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‘Is AIDS Exceptional?’

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Executive Summary

This paper outlines the debate over and history of AIDS exceptionalism. It addresses the question: 'should AIDS still be treated as exceptional?' The word 'exceptionalism', means to treat or to give something the status of being exceptional and can be positive or negative, depending on the context. Initially AIDS exceptionalism was seen as 'a good thing'. Today it is suggested AIDS is excessively favoured and exceptionalism is 'a bad thing'.

The first part of the paper traces the the origins of AIDS exceptionalism. Exceptionalism originated in the unique nature of the epidemic and virus. The disease was new, and from an unknown retrovirus, spread mainly through sexual intercourse, and first documented in the gay populations of the west. The exceptional status was possible due to an alignment of interests particularly from the medical field and gay advocates. This 'exceptionalist alliance' included: the gay community, liberal and left-wing parties and sections of the health-care and psychosocial professions. It was partly driven by the fear that standard public health interventions (for example testing and contact tracing) would force people underground. The debate on exceptionalism has been centered in the West.

The importance of the gay movement can not be underestimated. In the West many key national responses to the epidemic were led by gay men, who have also been very influential in framing the international debate and response. This legacy of the early years has implications for ownership and policy especially among leadership in high prevalence countries.

By 1996 there was a call for an end to exceptionalism because AIDS had become less threatening. The anticipated horror scenarios did not materialize in the rich world; the disease centered in small, defined groups of people; and treatment was becoming available. By 2000 AIDS exceptionalism in the West was over. However AIDS became increasingly 'globalized', the impacts in developing countries were deemed an issue of global concern with implications for the affluent and powerful. This, assisted by a trend toward securitization and language of 'global threats', created new space for mobilization around the disease.

At the beginning of the century the global picture of the epidemic was diverse. In the wealthy countries, and most of Latin America, North Africa and the Middle East it was concentrated and stable. In Asia, there were still some fears of a potential epidemic. Parts of sub-Saharan Africa had generalized epidemics but in others HIV had not spread beyond core groups. In the former Soviet Union HIV was spreading rapidly among injecting drug users (IDUs). The inequity of treatment availability came under the spotlight and there was a mobilization around treatment programmes and international pledging of increased resources. In 2002 the Global Fund for AIDS, TB and Malaria was established. In 2003 President Bush pledged \$15 billion toward his Presidential Emergency Programme for AIDS Relief (PEPFAR). In the same year the World Health Organisation (WHO) launched the '3x5' campaign to get 3 million people on treatment by 2005. Funding rose from \$300 million in 1996 to \$13.7 billion by 2008.

AIDS has been 'normalized' where prevalence is low or treatment is easily available for most people. However 2008 saw a movement against it being considered exceptional anywhere; a backlash against the amount of AIDS-specific funding; and even a call for the abolition of UNAIDS. Of particular importance was the claim that AIDS funding and programmes were undermining the health sectors of the developing countries.

The key arguments were put forward in books by Chin, Epstein and Pisani. Chin accused AIDS activists of accepting certain myths about HIV epidemiology to keep the disease on the political agenda and ensure funding and jobs. Pisani views funds flowing to AIDS as 'rubbing out common sense'. Epstein looks at Africa where she says the main driver of HIV infections is concurrent sexual partnering, about which silence prevails. Barnett writes of these debates: 'Responses to HIV/AIDS in Africa were distorted by the battles of a cultural civil war fought out across the USA'.

The strongest argument against AIDS exceptionalism is that it has undermined health systems in developing countries. This was argued aggressively by England in the *British Medical Journal*, who said the amount of money poured into AIDS was unwarranted and harmed existing health systems; AIDS was not the 'global catastrophe' it was claimed; and donor aid for AIDS was out of proportion to the overall disease burden. UNAIDS was accused of creating and imposing 'the biggest vertical programme in history', eroding the public health sector, undermining government efficiency and removing national control over spending priorities.

At present (July 2009) the world is entering a severe, sustained economic crisis with implications for the response to HIV and AIDS. It is unlikely the US\$25.1 billion required for low- and middle-income countries for 2010 will be forthcoming. The vulnerability of individual countries needs to be assessed in relation to the size of the existing total HIV expenditure and the size of the national economy, the 'HIV spending burden', and the degree of aid dependency for the HIV programme.

