Peris Jones

The "Dirty Work" of Public Health

Effective planning and policy amidst prejudices in response to HIV/AIDS

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Abstract:	The working paper explores the intersection of public health and HIV/AIDS discourse and policy amidst shifts in governance as well as the resilient stigma associated with the epidemic. HIV/AIDS is therefore used as an analytical lens through which to view the tensions between continuity and change in public health. AIDS is regarded as both a signifier of older more coercive traditions in public health and as a catalyst for creating new modalities of rights-based public health planning and decision-making. Exploring 'what works' in responses to HIV/AIDS therefore foregrounds the need for a contextual politics of the epidemic and public health. Reference is made to experiences from the 'West' with specific country case studies provided from Brazil, Russia, and South Africa.
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Foreword

The Norwegian Institute for Urban and Regional Research (NIBR) has a Strategic Institute Programme (SIP) on Public Health: "Planning and organisation for improved public health (POPHEALTH)", project nr: 172535/S30 of the Norwegian Research Council. The SIP is aims to enlarge the general knowledge and understanding of complex processes associated with the multilevel governance of local planning activities. Within NIBR the SIP finances a broad range of projects from those focusing on the actual processes of multilevel governance of local planning via planning of land use and the fostering of physical activity to other related thematic projects like the one reported here: "The "dirty work" of public health: Effective planning and policy amidst prejudices in responses to HIV/AIDS".

Oslo, December 2009

Marit Helgesen

Co-ordinator, NIBR's Strategic Institute Programme on Public Health

Table of Contents

Summary

Peris Jones
"The Dirty Work" of Public Health
Effective planning and policy amidst prejudices in the response to HIV/AIDS
Working Paper 2009:114

From the very first appearance of cases concerning AIDS-related illness in the early 1980s, the epidemic both provoked and challenged traditional policy responses within public health. Initially, public health responses were based on historical templates that belonged to another century, namely, those that emphasised containment and coercion of infectious disease. Conversely, the era of AIDS also overlaps with a more recent period characterised by an increasingly strong emphasis upon individual rights within 'advanced' liberal democracies and also global 'waves' of democratisation and civil society participation in decision-making, more generally, in other parts of the world. The working paper explores the intersection of public health and HIV/AIDS discourse and policy amidst shifts in governance as well as the resilient stigma associated with the epidemic. HIV/AIDS is therefore used as an analytical lens through which to view the tensions between continuity and change in public health: AIDS as both signifier of older more coercive traditions in public health and as a catalyst for creating new modalities of public health planning and decision-making. Exploring 'what works' in responses to HIV/AIDS therefore foregrounds the need for a contextual politics of the epidemic and public health.

The paper explores the types of governance relationships deemed most appropriate in planning responses to AIDS prevention, particularly claims made for partnership, multi-sectoral, participatory forms of planning and implementation. Broad western responses are then set in relief alongside an overview of some key dimensions in explaining state responses in selected countries, namely, Brazil, South Africa and Russia. These experiences bring to the fore the significance of not only political culture but also a cultural politics of HIV/AIDS in articulating public health responses. In relation, although a rights-based paradigm occupies the global moral high ground in responding to the epidemic, human rights protections are often in apparent tension with public health measures and the politics of AIDS. Whether any countries –either in the global North or South, former Soviet states- can dispense with human rights, especially in tackling HIV/AIDS and to ensure better governance of the epidemic, is extremely doubtful. But the working paper underscores the vulnerability of rights to broader political and ideological currents. In order to withstand such scrutiny it may be increasingly important to document the evidence

for when and why rights-based approaches to health are more effective in responding to HIV/AIDS.

1 Introduction[1]

> 'Tactics adopted 150 years ago to deal with cholera, leprosy and TB created a template for the responses to AIDS. Old mentalities and old ways of doing things remained remarkably consistent. Decisions about how to treat AIDS, and the subsequent violations of rights and dignity were taken into accord with a resilient public health ideology set in place during the last century. Health is the last location for people doubtful of the value of human rights' (Baldwin, 2005:1).

From the very first appearance of cases concerning AIDS-related illness in the early 1980s, the epidemic both provoked and challenged traditional policy responses within public health. The provocation was premised upon AIDS as a disease of signification: the nature of its (sexual and drug injecting, for example) transmission; and the implication of 'Other' groups in this (marginalised ones in particular). The disease therefore provoked particular religious, social, cultural and political points of view in the face of an epidemic perceived as fearsome. In many societies AIDS was – and still is- rendered a taboo subject, with implications for framing interventions. After all, as the early history of the epidemic shows in the West and elsewhere, however, it is *in spite of* and not because of public health approaches that marginalised groups mobilised in the face of the epidemic (Stoller, 1998; Valdiserri, 2003). A number of challenges were therefore posed by the epidemic to public health.

On one level, as the quotation suggests, above, deep seated public health templates required examination as to their appropriateness in responding to this modern day 'plague'. A fundamental challenge for public health has been to plot a course steering between approaches deemed either coercive or more voluntarist ('liberal') in character.[2] These historical memories associated with public health interventions also, as mentioned, had to be articulated amidst the powerful exclusionary and stigmatising attitudes associated with HIV/AIDS. These attitudes and the risk groups they were focused upon has rendered HIV/AIDS the 'dirty work' of public health.

Conversely, on another, confronting AIDS and its 'taboo status' also overlapped with an era associated with an increasingly strong emphasis upon individual rights, autonomy and 'governing at a distance' within 'advanced' liberal democracies (Rose, 2006). Elsewhere in the world, the epidemic also entwines with global 'waves' of

[1] The working paper was presented at a NIBR workshop on public health in December 2009. I would like to extend my gratitude to the participants at the workshop for their very constructive feedback.

[2] Simply put, a more coercive approaches places emphasis upon compulsory reporting of AIDS cases, partner notification, forced testing, even disclosure of states, and in some cases, isolation and quarantine. Alternatively, a voluntarist position seeks primarily to convince behaviour change by using communication, information and education.

democratisation and discourses of civil society participation in decision-making.[3] The era of human rights therefore poses a specific challenge to public health approaches premised, as they were at the outbreak of HIV/AIDS, upon traditional control of infectious disease. The focus here is therefore less upon emerging epidemics of chronic non-communicable diseases and contemporary western models of public health which emphasise prevention and life style interventions.[4] Rather, the other side of the 'double burden' of disease: namely, the (re) emergence of old and new infectious diseases like TB, malaria and, the focus here, AIDS, speaks to a deeper historical modality within public health which was reactivated following a long period of containment of infectious disease in the West in the twentieth century. Both disease burdens pose a combined challenge to the public health responses (Beaglehole and Bonita, 2004) and obviously overlap concerning state restructuring and down scaling to the local state and the rise of the rights-based citizen.[5] HIV/AIDS is used in a more specific sense in the working paper, namely, as an analytical lens through which to view the tensions between continuity and change in public health: AIDS as both signifier of older more coercive traditions in public health and as a catalyst for creating new modalities of rights-based public health planning and decision-making. Exploring 'what works' in responses to HIV/AIDS therefore foregrounds the need for a contextual politics of the epidemic and public health.

