in its fluidity: the self-appointed guardians of the human rights

project can choose what part, if any, they would like to play in this process. Their conspicuous absence from the daily struggles of ordinary people only alienates and removes from the armoury of the suffering one of the most potent weapons of the last half-century for effecting social change.

The human rights movement must not look back at the this period when the HIV/AIDS epidemic was at its peak as a lost opportunity: for the issues such as those affecting PLWHAs are a chance to firmly implant the issue of rights in the national conscious and invite to join the dialogue entire sections of the population that have been locked out of it. To be fair, this has already happened to some extent but the connections between basic needs and legal entitlements must be made more often and more explicitly if they are to catch on. If human rights organizations do not take up the challenge such opportunities will pass altogether. In Odinkalu words:

[p]eople will struggle for their rights whether or not the language of human rights is accessible to them. But they will not build their struggle around the notion of human rights unless that language and those who wish to popularize it speak directly to their aspirations and survival.³

³ Odinkalu, Chidi Anselm, 'Why More Africans Don't Use Human Rights Language,' *Human Rights Dialogue*, Series 2, No. 1 (1999), Carnegie Council on Ethics and International Affairs, at http://www.cceia.org/resources/publications/dialogue/2_01/articles/602.html, accessed 20/05/09.

Appendices

Appendix 1: Questions: English Version

Briefly, the purpose of my research here is:

- To find out directly from PLWHAs what they consider to be their most important needs/requirements as people living with HIV or AIDS, and
- What they personally know about the issue of human rights generally, if anything, and about socio-economic rights in particular.

QUESTIONS:

Questions aimed at facts:

1. Name:
2. Sex:
3. HIV/AIDS status:

When did you find out that you were HIV positive?

Have you developed AIDS?

Questions aimed at beliefs or attitudes (subjective):

4. *What are your basic health needs, that is, what do you require to keep you strong and healthy from day to day?*

Alternative Question: *as a person with HIV/AIDS, tell me 5 of the most important things you personally take/need every day to maintain your health and strength.)*

5. *Do you usually get all these requirements- if not, what do you usually get and what do you usually not get?*
6. *Who is currently providing you with what you require, that is, who is paying for your requirements?*
7. *Whose duty is it, in your view, to provide your requirements?*

8. *Why?*

9. *Generally, are you personally satisfied or dissatisfied that your requirements/needs for these 5 important things as a person living with HIV/AIDS are being adequately met?*

10. *If 'yes', why?*

11. *If 'no', why?*

12. *The government IN September 2003 announced that ARVs would be available at all District Hospitals by the end of September 2003. It was added that patients would have to pay for the drugs although the cost would be reduced.¹ Did you hear about this?*

13. If 'no', **NOTE** that the interviewee was not aware of this development **BUT** continue questioning. Just remind the interviewee about it and the justification given by the government (SEE footnote below and proceed with the interview.

14. *If yes, do you recall the justification given by the government for this cost-sharing system?*

(Continue questions even if the interviewee does not remember the reason given by the government. Just inform them of the reason, below.)

(Answer: It was stated that this was aimed at making the programme sustainable.²)

¹ *The Daily Nation*, 'State accused of betrayal on Aids medicines', 17th September 2003: "On Monday, Health assistant minister Gideon Konchellah said although all district hospitals would be stocked with anti-retrovirals by the end of the month, patients would have to pay for treatment under the cost-sharing system. Currently, the cheapest anti-retroviral treatment costs Sh3,000 a month. Mr Konchellah clarified that only a selected number would get free anti-retroviral treatment under the Prevention of Mother to Child Transmission programme. The others would have to pay for their treatment though the cost would be reduced, the assistant minister added."

² *The Daily Nation*, 'Move to sell Aids drugs explained', 18th September 2003: "Plans to ask Aids patients to pay for drugs at public hospitals is aimed at making the programme sustainable, the Government said yesterday. The move to sell the life-prolonging drugs commonly known as anti-retrovirals, would remove stigma from HIV treatment, the National Aids and Sexually Transmitted Infections director, Dr Kenneth Chebet said. Dr Chebet said in Nairobi: 'Anti-retrovirals are just like any other essential drugs...Due to the existing cost-sharing system in public hospitals, respective district

What do you think about this?