This paper argues AIDS is exceptional in some places and must be treated as such. The exceptionality is determined by:

- The prevalence
- The demographic dynamics of the country
- Availability and domestic affordability of treatments.

In all developed countries and most developing countries with low prevalence (less than three percent) AIDS can be normalized and treated as a public health issue. Here it is located largely on the margins of society and in groups known as the 'most at risk populations' (MARPs). For these groups AIDS is exceptional, but nationally the appropriate response is to normalize and destigmatise the disease and the actions that put people at risk.

In developing countries with low prevalence there should be continuous monitoring. UNAIDS should maintain surveillance and interpret and act on changes in the location or direction of the epidemic. It must be an advocate for marginal groups, and increasingly for correctly targeted funding. It should function as information broker.

Demographic dynamics are important. Outbreaks may be small but have a disproportionate impact because of who is infected. This is the situation in some countries of the former Soviet Union where AIDS exacerbates an already troubled demographic situation of low total fertility rates and declining populations.

In countries with prevalence of over three and less than 10 percent, the exceptionality 'rule' will be a function of prevalence and wealth. Where people are able to access domestically supported

treatment, then we cease to regard AIDS as exceptional. If treatment is dependent on outside resources, and if the expenditure per AIDS patient exceeds the per capita health expenditure, then AIDS must be treated as exceptional.

AIDS is always exceptional in countries with high prevalence due to the increased in mortality and/or the challenges of providing treatment. Effects flow from these illnesses and deaths and the decisions relating to provision of treatment and its cost and financing. The demographic consequences of declining life expectancy, changes in the size and structure of the population, and increased orphaning make the consequences long-lasting and socially impoverishing.

Prevention and treatment are also extraordinary issues. In poor countries international aid is literally keeping people alive. The poorer the country and the greater the disease burden, the more they will be dependent on such assistance.

Because AIDS is a long-wave event, in 2031, there will be people who were infected in 2009 living on treatment. There will be children who have grown up without parents. The demographic, social and political repercussions will still be being felt in some nations. The project must engage in long-term thinking and planning. It must ensure leaders take on the ideas and lessons.

Aids2031 and UNAIDS must make sure prevention is high on the agenda, advocating for what works and ensuring MARPs and marginal groups are considered. Treatment guidelines are critical, as is advocacy for increased resources. The issues of vertical versus horizontal programmes for AIDS treatment are vexing. The hard questions we need to ask are: why we do not give more priority to prevention?; what is the cost of treatment and how it will be maintained?; and how should issues of sustainability and national sovereignty be considered?

Introduction

When AIDS was first identified it was treated as an exceptional disease for good reason. It was not clear how the virus was transmitted, how rapidly, or how far it would spread. There were concerns over the challenge of a new, apparently rampant, infectious disease; the sexual nature of transmission; apparently inevitable mortality; and its location, primarily among gay men in the west. However there was also hysteria stoked by the media.

What does exceptional mean? The Oxford English Dictionary defines an exception (a noun) as something that ‘proves the rule, shows that the rule exists or the exception would be needless’. Exceptional is the adjective. There are numerous synonyms such as aberrant, extraordinary, inconsistent, peculiar, remarkable, singular, and unique. The word ‘exceptionalism’, not found in most dictionaries, means ‘to treat or to give something the status of being exceptional’. This can be positive or negative depending on the context. In the early years AIDS exceptionalism was seen as ‘a good thing’, today it is being used, by some, to suggest AIDS is excessively favoured and is ‘a bad thing’. The origins of exceptionalism have been documented and debated.¹ This paper asks if AIDS is still exceptional and why defining it as such is important and helpful.

It is important to stress the framing discussions of AIDS as being exceptional originated from, and were centered on the rich world, and for its medical, human rights aspects rather than in the poor world and for the demographic, social and political features. This paper outlines the debate and its history, addresses the attacks on the way AIDS is regarded and funded, and lastly looks at the future of the epidemic response, concluding that AIDS must be treated as exceptional in some situations.