In planning responses to HIV/AIDS, for example, is this most appropriately undertaken by public sector health services and agencies; or, community driven in partnerships? In particular, to what extent should those at greatest vulnerability, or, actually living with HIV/AIDS, be able to participate in decision-making? Furthermore, what is considered the appropriate scale to articulate responses: national, regional or local level? If, indeed, regarded even more narrowly as the terrain of public health alone, what implications follow for the scope and nature of responses to HIV/AIDS depending upon how we define and legislate public health? How the prevailing degree of exclusion or inclusion of marginalised groups influences planning processes is another critical consideration.

Some of these questions may appear curious, at first glance, given that in many countries there has been and still is a struggle to recognise the epidemic as a serious public health issue at all. A global discourse, however, has also emerged and now gives a special place for 'partnership' and participatory approaches to solving public health and other societal problems. Shifts in governance and state planning within Western countries and those of the so-called global South and Post-Soviet states have been conducive to enabling more inclusive decision-making for more efficient and supposedly, sustainable, planning. States now collaborate with a diverse range of actors, characterised especially through new public management, partnership

[3] One is thinking here of the so-called 'third wave' of democratisation and, with it, democratic transitions in most regions of the world.

[4] See other papers in NIBR's public health programme, http://www.nibr.no.

[5] Areas of overlap between the West and the global South and former Soviet states include the context of the treatment era of HIV/AIDS, whereby new modes of public health governance are developed through bio-therapeutic medical interventions (see section on Brazil, and especially, Biehl, 2007) that place more emphasis upon the individual and less upon state responsibility

approaches and rediscovery of the local scale of planning. Shifting trends in decision-making mechanisms inevitably frame, and are framed by, how the epidemic is conceived and responded to.

To complicate matters, in recent years there are also increasing calls to assert more coercive means to enact behavioural change regarding HIV/AIDS (Chin, 2007; Pisani, 2008), which means that the liberal approach is not infinite. Vocal critics (Pisani, 2008) maintain that contemporary efforts to prevent new HIV infections might well be foundering. Health agencies' responses are criticised for shying away from using effective and proven means, sacrificed on the alter either of prevailing social norms, or, perceived political correctness. Certainly, these arguments are emboldened by the increasing availability of treatment for HIV/AIDS. But at the same time, surely the accusation of political correctness indicates that underlying prejudices, intolerance to diversity and specific patterns of behaviour also can not be wished away. Whether public health interventions may be implicated in exacerbating 'othering' of particular groups is another important consideration. AIDS has brought many of these debates to the fore.

The paper therefore explores the intersection of public health and HIV/AIDS discourse in order to suggest what this may tell us about each and what effective responses to the epidemic look like. It does so by locating public health responses to AIDS in the following contexts for discussion. First, the paper will explore definitions of public health, to identify a broad spectrum of meanings, as well as tensions, to identify common elements but also shifting understandings. Second, the shifting relationship between public health and AIDS is then reviewed. The purpose is to suggest not only how public health has impacted upon AIDS but the ways in which AIDS has actually played a catalytic role in *rethinking* public health planning more generally. Third, the paper explores the types of governance relationships deemed most appropriate in planning responses to AIDS prevention. What is the basis of claims made for partnership, multi-sectoral, participatory forms of planning and implementation? And do similar arrangements correlate to better AIDS prevention outcomes? Fourth, an overview of some key dimensions in explaining state responses to AIDS are identified in selected countries, namely, Brazil, South Africa and Russia. Identifying common themes and contrasts may be used to inform broader understanding of effective responses to HIV/AIDS.

2 Locating public health

Public health's primary role is characterised historically as one of controlling and preventing infectious diseases (Mann et al, 1999). Of course, this has purportedly been justified in line with the important objective of safeguarding and improving the collective public health. In her book, *City of Plagues*, Susan Craddock (2000:3), however, makes the important point that it "is not to say that public health policies through the years have not been responsible for much that is beneficial, but it is to say that there is a sustained failure within medicine and public health to recognize the effect institutional practice has upon those suffering real or ascribed burdens of disease". In other words, there is a long history of responding to infectious disease control that is also driven as much by prevailing social and moral attitudes rather than actual scientific or evidence based 'facts'. Baldwin, for example, confirms the disproportionate historical burden placed upon specific groups such as prostitutes, for example, in the context of public health responses to curtailing sexually transmitted diseases (Baldwin, 2005). If the relationship between medical discourse, institutional practice and the social and political roles of disease is not a new area of enquiry, then in terms of AIDS it is argued that they took on a new lease of life.

What is ascertained at this stage is that a variety of methods are necessary to encompass a 'public health approach'. Combining strategies and identifying what actually makes a difference is often, however, difficult to determine (International Federation of Red Cross et al, 1999). How are we to begin to understand public health, let alone conjure a definitive definition from the many that exist?

2.1 From Snow to a broad Spectrum of public health responses

All the evidence proving the communication of cholera through the medium of water, confirms that with which I set out, of its communication in the crowded habitations of the poor, in coalmines and other places' (Snow, 1855).

(Cholera epidemic in Zimbabwe, photo by Getty 2008). [6]

Between 31st August and 10th September 1854, during an outbreak of a particularly virulent cholera epidemic in the Soho area of London, over 500 people died. Orthodox explanations of infectious disease outbreaks around the time of the Soho epidemic focused upon air-borne factors. However, through mapping the demography and geography of the fatalities, Snow was able to correlate the outbreak of infections with a contaminated water supply at the pump on Broad Street. Snow's findings convinced the local authorities to remove the handle of the pump so that people could not draw water from it.[7] The larger contribution Snow made was in identifying the roles poor sanitation, contaminated water supply (and, indeed, whether the supply should be public or private-owned) and crowded inner-city living conditions play in health and ill-health. As such, he is often accredited with creating modern epidemiology, the science for what would become the public health movement. As his quotation, above, reflects, conditions for being healthy were therefore identified far beyond the realm of individual health care mediated by a physician. Indeed, Snow's really outstanding contribution was not only to identify channels of infectious disease transmission but also the social and economic determinants of poor health, namely, what is now recognised as the role of factors such as gender, class, race and geographical location in health. Because it is often beyond a narrow bio-medical realm, although clearly overlapping with it, public health represents an epochal shift away from dominant medical based meanings of health. Future generations have built on the work of Snow to create a modern public health movement that embodies the drive to understand these broader determinants of 'health'.

Since this time, many of the great infectious disease threats to Western society have been eradicated or at least controlled by vastly improved living conditions and public health interventions. But, sadly, Snow's work still resonates across many countries in the contemporary era. For example, since August 2008, Zimbabwe has encountered a severe cholera epidemic. By February 2009, the number of cases and deaths is

[6] *Independent*, '3,000 dead from cholera', photo by Getty, 26 November, 2008.