15. *What do you think are the most important things that PLWHAs generally need to stay healthy and strong (if they are different from the ones you mentioned for yourself?)*

16. *Do you think that the needs of PLWHAs generally are being adequately met?*

17. *If yes, what informs your answer?*

18. *If no, what informs your answer?*

Human Rights:

By way of introducing the topic of rights: *“As I mentioned earlier, I would also like to ask you about your thoughts on the issue of human rights.*

19. *Firstly, may I ask what you understand by the words “human rights”?*

20. *What are some of the Human Rights you’ve heard of or you know?*

21. *How or from whom did you hear about these Human Rights?*

A filter question:

Recently, we have been hearing people talk human rights in relation to HIV/AIDS.

22. *Have you thought much about this issue or have you not heard much about it?*

NOTE THE ANSWER TO THIS QUESTIONS AS IT BECOMES IMPORTANT IN QUESTION 23

health management boards will determine a very nominal fee they will charge to ensure anti-retroviral therapy is not stigmatized...’ He said the boards would ensure that those who were unable to pay for the drugs would be able to access them since every hospital had a waiver system. On Tuesday, the Kenya Network of Women with Aids executive director, Ms Asunta Wagura, said the government move would deny the majority of more than 200,000 people living with Aids access to life-prolonging drugs.”

- If **'no'**, TRY ANOTHER APPROACH, below.
- If **'yes'**, proceed with this question anyway.

Do you think that

- a) *local authorities like chiefs, or D.O.s, or provincial administrator, and people in such positions or*
- b) *GOVERNMENT or*
- c) *LOCAL or FOREIGN NGOs or*

can or should do to help you and your family deal with your being ill?

If so, how can they help?

- d) *Are there other people/groups I have not mentioned that you think can and/or should help? And if so, how?*

If 'yes' to Question 22, that the interviewee has heard about and thought about recent talk on human rights in relation to HIV/AIDS:

23. Do you think the issue of HIV/AIDS is related to human rights?

24. If yes, how?

Health and Human Rights:

FILTER question:

25. Some people have stated there is a link between the issue of health generally and that of human rights.

Have you thought much about this issue or have you not heard much about it?

- ***If 'yes', proceed with the interview.***
- ***If 'no', go to questions at the end of the questionnaire: Question 41***

26. Do you agree with this view?

- If 'yes', in your opinion what is this link?*

- *If 'no', why?*

Another FILTER question:

27. *It has also been stated by some people that there is a human right to healthcare- have you ever heard about a human right to healthcare?*

- ***If 'yes', proceed with the interview.***
- ***If 'no', go to questions at the end of the questionnaire: Question 41***

28. *Where and/or from whom did you hear about it?*

29. *In your own words, what does a human right to healthcare mean to you?*

30. *In your opinion, are there any practical benefits of having a right to healthcare?*

31. *In your opinion, do you think you would benefit practically from having a right to healthcare?*

32. *If yes, how?*

33. *If no, why?*

34. *Who, in your opinion, is meant/should benefit (is the beneficiary) of the right to healthcare?*

35. *Who, in your opinion, is meant/should provide these benefits?*

36. *Why do you think that this (or these) group(s) should be the ones to provide these benefits?*

37. *In your opinion, can the government help in providing the benefits of a right to healthcare? If so, how?*

38. *Do you think the government can afford to do these things (that you just listed)?*

39. *If 'yes', how?*

40. *If 'no', why?*

Age:

41. *What year were you born?*

Education:

42. *Have you ever had any formal education?*

43. *How many years of primary school did you complete?*

44. *How many years of high-school did you complete?*

45. *How many of University or College did you complete?*

Occupation:

46. *Do you have an occupation?*

47. *If 'yes', what is it?*

Finally:

48. *Anything to add?*

Interviews

1. Preliminary Inquiry with Mbagathi District Hospital Administration Officer, 3rd March 2004
2. Informal exploratory discussion with WOFAK Program Officer, 22nd March 2004
3. Interview with Maina Kiai, Director, National Commission on Human Rights 26th May 2004
4. PLWHA interviews:
 - Interviews 1-7: 6th April 2004
 - Interviews 8-12: 30th April 2004
 - Interviews 13-15: 7th May 2004
 - Interviews 16-22: 11th May 2004
 - Interviews 23-26: 14th May 2004
 - Interviews 27-29: 18th May 2004
 - Interviews 30- 37: 21st May 2004
 - Interviews 38-44: 25th May 2004
 - Interviews 45- 49: 28th May 2004

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