The History of AIDS Exceptionalism

The first phase 1981– 1996

Fear was amongst the first responses to AIDS . During the early period (1981-1984) when the cause of the illness was not understood AIDS attracted special attention from media, governments, and scientists and was exempted from many rules in health policy, public health, prevention and patient care.

This resulted in innovative responses to the disease and significant allocation of resources, especially to science (Rosenbrock et al., 2000). Research was dominated first by the medical and life sciences, and then public health and epidemiology. Scientists sought to understand the origin and mechanisms of the disease and how it was transmitted in order to prevent its spread, alleviate symptoms, prolong lives and, ultimately, eradicate the virus. Once HIV was better understood, the hysteria began to abate. Correctly, early and non-exceptional responses were advised by science and technology and included improving blood safety, providing condoms, encouraging safe injection practices, public education and the search for potential treatments and vaccines.

¹ See the annotated bibliography submitted as a separate document. An additional valuable document is Lindsay Knight, 2008, UNAIDS the First 10 years, UNAIDS, Geneva

More broadly AIDS was given 'exceptional' status. The syndrome was new, there were no treatments and it led to death. This was unsettling for clinicians, who could do little for their patients, and more broadly for a society that had believed science had conquered disease. The paths of transmission: unprotected sexual intercourse, men having sex with men (MSM), injecting drug use, and from mother to infant, meant it was highly politicized and potentially stigmatizing. It was feared standard public health interventions (for example testing and contact tracing) would drive people at risk or infected underground due to stigma and because on an individual level, little could be done for them. There was a dynamic combination of medical response and gay advocacy. The advocacy aspect can be seen in the context of the highly activist gay movement in the West that evolved in the late 1970s and early 1980s. (Shilts 1987).

Mobilization led to new style public health interventions, with involvement and responsibility being shared by those most at risk. This "was made possible by the emergence of an 'exceptionalist alliance'. Depending on the countries this alliance included: the gay community, liberal and left-wing parties and, or large sections of the health-care and psychosocial professions". (Rosenbrock et al. 2000, p.1610). Thus political advocacy and action, driven mainly by gay activists, calling for exceptionalism had the backing of the scientific and public health community, a powerful and unique alignment of interests.

The concept of 'exceptionalism' was neatly encapsulated and possibly coined in Bayer's 1991 article *Public Health Policy and the AIDS Epidemic: An End to HIV Exceptionalism*. (Bayer 1991). In 1994 he stated, 'the embrace of exceptionalism must be understood in broad political terms, as representing in large measure, a singular victory on the part of gay men, their community-based organizations and their allies' (Bayer 1994, p.16).

The importance of the gay movement can not be under-estimated. 'Descriptively exceptionalism posited that in the early years of the HIV epidemic, HIV was considered so different, so 'exceptional' in comparison to other communicable diseases that advocates and public health officials agreed that HIV policy should cater to the uniqueness of the epidemic rather than treat it like all other communicable diseases. Supposedly, the argument goes, public fear was so great, the political power of gay men so substantial, and concern over stigmatization so real, that public health authorities abandoned 'traditional' and effective approaches to communicable disease control in favor of a civil liberties approach' (Lazzarini 2001, p.149).

In the West, many key national responses to the epidemic were led by gay men, who have also been influential in framing the international debate and response. The UN agencies and international AIDS organizations have had significant numbers of gay activists in senior positions. This has had implications for ownership and action.² One of the key issues for the AIDS agenda is to ensure that this disease has the ownership of the leaders in high prevalence countries. It is telling that, in the early years in the US, icons such as Magic Johnson, Arthur Ashe and Elizabeth Glaser were prepared to admit to living with HIV. There are few such examples outside the developed world.

² This was positive in ensuring AIDS was on the agenda and brought experience and commitment, but had a different impact in more homophobic societies, particularly in Africa.