[7] Although they also later replaced it, not entirely believing Snow's account after the emergency subsided.

estimated by WHO to be approximately 79,000 and almost 4000, respectively.[8] The main reason is Zimbabwe's collapsing public health and sanitation system, with people using contaminated water from bore holes not unlike Soho. Once its infrastructure was the envy of the rest of Africa but now Zimbabwe's acute crisis plays out in terms of severe consequences for health and with calls that its health system be placed under international supervision by the United Nations and WHO. Set amidst the backdrop of a collapsing economy and state, Zimbabwe's devastating cholera epidemic provides a stark contemporary illustration of the broader determinants of disease. The point is that public health is therefore often defined as a collective approach to health, implying state and community level efforts at preventing disease and promoting health. Public health is often depicted as being about promoting the health of the community, dealing with society and, in it, groups of people and actions affecting people. Public health therefore works to assure the underlying conditions in which communities can be healthy. This can be defined in numerous ways.

One common definition is given by the WHO as "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 1986). Similarly is the notion that what is required is to 'ensure the conditions in which people can be healthy' (in Mann et al, 1999). These definitions conceptualise health as something constituted beyond health itself, a part of a condition that is broader and constitutes 'well being'. Focus on the preconditions for health has cast the net wider, therefore, in also recognising that community participation is important to meet these conditions. There have been global calls for local participation through primary health care, and involvement of community groups. In other words, influential conferences, such as the Alma Ata Declaration in 1978, seek to embody transformation of society. This is regarded as shaped therefore by social forces, and as, as such, the Alma-Ata provides a useful expansion of health as: a 'social goal whose realization requires the action of many other social and economic sectors in addition to the health sector' (in Mann et al, 1999). A significant plank to achieve these ends was therefore intended to be Primary Health Care (PHC). PHC was described as 'more than just providing basic services' (see Usdin, 2007). This was because it sought to eradicate inequity especially by working closely with other health related sectors- such as water, sanitation, education and food security. 'Health for All' lost favour as an international concern for various reasons beyond the scope of this paper.[9] The contribution made by PHC was essentially to foreground the collective and social role in tackling public health challenges.

Modern public health, as already suggested, however, is indelibly marked by its origins. This imprint is related to the 'control' dimension of public health that is often the entry point when encountering complex social context. An important observation to note, however, is that 'because human behaviour is the most complex

[8] As of 18 February 2009, the WHO estimates that there were 79 613 suspected cases, including 3 731 deaths, see http://www.who.int/csr/don/2009_02_20/en/index.html.

[9] For example, changing priorities in donor financial aid and political preference for less costly 'selective primary health care', rather than the comprehensive package of measures and fundamental changes in macro-economics deemed integral to PHC.

challenge imaginable, public health has often neglected the behavioural dimension of health' (International Federation of the Red Cross, 1999). Sexually transmitted infections, for example, may be dealt with by diagnosis and treatment rather than addressing sexual behaviour. Similarly, family planning tends to focus upon contraceptive options rather than discussing sexuality. There is a tendency towards seeking technical solutions because behaviour change is extremely difficult. According to Mann (1999:442) there are three particular reasons for the lack of consistency in dealing with social factors.

First, 'examining public health programs designed to address the health problems associated with these same behaviours reveals that they generally consist of activities that assume individuals have essentially complete control over their health-related behaviours'. Other observers, such as Epstein, tend to reinforce this perception, because, she says:

> "Most public health interventions tend to address health problems on a case- by- case basis- by, for example, delivering drugs, vaccines, contraceptives, and other items to individual people, or by supplying individuals with information on which to base personal decisions concerning their health" (Epstein, 2007: 249).

Societal factors are not adequately addressed, in other words because public health lacks a conceptual framework within which essential social factors may be unpacked.

Second, public health lacks a vocabulary to identify more common elements of health problems across different populations.

Third, and in relation to the first two observations, the role of social determination (e.g. education, income, occupational position and cultural factors) of health outcomes has been placed on the global public health agenda. But according to Mann (1999:442) there still appears to be little consensus within public health concerning social change and the measures necessary for tackling socio-economic determinants of health. This omission, according to Siegrist and Marmot (2006) is related to the problem of identifying causation and, with it, a need to go beyond description to explanations of health outcomes. For example, rather than being overly socially deterministic, more recent accounts can locate explanations –often surprising- in terms, perhaps, of the interaction of biological ('nature') AND socio-economic ('nurture') factors, and/or psycho-social phenomena (see Siegrist and Marmot, 2006).

Some core areas common to public health can, of course, be delineated: it is perhaps more useful to regard it as straddling a broad spectrum of approaches. At one end is the tendency to reify a focus upon the individual risk or risk groups ('host'), whilst at the other, there is an awareness of the role of social and community-level factors ('environment'). Somewhere in between, critically, is the mode of transmission, associated especially with epidemics, which is often pivotal in tilting responses to one or other pole of the spectrum. Despite the 'see-saw' in prevailing approaches to public health, a core area of public health concerns prevention (and health promotion), with three levels often outlined: Primary prevention ("pure" prevention-preventing the health problem from arising at all)- whose basis is health promotion through education and active participation; Secondary prevention- whereby the

health condition in question occurs and prompt detection and treatment of condition can avoid actual damage; Tertiary prevention- which follows after 'one' and 'two' have failed and a person's health has been damaged.

Notably, for the discussion that follows, tensions can be flagged up between the collective good and individual and group level concerns. Particular groups can be ascribed characteristics or 'risks' in relation to disease. This is a particularly important consideration in tackling HIV/AIDS, as we will see. Balancing the 'public good' with individual rights and freedoms is one of the core challenges to public health approaches.

2.1.1 Public health and Restricting freedom

> Public health is inherently a somewhat fascist discipline. It accepts that we must sometimes violate the rights of a few to protect the health of the many'. (Pisani, 2008:154).

One particular tensions lies between safeguarding the autonomy of individuals and groups and restricting 'freedoms' through more coercive approaches purportedly intended to curb infection. Because most of the urgent threats to health were (and for many parts of the world, still are) associated with often terrifying infectious diseases, the historical role of public health has been of coercive measures necessary for traditional communicable disease control: mandatory testing and treatment, quarantine and isolation (Mann et al, 1999). The extent to which there is a direct correlation between a country characterised as having a high degree of civil liberties and whether it possess a more liberal public health response is not necessarily to be taken for granted. Rather, public health responses tend to show great variations across countries, including within those characterised as western liberal democratic (Baldwin, 2005). Nonetheless, in an era of HIV/AIDS the issue of balancing freedoms in the context of curtailment of public health threats is one in which states have had to become increasingly involved.

A fundamental issue for public health is therefore when this more coercive character is necessary and under what conditions, such restrictions on liberties are permissible. As Crewe (2008) suggests, where scepticism towards freedoms and rights emerges is precisely in the 'no-mans land' between understanding cause and effect in interventions. In other words, when seemingly rational 'neutral' interventions crash into stubborn behaviours moulded in specific contexts unbeknown to the practitioner, rights and freedoms are often the fall-guy to explain failed implementation. Certain rights are non-violable, such as freedom from torture, and right to life. But at times, it is recognised that restrictions –such as banning smoking in public places- are necessary for the greater (public) good or order and social welfare. This begs issues of under what conditions limitations on rights can be imposed. It is generally recognised in order to restrict liberties that due process and a legitimate objective should be primary 'tests'. In other words, restrictions should not be arbitrarily imposed, be as least intrusive as possible and only considered strictly when necessary.

In the contemporary era of a world wide Tuberculosis (TB) epidemic, for example, Extremely Drug Resistant Tuberculosis ('XDR TB', a particularly infectious type of TB) poses challenges to individual rights in order to serve the interests of public health. While limitation on rights may be warranted, however, what is imperative is that 'the manner and conditions of isolation [for example] must meet [certain constitutional, human rights, or, legal]…standards'. There is an historical pattern, however, whereby the coercive elements are permitted for the 'greater good' (a utilitarian argument), which is deemed higher priority than the rights of those affected. An important consideration is therefore to what extent coercive measures actually improve public health outcomes. Human rights violations, for example, may serve to undermine public health approaches. In the example of TB isolation, if this is perceived to violate the dignity and autonomy of individuals with TB, then it may encourage the infected to evade services thus pushing the disease more under ground, and making it harder to tackle.

How, then, have these elements impacted upon and, in turn, been impacted by the juggernaut of the AIDS epidemic?

3 Public Health and AIDS

3.1 The rise of a 'voluntarist' response

HIV infection has been strongly associated in popular perception with stigmatised groups. HIV/AIDS was marked by stigma, literally regarded as a disfiguring abnormality. In addition to disfigurement, AIDS also came to occupy a modern day place in a long history of public fear of infectious outbreaks. Public health planning can be understood as a synonym for *intervention-oriented policy making*. Planning is constructed at a macro-social national level aimed at improved public health and responding to perceived threats, like HIV/AIDS. Initially, the disease saw both public health planning and social responses going into a mode of containment described as the 'default mode': early US policy was to quarantine HIV positive Haitian refugees in holding camps in *Guantamino*, and to place restrictions on infected people related to travel. While the former was lifted following court judgements that saw little public health benefit in quarantine, the former travel restrictions are still in place.[10] Many states in the US also introduced specific HIV related legislation, which enabled use of criminal law to punish transmission of HIV/AIDS. More generally, social responses centred upon excluding people living with HIV/AIDS from services and employment. Exclusion and rejection within communities –including even within families- was not uncommon. Hence, because of its focus upon risk groups such as men who have sex with men (MSM), sex workers and their clients, injecting drug users (IDU), and, the emotive terrain of race and sexual relations *per se*, AIDS, as suggested, deals with 'demonised' and/or marginalised subjects.

One can argue that rights come into play exactly when the exercise of authority becomes arbitrary, due to some combination of democratic deficits (including tyranny of the majority) and misuse of power. As mentioned earlier, when programmes founder the scapegoat increasingly cited tends to be liberal approaches to public health. Recently, there is evidence of an emerging back lash to these approaches. This resembles a 'back to public health basics' approach. In a highly informative and refreshing read, Pisani (2008) depicts, amongst many other colourful arguments, how human rights measures serve to undermine effective public health responses to AIDS. This is also echoed by Chin (2006), with both regarding core public health principles sacrificed to political correctness pervading global responses to AIDS. But given her concern for high risk groups she has worked amongst, and which encounter political and public disfavour, outright hostility and stigma and discrimination, Pisani's argument is somewhat inconsistent and contradictory. Surely

[10] The US has recently made the historic decision to finally lift these travel restrictions.

then, in many national contexts, dealing with such high risk groups for HIV/AIDS as drug users, sex workers, and men who have sex with men, one would rather hope that human rights in fact provide some political space and protection for such groups who comprise the 'dirty work' of public health?

Burris and Gostin (2003) suggest that HIV is ill-suited to coercion, especially due to the nature of private behaviour and safe behaviour can not be coerced, as well as the latent nature of the disease (i.e. taking years to develop, see also Baldwin,2005). This is a warning to public health attitudes mentioned earlier that seek to (re)assert more coercive measures, premised upon what is claimed as 'dispelling glorious myths or misconceptions' or exploding 'sacred cows' (Chin, and Epstein respectively) concerning responses to the epidemic. Some public health practitioners therefore apparently revel in contesting prevailing attitudes which are regarded as 'politically correct' and which are deemed to sacrifice sensible public health principles.

A more general need, however, is suggested by Burris and Gostin (2003) not to force certain recalcitrant people to change behaviour but rather to use law to create structural interventions which enable people to make choices which lessen their vulnerability in the first place. There is little dispute that, as mentioned in an earlier section, certain situations permit restrictions on rights –as encoded in the international human rights covenants- and which due process allows for. Reactions have wavered between fear mongering and need for containment, to sweeping the issues under a carpet of complacency. AIDS therefore churns up a range of moralising concerns which confront planning public health responses. Where the stigma associated with HIV/AIDS is superimposed upon pre-existing group experiences prior to AIDS, a double stigma occurs. This double stigma influences policy responses to varying degrees. Two fundamental issues therefore underpin the interaction of public health and AIDS. One concerns how public health has sought to assert itself in dealing with AIDS, especially in curtailing new infections. But reciprocally, we should also be addressing in what ways public health approaches have been altered by the specific challenges presented by AIDS.

Responding to the immense challenges of HIV/AIDS has involved evolving awareness of the need to go beyond it as narrowly public health, nor, even merely as a health issue. Rather, the understandings of the epidemic have turned increasingly to also look at it through different lenses. To that end, a human rights discourse has imprinted itself upon AIDS policy and practice. From early in the epidemic, human rights norms entered into these debates. Policy and debates have been infused with issues concerning confidentiality about status and informed consent in testing. Furthermore, concerns regarding the need for equality and non-discrimination to counteract marginalisation and prejudice were powerful arguments. This led to what Burris and Gostin (2003) term as the development of 'a volunterist consensus'. This consensus is premised upon recognition that HIV control would not be successful without the voluntary co-operation of those with and at risk of infection (see Burris and Gostin, 2003).

3.2 Participation in planning

Critically, these rights-based norms were also promoted at the same time as planning discourses were also shifting in western countries. Planning emphasised a more inclusive and participatory decision-making style. Fundamental shifts were occurring in terms of understanding representative democracy and identifying its limitations. New forms of economic organisation changed from Fordist to Post-Fordist systems of production, which led to less hierarchical decision-making processes. Many cities and communities became fragmented and run down. Perhaps the spur for attention to civic renewal and involvement was that states increasingly recognised that they required collaborative partners. States could no longer be the sole actor in policy planning and implementation (see Putnam, 1994; Evans 1996; Jones, 2003). In the last two decades increasing attention has turned to the role of institutions in creating more beneficial change especially through interaction with civil society to produce 'state-society synergy'. This synergy is created when public agencies promote and use the networks of cooperation and engagement with ordinary citizens.