Despite rapid medical and scientific advances, it was soon apparent that a cure or vaccine was not going to be easily developed. At the same time, understanding transmission mechanisms and the way the virus operated demystified the paths of infection. In the West, at least, it became apparent that the epidemic would be contained. In the poor world prevention efforts seemed to have limited success. Providing information via public education campaigns and the distribution of condoms did not lead to the widespread adoption of safer sexual practices. There were some early exceptions. In Thailand the 100% condom campaign dramatically reduced HIV incidence. Uganda's mixture of leadership, communication, social capital building and condom provision resulted in decreases in levels of infection. Senegal brought together religious and political leaders with a realistic attitude to commercial sex work, which kept prevalence low. In Cuba the entire population was tested and those infected were quarantined (and cared for), which contained the epidemic, but this was on an isolated island and rode roughshod over human rights.

By the 1990s, AIDS research broadened from the initial medical, scientific and technical foundations. There was growing scholarly interest in the individual, social, and economic milieu that led to vulnerability to HIV infection, and a recognition that social justice, poverty and equity issues were driving the uneven spread of the virus within and between communities and societies (Gruskin, Hendricks, & Tomasevski 1996; Barnett and Whiteside 1999).

In the international organizations, after the first fears of a rampant unstoppable epidemic were allayed, AIDS was not seen as a global priority, or indeed even an issue. The Global Programme on AIDS (GPA) in the World Health Organisation (WHO) was under-resourced and faced an uphill battle in responding to the epidemic. Outside of the WHO, AIDS was not on the agenda of any United Nations (UN) agencies; indeed, international responses between 1986 and 1996 were characterized by denial, underestimation, and over-simplification (i.e., conceptualizing HIV/AIDS solely as a medical issue) (Behrman 2004; Knight 2008). At the end of this period there were calls by social scientists, activists, and international advocates for human rights approaches in understanding and responding to the epidemic.

The First 15 Years 1981–1996

- The early response, combined epidemiology and public health perspectives, aimed at understanding transmission: who was at risk, and how the spread could be prevented.
- Once the virus was identified and while science sought treatments and biomedical answers, preventing the spread was addressed by protecting blood supplies and promoting safer sex and injecting practices.
- By the end of the period, social science and human rights approaches were developing and attention turned to understanding why people are exposed to HIV. There was little focus on broader social and economic determinants of the epidemic or its impacts.
- AIDS exceptionalism was possible due to the coincidence of scientific and activist responses and interests.

At the same moment as AIDS was recognized as exceptional, leading western thinkers were calling for an end to exceptionalism. Bayer wrote, 'as AIDS has become less threatening, the claims of those who argued that the exceptional threat would require exceptional policies have

begun to lose their force' (Bayer 1991) (see also Bayer 1999; Rosenbrock et al. 2000). Thus, in the developed world, AIDS began to be normalized.

This was possible for two reasons. First, expected horror scenarios failed to materialize in the rich world, where the disease centered in small, defined groups of people, and, as a result, there was a decline in interest in the epidemic. Second, the development of treatment was crucial. One author noted: 'HIV exceptionalism may be in its final stages. Many have argued for an end to it. ... the availability of more advanced antiretroviral therapies has made it possible to treat effectively those with HIV infection, thereby increasing the importance of early identification and tracking. These developments establish a strong case for moving beyond HIV exceptionalism and treating HIV antibody tests like other blood tests' (Jansen 2004, p.322).

It should be emphasised that the debate took place among western intellectuals, and the ending of exceptionalism was in countries where the epidemic was contained. Elsewhere there were continued fears about how far HIV would spread and what the impact of the disease would be. Here there were calls for multi-sectoral responses and for the disease be seen as an issue beyond the health sector.

The advent of treatment and securitisation of the epidemic 1996–2006

At the XI International AIDS Conference in Vancouver 1996 the availability of new but costly drugs and therapies was announced. Had they remained expensive, AIDS exceptionalism would have been perpetuated. Casaratt and Lantos noted: 'Medical therapy has become more effective but also prohibitively expensive. A medical tragedy has been transformed into a financial crisis and society has responded by establishing special programs and sources of funding for AIDS. These maneuvers parallel earlier approaches to HIV testing and reporting that have collectively come to be known as 'exceptionalism'.' (Casarett & Lantos, 1998).

By 2000 AIDS exceptionalism in the West was over. There was not the same questioning of the concept in the developing world, although De Cock and Johnson (1998) called for a normalization of attitudes and practices in HIV testing. Indeed, in the worst affected African countries, AIDS response faced a studied lack of analysis and, in the extreme case of President Mbeki of South Africa, a questioning of the science and origins of HIV and AIDS. The access to treatment which enabled normalization in the rich world was still a distant dream for the poor world. The perplexing absence of debate on exceptionalism is important but not the subject of this paper.

Internationally the response was changing, due in large part to the effective work of UNAIDS, the new agency charged with harmonizing and co-ordinating the UN response to HIV/AIDS.³ UNAIDS acknowledged the need for comprehensive responses to AIDS epidemics, and recognized that such multi-faceted (e.g., social, economic, behavioural, developmental, medical) responses reached beyond just 'health' (Levine et al. 2009). Among researchers there was a shift from the 'science-epidemiology' focus to a proliferation of scholarship and institutional interest in understanding the social and economic dimensions of the epidemic.

³ UNAIDS was established in terms of UNECOSOC (Economic and Social Council of the United Nations) resolution (1994/24).

Discourses around AIDS became increasingly ‘globalized’ (i.e. the impacts of AIDS in developing countries were deemed an issue of ‘global concern’). The impetus for global response was further propelled by securitization and language of ‘global threats’, which also identified AIDS as a homogenous issue. In 2000 US Vice President, Al Gore said: ‘it [HIV] threatens not just individual citizens, but the very institutions that define and defend the character of a society. ... It strikes at the military, and subverts the forces of order and peacekeeping.’ (Gore 2000). Shortly afterwards the US NIC produced the ‘The Global Infectious Disease Threat and Its Implications for the United States’ (U.S. National Intelligence Council 2000).

Six months later, the UN Security Council passed Resolution 1308, stating: ‘the HIV/AIDS pandemic, if unchecked, may pose a risk to stability and security’ (UN Security Council 2000). This marked an important shift in thinking about HIV/AIDS. It was seen as an epidemic that could potentially have widespread repercussions for the most affluent and powerful, even though risk of infection and disease spread in these populations had abated.

In 2000 the global picture of the epidemic was diverse. In the wealthy countries, and most of Latin America, North Africa and the Middle East it was concentrated and stable with low incidence and prevalence. In Asia, there was concern there might be a sizable epidemic, although there were few data. Much of eastern, central and southern sub-Saharan Africa (with the exception of Uganda) appeared to have generalized epidemics with numbers rising. In the former Soviet Union countries of Russia and Ukraine, HIV was spreading rapidly among injecting drug users (IDUs). In Ukraine, there were only 398 HIV infections identified between 1987 and 1994 most of whom were foreigners; in 1995 and 1996 there were 1489 and 5422 new infections respectively, almost all of whom were Ukrainian IDUs (Barnett & Whiteside 2002, p.112).

The inequity of the treatment availability came under the spotlight. The XIIIth International AIDS conference in Durban 2000 called for treatment to be rolled out in the developing world and for prices to be cut. The rapid fall in drugs prices was matched by mobilization around treatment programmes and international pledging of increased resources. In 2001, UN Secretary General, Kofi Annan called for spending on AIDS to be increased ten-fold in developing countries. In 2002 the Global Fund for AIDS, TB and Malaria was established. In 2003, President George W. Bush pledged \$15 billion toward his Presidential Emergency Programme for AIDS Relief (PEPFAR) and the World Health Organisation (WHO) launched the ‘3x5’ campaign aiming to place three million people on treatment by 2005. In 1996, there was about \$300 million available for HIV/AIDS in low and middle income countries; by 2008, this increased to \$13.7 billion (UNAIDS 2009). In this international mobilization, concerns for social drivers and underlying vulnerabilities were largely subsumed by renewed hope in medical solutions and AIDS responses were remedicalized.

The Middle Years 1996–2006

- Drugs became available and their cost plummeted. Academic concerns about social drivers and underlying vulnerabilities were overtaken by enthusiasm for treatment and renewed hope in medical intervention.
- The language of security and threat to global order was used, resulting in a globalized AIDS response and discourse.
- The level of resources grew rapidly and new global initiatives were announced.
- The number of infections continued to rise, especially in the former Soviet Union and southern Africa. Southern and parts of eastern Africa were the epicenter of the disease.