These dimensions concern the social context of civic engagement and types of endowments of social capital within communities. The greater the level of inequality or marginalisation, the harder it may be to organise communities coherently. Furthermore, a wealth of evidence suggests the importance of scaling-up social capital beyond communities and into political and institutional fora. A vital ingredient in scaling-up therefore concerns the role of competent and engaged public institutions (Tendler, 1997). This can be enhanced by rule bound laws, backed up by state intervention, or, equally restricted by an absence of both laws and discourse that enables and legitimises participation. An important variable is the role of elites and knowledge networks at regional and national levels that can facilitate civic engagement or thwart it. In other words, multisectoral collaboration will not occur by itself but requires specific discursive, political and social conditions. The need to identify specific synergistic conditions hold as much relevance for community-state partnership initiatives in the global North (Jones, 2003), as it does for countries undergoing rapid political and economic transition. While some degree of trust, backed up by political capital may be necessary for successful partnerships, in the context of public health initiatives trust is arguably even more important. HIV/AIDS involves profound and sensitive issues concerning sexuality, difference and 'othering'. Interventions are especially dependent upon stocks of trust between service providers and infected and affected communities.

3.3 Planning for Prevention of HIV/AIDS

For much of the 1980s and 1990s, the 'behavioural change hypothesis', was the prevailing public health orthodoxy explaining peoples' risk to HIV/AIDS, especially in the global South. It is an approach premised upon narrow epidemiological definitions of the individual and certain 'risk groups', assuming that people make rational choices based upon the information given to them about health risks, such as condom use. This approach does not tend to recognise the interplay between broader societal factors and the HIV/AIDS epidemic. Furthermore, public discourse

can have the affect of ascribing social identities to particular groups, often acting to reassure those 'normal' groups who project their own fears of disease onto 'high risk' groups, and women in particular (Craddock, 2000; Altman, 2005). It is not to imply that individuals should be absolved from all responsibilities, but that our understanding of 'vulnerability' of specific individuals, groups and regions to HIV/AIDS should be situated within a more thorough analysis of the 'interaction of institutional, cultural, social economic and historical contingencies of place' (Craddock, 2000:154; Campbell, 2003). This is something gradually learnt in the course of public health planning for AIDS.

Ensuring an enabling environment for broad based involvement in decision-making has now become common place and integral to public health and rights-based approaches to the epidemic (Jones, 2009; de Waal, 2006; Valdiserri, 2003). Public health approaches –encompassing dimensions such as planning, policy development, including surveillance of needs, and financing and delivery- have undergone a process of enhanced liberalisation (Valdiserri, 2003). Greater awareness of community group dynamics and the need for stronger community relations, and greater participation is now reflected in service delivery. These approaches are often more appropriate and better targeted, particularly in research design and planning. And, given that the importance of allocative health planning is cited as an extremely important dimension of public health planning, community-based planning in the context of AIDS is regarded as innovatory (Valdiserri, 2003:66). So, although practices vary greatly across states, some with more coercive legislation, generally the US experience of building HIV prevention work around community norms and the involvement of these communities in a collaborative approach to governance, for example, are often cited as exemplary (Valdiserri, 2003).

3.3.1 Collaborative planning: The Centres for Disease Control (US)

The Centres for Disease Control (CDC) is the overall federal funding entity in leading prevention of HIV/AIDS in the US. The CDC claim that one of the main reasons why prevalence has stabilised (at around one million Americans HIV positive) is because of well designed and well delivered HIV prevention. High risk groups have been targeted, with results reflecting 'sustained, focused, and collaborative efforts among CBOs, federal agencies, foundations, prevention scientists and state and local health departments'.[11] Of particular interest in how early experiences of the epidemic shaped a response that became better grounded in community realities. The CDC's 'HIV in the Third Decade' report give priority to a response that is based upon community planning so that 'priorities for HIV prevention are determined locally with input from affected communities and that they are consistent with scientific findings about what interventions are most effective for decreasing HIV transmission'. In their work with 65 state, local and territorial health departments, CDC give emphasis to community level needs, which is explicitly a precondition for funding:

'A requirement for CDC funding is the development of a community planning process, which unites health departments and community members in developing an

[11] See www.cdc.gov/hiv/resources/reports/hiv3rddecade/chapter1.htm (accessed December, 2008).

HIV prevention plan that reflects their local epidemic and guides prevention efforts in their local area'.

In their most recent approach to prevention, CDC identifies the role of social networks centred upon local sites and recruiters that can reach persons at high risk of HIV infection. Untraditional non-clinical sites, for example, at nightclubs, can offer rapid testing. Valdiserri (2003) cites surveys from public health officials across a number of programmes in the US who affirm how AIDS has generated new experiences and information that has enabled better public health targeting of marginalized groups.

Although clearly not without some problems, especially concerning underrepresentation by marginalized groups, the fundamental point is that better targeting of resources and data driven community based decision making about priorities has been immensely beneficial to public health planning. This locally and minority group responsiveness in public health, may, however, also probably reflect the distinctive cultural heterogeneity and social stratification of the US (Baldwin, 2005). The example of the CDC nonetheless, arguably, shows the essential role of community backing and adequate planning is paramount in responding to HIV/AIDS.

3.3.2 (Whose) Knowledge Transfer to the global South

Initially these important lessons of community norms and priorities learnt in the West did not tend to be at the forefront of funds to global South prevention programmes. An unfortunate characteristic of many donor driven programmes has been to root them in Western science, which often underplays complex social dynamics within recipient countries. Whether such information- for example, about condom use- has altered behaviour, is very doubtful in many settings. Rather, economic and ideological constraints, most notably to do with constructions of gender (like 'being a man', the expectations about 'the role of a woman') appear also to be determining factors in shaping behaviour. In one donor's assessment in their own regional strategy papers for Southern Africa, it is recognised that for all the information and condom programmes, condom use is still low (DFID, 2002). Although awareness about HIV/AIDS was claimed to be 'nearly universal', DFID claimed that this was 'not translating into behaviour change'.[12] Elsewhere, it has been an effort to get to a stage whereby the epidemic is even regarded in these narrow terms.

In more recent years, public health approaches have, however, shifted to embrace a broader analysis of how individual behaviour is structured in very different societies. There is much greater interest in what are termed 'environmental-structural' factors in understanding a persons or group predisposition to infection. Again, AIDS has been very influential in new understandings. Now greater emphasis is placed upon

[12] Nonetheless, '[I]mproving access to relatively simple treatments required for frequent opportunistic infections is', it was stated, 'a more immediate priority than provision of anti-retroviral drugs' (DFID, 2002). Of course, the struggle over treatment has been one of the key engines of greater accountability and mobilisation in recent years. Treatment is know more readily –although far from universally-available. The point being made, however, is that these prevailing wisdoms structure global responses.

elements outside the control of the individual such as social norms, material and human resources, policies and legislation that facilitate or constrain individual behaviour.

In their study of factors in sex worker condom use, Kerrigan et al (2003), for example, stressed not only the important role of these environmental-structural factors but also multi-level factors. So, in terms of the environment and structure- the nature of the policy in place, level of agreement on it, collective response of sex workers and owners of the establishments were they worked, and inspections were critical. However, equally important were relational factors (such as with their client, and degree of intimacy and renumeration involved), and also the individual self-efficacy (correlated with exposure to NGO peer education projects) in negotiating condom use. All of this suggests a broad milieu within which planning and interventions should be located should they be more efficient.

3.3.3 Politics and planning

These responses also reveal a keen awareness by some state leaders and bureaucracies of the need to build new inclusive forms of cross-sectoral networks premised upon civil society and state partnerships. The era of AIDS not only coincided with these profound transitions but, arguably, provided much momentum to reconceptualising public health planning. The hard won political gains in responding to AIDS, such as community involvement in decision-making, have meant that AIDS is credited with a catalytic role in deepening democratisation and news ways of governing both in the West but also especially in less-developing countries (de Waal, 2006). Although fragile and contested and often falling short of the ideals because policy still needs to be rooted in specific national and local contexts (Jones, 2009), the prevailing global discourse has been to focus upon creating synergistic relationships between the state and other actors, such as communities, and People living with AIDS themselves. From the first appearance of illness, certain groups have been disproportionately affected by AIDS in the West, as elsewhere. Understandings of the epidemic have always been premised upon recognising the role of political barriers- as Altman alludes to:

> 'The literature tends to emphasize immediate problems- lack of condoms or clean needles, safe sex fatigue, unwillingness to interfere with the immediate gratification of sex or drugs. There is less emphasis on the political barriers that are accelerating the epidemic- the deliberate neglect by governments, the unwillingness to speak openly of HIV and its risks, the hypocrisy with which simple measures of prevention are forestalled in the name of culture, religion and tradition' (Altman, 2005:89).

But it has taken almost two decades for mainstream research and policy finally to take an interest in institutional and political decision-making in responses to AIDS beyond the West. And this analysis has become more nuanced. The epidemic gradually came to be more broadly understood not only as health-oriented but also socially and politically driven. Human rights abuses and the roles of gender relations, race, class and exclusion, have been a mainstay of analysis. But political scientists have also added attention to nature of bureaucracy, health system capacity and

leadership. Furthermore, the broader development implications of AIDS were also identified, with threats posed to both household economies and that of the state itself.

In the current phase of response, political systems and democratic decision-making are receiving even greater attention. Some even describe the epidemic as symptomatic of the crisis in democracy in many parts of the world. There has therefore been increasing momentum for civil society participation in policy making, as embodied in the WHO/UNAIDS (1996) guidelines on 'HIV/AIDS and Human Rights'. These guidelines explicitly link the political realm by identifying the duties of states and also the need for greater community participation, especially by those groups directly affected. This momentum, what might be termed a democratising impulse, has been a feature of AIDS policy making and has impacted public health itself. Almost three decades into the epidemic, a common global response has now been established. This orthodoxy –as expressed particularly by the UN, UNAIDS and the WHO especially- sets out the institutional architecture deemed necessary in the face of the epidemic. How these institutional responses are played out across different country experiences will inform us about both the scope and nature of both public health and AIDS. This is because, like other policy areas, the formulation and execution of public health can therefore be regarded as a public *policy field* that is constructed at international and national levels. In other words, like any policy field, these interventions are supported either by 'soft power' (knowledge and institutions), or, by 'hard power' (the force of the state). Undeniably, responses to AIDS meet at the intersection of both kinds of power.

Not least, the analysis by Burris and Gostin, again, suggests especially for AIDS the need to build trust between state agencies and communities. This appears to be a vital bridge between the kinds of state and political interventions needed but also to connect with the lived reality of communities, and, especially, marginalized groups within them.

The following section briefly turns to specific country contexts, namely, Brazil, Russia and South Africa to illustrate the complex institutional and societal discourses in specific responses to HIV/AIDS.

4 Contextualising public health and AIDS in case studies from the global South and former Soviet Union

Three countries will be briefly explored in order to identify common themes affecting organisation of public health and planning responses to HIV/AIDS.

4.1.1 Brazil: the role of effective partnerships

Brazil is globally credited, celebrated even, for its progressive response to AIDS that has successfully brought the epidemic under control. From early in the epidemic, common ground was built between activists and government at national, federal and local levels that came to characterise responses based upon mutual progressive commitments (Biehl, 2007:61). This has involved a progressive public health movement seeking engagement with communities, and state leadership that embraced such a positive response. History provides some lessons here as a prelude to responses to AIDS.

Tendler (1997) for example, identifies the critical role of trust and respect generated between clients and public servants in the context of public health interventions. Her work is cited by Gupta et al (2004) as indicating the contributory factor of dense networks of interaction –through media programmes, support to frontline health workers, and especially direct budget control to communities- that enabled state and communities to collaborate productively. Above all, given the threat of clientalist relations, central government has apparently 'kept an iron hand' to keep mayors and local power holders from exercising patronage. These kinds of experiences are therefore an important forerunner to responses to AIDS. State activism and grass-roots and NGO organisations therefore forged efficient partnerships to pressure poorly performing municipalities from above and below.

Whilst this proved to be phenomenally successful in extending access to prevention and medication, Biehl reveals reasons to be less celebratory. He demonstrates how the social and economic circumstances of the poorest and most vulnerable in Brazil's cities still endure unacceptably high levels of mortality. In relation, Biehl (2007) therefore suggests that access to prevention services and treatment outcomes are unequal and can only be properly understood in the context of three predominant forces.

First, the changing organisation of states has had consequences for the poorest in Brazil. Neo-liberal state reform claws back resources for health-care and considers prevention and treatment to be a private rather than public matter. The poorest, Biehl observes, has in effect been abandoned. In contrast to the earlier phase of active collaboration and demands placed on state policy, AIDS services are outsourced to CSOs. Foreign aid's role in inflating the role of CSO involvement (many more generalist rather than AIDS organisations) is identified as contributing to increasing cooption rather than collaboration, service providers rather than policy priority setters (Rich, 2006).

Second, in terms of Brazil's oppositional stance on patent protected medication, pharmaceutical companies and the market in fact undergo more and not less institutionalisation. As if to capture this development, mention is made of how pharmaceutical companies dramatically impact government spending, with over two thirds of Brazil's ARV budget going to these companies. There is also the growing influence of drug companies through 'Pharma philanthropy', which has embedded itself more deeply within states and societies, influencing drug regimens for example.

Third, patient-driven political demands are transformed into biological-based rights concerned with a micro-politics of survival. Biomedical intervention reflects a medicalization of marginalization. If this is taking place within Brazil, so influential in terms of the global efforts to extend access, we should surely be scrutinising the broader impact of global funding elsewhere in the world. Crudely put, as AIDS organizations and activists sit with the state in collaboration, they begin to justify in Brazil both state polices and, more alarmingly, themselves.[13] Again, the role of global funding seems to have prompted the institutional supply of thousands of Civil Society organisations (CSOs) - and their substitution of state provision.

With these important qualifications in mind, an other wise successful response was based on pro-active state leadership and strong state-society collaboration.

For all the faults, such multisectoral collaboration can only be dreamed about in other countries.

4.1.2 South Africa: the politics of denial

With an estimated 900 people daily dying, and 1 in 9 of the population infected, there is compelling evidence suggesting that on AIDS policy, nonetheless, government forced its forced. Outright denial and lingering scepticism have been long-standing features of the government's response to the epidemic. In assessing the tortured path of AIDS policy in South Africa, Nattrass provides a fair indictment that it is "a sorry tale of missed opportunities, inadequate analysis, bureaucratic failure and political mismanagement." (Nattrass, 2004:40). South Africa, for example, is possibly the most infamous example of AIDS simply being denied by national leaders, described as 'a deafening silence' (Cameron, in Jones, 2009). So, for example, whereas one would expect that a middle income country like South Africa performs well in terms of their "AIDS Program Effort" in comparison to most other African countries, it is

[13] The latter point refers to Brazil, in Biehl (2007:67).

apparently outperformed by Uganda, and more so by Rwanda.[14] AIDS policy, unlike other areas of policy in South Africa, experienced a much higher level of centralization. Political characteristics of the state enabled the particular stance presented by Mbeki and others to become manifest in the fabric of its institutions. In so doing, with such leadership so negative and even denying the science of AIDS, executive control of institutional structures undermined the potential for transparency, multisectoral mobilization, and steering of responses. Take the South African National AIDS Council (SANAC) as an example. This was created as the main national institutional structure to steer national responses to AIDS. One of its major tasks was to encourage multi-sectoral collaboration and partnership. However, whereas representatives from the government sector (sixteen in total) dominate SANAC, there has been only one NGO representative to represent the 600-plus organizations involved with HIV/AIDS. Scientists and researchers were not recognized as a sector and were therefore not represented, while traditional healers were the only representatives from the medical profession.[15] Notable oppositional civil society organizations, such as the Treatment Action Campaign, have also been excluded. More recently, it finally looks like this is being changed following a broadening of political space for civil society inclusion in AIDS policymaking. To devise a coordinated and appropriate response requires also leadership from the highest echelons of the state. Explaining the lack of leadership in South Africa is a highly complicated affair (see Jones, 2009) and there is not the space to address it here. The main point is that there was neither a political, nor, social consensus, until now, on what needed to be done. This affected all subsequent efforts to plan and mobilize against the disease at all scales.

Then, in addition to profoundly damaging leadership on AIDS, the poor state of the health service inherited from the apartheid era is another contributory factor. In 1994 the new post-apartheid government inherited a system of more than a dozen different health systems defined mainly by ethnicity and race. There is analytical evidence to suggest that despite the intentions of the ANC government to improve access to health care for the poor majority, in fact health care is in a poorer condition now than even in 1994. Within this, public health has only been present in terms of a handful of highly visible interventions rather than a broader institutionalised response. Whilst primary health care has benefited, the overall standard of care in hospitals has decreased. Furthermore, the government has done little to alter the grossly unequal resources going in to health care. Whereas a minority of around 15 per cent of the population access private health care insurance, this accounts for around 80 per cent of total amount spent on the health of South Africans.

Another factor is the quasi-federal state system, which has given responsibility to health to provincial government. Whilst seemingly sensible, very different levels of provincial capacity have been revealed. Dependent upon transfers from central government, the capacity of these provinces differs dramatically between those in

[14] The AIDS Program Effort is a useful measurement of AIDS policy responsiveness, as based on USAID, UNAIDS, WHO, and the POLICY Project definitions (in Patterson, 2006: 24–25).

[15] The sectors represented within SANAC include: government; parliament; business; people living with AIDS; NGOs; faith-based organizations; trade unions; women; youth; traditional leaders; legal and human rights groups; disabled people; celebrities; sporting bodies; local government; and the hospitality industry. (Van der Vliet, in Jones and Koffeld, 2008).

areas formerly designated as black homelands under apartheid, lacking in adequate institutional infrastructure and those with better capacity. Quite often, it is these poorer provinces that despite the need for spending are either not able to spend or mismanage the money allocated from government. Another dimension has been the role of party politics in determining provincial leader responses. A clear difference in policy responses to HIV/AIDS is reflected in province(s) led not by the national ruling African National Congress. Hence, the Western Cape is accredited with many more people on treatment, not only because of better infrastructure, but also greater commitment of leaders and progressive public health practitioners. However, another concern is the role of health care providers and several examples of highly negative treatment of people living with AIDS and judgemental attitudes.

There are also provincial AIDS councils and even local AIDS councils. However, their roles and mandate are a source of much confusion, with limited powers and their visibility to the public is poor. Particularly at a local level it appears that most local municipalities have not adequately empowered local aids councils. In part political and senior figures do not participate. As some have observed, there is a disjuncture between roles and responsibilities and actual integration in municipal planning and implementation processes. Furthermore, some have also been captured by local patronage centred upon party politics (again, in contrast to Brazil) and which barely function. Since the removal of President Mbeki from Office, there are, however, encouraging signs of a renewed genuine multi-sector response to AIDS. And a new HIV/AIDS and STI Plan for 2007-2011 holds out the possibility of real multisectoral collaboration and specific target led benchmarks for government performance.

South Africa provides a powerful illustration unfortunately of poor leadership, political interference, but also conflicting social and cultural attitudes. Racialized interpretations of HIV/AIDS have also had a clear imprint upon responses to HIV/AIDS.

4.1.3 Russia: the role of federalism and elites[16]

The Russian Federation has been described as amongst the worst cases of government response to HIV/AIDS, and the worst among the larger, highly decentralised federations (Gómez 2006). Although the rate of new incidents has stabilized since 2002 and some harm reduction programmes have achieved good results, Russia is still the country with the highest incidence of HIV infection in Europe, and one in 100 residents are estimated to be infected with HIV.

Like South Africa, prevailing understanding of HIV/AIDS in Russia were important. For many years the epidemic was considered to be a Western disease, surrounded by rejection and negativity, linked to immoral behaviour and associated with the most criticized social groups – first homosexuals, and later drug addicts and prostitutes. Although much of the social stigma is still present in recent years the federal authorities have started to demonstrate a higher commitment to the AIDS epidemic.

[16] This section draws exclusively on Aadne Aaasland's 'HIV/AIDS as a public health issue in Russia' (unpublished).

In October 2006, for example, a high-level multi-sectoral governmental Commission on AIDS was established with the task of coordinating general and regional authorities in the implementation of key directions of the national AIDS policy. Federal funding of HIV/AIDS programmes increased 20-fold in one year, from 2005 to 2006. A new Federal AIDS programme 2007-2011 has been adopted. The key policy aims are to coordinate federal and regional authorities in the implementation of the new key directions, organisation of multi-sectoral participation to ensure scale-up of prevention, and a review of legislative regulations. Some of the major challenges in responding to the HIV/AIDS epidemic in Russia are the size of the country, the autonomy of the regions in terms of budgeting and decision-making, as well as the vertical health system with limited multi-sectoral collaboration between entities. Coverage of prevention programmes for people whose behaviours are likely to put them most at risk are still low, i.e. a significant impact of the increased efforts has not yet been observed. Lack of full commitment to comprehensive education on sex and drugs in schools hampers effective prevention programmes among young people.

Many of the obstacles in dealing with the HIV/AIDS issue in a constructive manner are rooted in the legacy of public health and rapid transition, like South Africa, from the Soviet era. Decentralisation has also been an important theme but with vague delineation of federal government responsibility. While there is a clear need for a national approach to public health issues, the Ministry of Health funds little of the health care provision and therefore has limited influence. There appears to be a consensus that links between different ministries and governmental committees are weak and that many institutions are preoccupied with their own problems. Public participation tends to be only symbolic. In addition to the lack of cross-sectoral collaboration and partnerships in the public health system has become strongly decentralised. Central public health institutions have remained under the control of the Ministry of Health, but local public health services are incorporated into local government.

The results are mixed. Public health institutes respond better to local problems, for example by providing specific services that are needed in certain communities or regions. On the other hand, although health institutions have the freedom to raise extra funding for additional activities, it is also common that health is lower on the list of priorities of district or municipal politicians than at the federal level, and one often finds that HIV/AIDS policies are put low on the local policy agenda in a number of districts and municipalities. The combination of decentralisation and new legislation often brought about a reduction in control and blurring of responsibilities. Another by-product of decentralisation was that public health was removed even further from the interests of the ministries.

Another feature of the health care reform has been the establishment of a mandatory health insurance system whereby independent insurance organisations purchase health care on behalf of subscribers, a system that has met with numerous obstacles with very large regional variations in the financing patterns. There is also an emerging private sector in health care provision, which is not yet very large but is fast growing. This also mirrors developments in South Africa.

Civil society, in academic as well as popular literature on Soviet civil society is usually characterised as quite or very weak, especially at an institutional level. The concept of 'path dependency' has been used to explain the lack of a strong civil society in Russia. Due to the weakness of civil society actors in Russia, HIV/AIDS harm reduction strategies have been strongly influenced by international agencies. This has provoked criticism from the Russian authorities –again, echoing South Africa's own criticism of outside agencies usurping sovereignty. There are, however, many examples of successful policy measures as well, involving collaboration between government and civil society actors. The Advisory Council on HIV/AIDS at the Ministry of Health of the Russian Federation, comprised of government and civil society leaders and supported by UNDP, represents a successful example this type of a partnership.

The role of elites is highlighted as particularly significant. This is because it is the elites that devise federal agencies in response to the epidemic and decide whether or not to maintain them over time, while civil society's role always depends on the elites willingness to respond to society's needs.

Gomez highlights the historical, institutional and cultural factors that shape the Russian government's capacity to respond to HIV/AIDS, and looks beyond the immediate politics of reform. As reasons for the slow Russian response to the HIV/AIDS epidemic, Gomez mentions the persistence of a Victorian discriminatory outlook towards 'sinners' and the presence of a deep historical institutional presence of Christian morality. He argues that the institutionalisation of these moral outlooks entered the public sphere and continues to shape the way administrations and health officials respond to the disease (in contrast to the Brazilian case). Furthermore, contemporary debates concerning treatment distribution are played out against some of the judgemental features of the HIV/AIDS epidemic. HIV/AIDS, for example, as mentioned, is never far away from stigmatizing discourses apportioning blame and shame, which also exacerbate pre-existing discriminatory attitudes. In a context of chronic shortage of antiretroviral treatment (ARVs) in Russia's second largest hospital, in St. Petersburg, for example, one doctor was quoted as saying:

'I can't take the pills [i.e. ARVs] away from a child and give them to someone who's using drugs…The day a junkie needs to take pills, he shoots up and is in a state of oblivion (and) he skips his pill'.

Such judgemental attitudes prompted one AIDS activist to claim: "The situation now is plain genocide... Genocide is when doctors have to decide who gets and who doesn't get medicine ... because they don't have enough. That's fascism.'[17] Indeed there is growing awareness of the political dynamics of the epidemic and the need to explain state responses in terms of what social and cultural forces also condition such attitudes.

Again, like South Africa, prevailing attitudes appear extremely influential in directing policy in Russia.

Finally, an increasingly important issue for Russia, unlike South Africa, concerns funding almost exclusively provided by multilateral agencies and foreign bilateral

[17] Fighting for AIDS drugs in Russia' (www.cnn.com/2004/HEALTH/11/19/aids.russia/index.html

donors. Many international donors are preparing to reduce their assistance to Russia in coming years as Russia's economy has been growing rapidly over the past years. It is still an open question whether national federal funding to HIV/AIDS programmes will compensate for the decrease in international economic support. Furthermore, this global source of funding has been important in circumnavigating prejudice and lack of targeting of at risk groups.

5 Conclusion

> When an epidemic illness hits hardest at the lowest social classes or other fringe groups, it provides that grain of sand on which the pearl of moralism can form' (Musto in Rickard, 2008: 38).

In treating and preventing HIV/AIDS complex factors that underpin behaviour and, critically, therefore, the multiple levels at which behaviours are constructed, have been increasingly recognised and engaged with by public health policy. In this endeavour the working paper has shown that HIV/AIDS should be considered a catalyst in reorganising public health planning and approaches. This is therefore perhaps the key characteristic of responses to the epidemic: historical experience shows the need for social and political mobilisation for AIDS to be given appropriate recognition in public health responses and to ignite political will of state leaders and institutions. This is not to say that social mobilisation has not accompanied other health struggles but rather that this has been particularly strong in relation to HIV/AIDS.

It was also suggested that shifts in governance provide an important contextual factor in explaining the liberalisation of public health and responses to AIDS. Whilst there may now be an established global orthodoxy on the benefits of multi-sectoral collaboration, the paper also showed some of the factors in explaining why this very often falls short of the ideal type of response. Important dimensions –*across* the global North, South and former Soviet states- concern whether community participation actually serves to genuinely influence both decision-making and public health outcomes. Critical elements include not only the scope and nature of community relations or level of social capital, but also the framing of public health responses and the political space opened up by the state. Even amongst wealthy stable democracies in the West, for example, there are surprising anomalies in terms of public health discourse and legislation restricting political space and freedoms. It is not only the prevailing political culture that has a significant bearing upon institutional responses but also the specific cultural politics associated with AIDS. In particular, even when getting the institutional planning mechanisms in place, the role of prevailing social, cultural and political attitudes is still immensely important in whether these institutions actually can achieve anything. The attitudes of health care professionals and relations with patients also have an important bearing upon implementation of effective responses to AIDS (Jones, 2009). The case studies showed that in countries where democratic systems may be weaker the issue of the role of the state and civil society is particularly critical. The state often must step in to control sub-national structures or elites blocking reforms. Leadership is paramount in enabling vigorous responses. Another important aspect is therefore the role of elites and how they enable or disable collaborative responses. There are often finely

balanced relations between state-civil society relations mediated by many factors outlined.

In conclusion, HIV/AIDS continues to conjure up an array of deep seated attitudes from the depth of social consciousness, which remain intertwined with public health responses. In view of this, a particularly significant role has been given to human rights protections, sometimes in apparent tension with public health measures. In the current era there are indications that rights and the liberal model they underpin, are being increasingly scrutinised, whether in the context of the 'war on terror', HIV/AIDS, or, indeed, both (Viljoen and Precious, 2007). Whether *any* countries – either in the global North or South- can dispense with human rights, especially in tackling HIV/AIDS and to ensure better governance of the epidemic, is extremely doubtful. Moreover, human rights may provide a more universal analytical framework for comparing countries in international perspective. In order to withstand such scrutiny, however, it may be increasingly important to document the evidence for when and why liberal and rights-based approaches to health are more effective in responding to HIV/AIDS.

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