In this period in middle and high prevalence countries national responses remained focussed on the need to take AIDS outside Ministries of Health and maintain multi-sectoral, cross cutting responses. However three factors had the effect of reducing local leadership and ownership of AIDS. First, the language of globalization and securitization meant it was seen as an international problem. Second, the idea that there were medical solutions (albeit not from Africa) resulted in a view that the disease would be dealt with by the scientists and men in white coats. Thirdly, the bulk of the funding and new initiatives came from the international community thus leaders and (especially) Ministries of Finance were not engaged with the response and its cost. AIDS was seen as exceptional because it was treated as such, this was disempowering to the worst affected countries. The Global Fund's application procedures were designed in the hope that they would empower countries submitting requests for funding . Unfortunately in some cases these were prepared by international consultants with little local engagement.

The push against HIV/AIDS exceptionalism 2006– 2009

AIDS has, correctly, been 'normalized' where prevalence is low or treatment is easily available for most people. However there is a push against AIDS being considered exceptional anywhere; a backlash against the amount of AIDS-specific funding; and even a call for the dissolution of UNAIDS. Some argue that the 'AIDS industry' has garnered an 'unfair' level of funding, resources were wasted on socially dubious expenditures, including ones that did not work, and damaged the health sectors of developing countries.

There are three particularly important books: Chin (2007), Epstein (2007) and Pisani (2008). Chin argued UNAIDS and AIDS activists accept certain myths about HIV epidemiology⁴ to keep the disease on the political agenda and, by implication, ensure funding and jobs. Pisani's view is the flow of funds to AIDS 'rubs out common sense', (p. 318) and scientists have allowed themselves to be compromised by the money and politics of the disease. These books focus on the Asian experience of the epidemic

⁴ The myths are from page 165 of the book. These are: a. virtually everyone is at almost equal risk of infection with HIV; b. HIV 'bridge' populations will invariably ignite heterosexual HIV epidemics; c. all high HIV risk behaviours will result in HIV epidemics; d. poverty, discrimination and lack of access to healthcare are major determinants of high HIV prevalence; e. HIV prevalence is increasing to record highs; f. In 2005 there were more than 40 million persons living with HIV and there were 5 million new HIV infections.

Epstein's *The Invisible Cure* reviews the African epidemic. She suggests that the main driver of the epidemic in hyper-epidemic countries is concurrent sexual partnering and there has been a silence around this. Reviewing the book in the *Lancet*, Barnett writes, “she suggests that since the earliest days of the African HIV epidemic observers have been reluctant to say this publicly and take the implications into policy formation. Why? Because to do so might resonate with racist discourses about ‘hyper-sexualised’ Africans, blaming the victims of this pandemic for their own sickness, deepening pre-existing prejudices, and losing the political support of African leaders for various kinds of intervention. And this fear was real: South Africa's President Thabo Mbeki is an example of just such a politician. And why should this have happened? For the best and the worst of reasons originating in what Epstein calls ‘the din of the culture wars’.

Responses to HIV/AIDS in Africa were distorted by the battles of a cultural civil war fought out across the USA.” (Barnett 2008).

All three scholars suggest the epidemic was overstated and money and resources were put into inappropriate responses in situations where HIV would not spread anyway. As Chin says: ‘AIDS programs developed by international agencies and faith based organizations have been and continue to be more socially, politically, and moralistically correct than epidemiologically accurate’. This resulted in calls for a ‘major over-haul of the international AIDS response’ (Lewis and Donovan, 2007, p532) and defensive responses from UNAIDS and the WHO (De Lay and De Kock, 2007 and De Lay et al 2007).⁵

The strongest argument against AIDS exceptionalism centres on the claim that AIDS has undermined health systems in developing countries. This has been articulated most aggressively (and polemically) by Roger England, who holds the amount of money poured into AIDS was unwarranted, and actually harmed health systems. In three articles/opinion pieces in the *British Medical Journal* (2007a and 2007b, 2008) England argued AIDS is not the ‘global catastrophe’ claimed by ‘AIDS exceptionalists’, in fact donor aid for AIDS is out of proportion to the contribution of AIDS to overall disease burden. England asserts it would have been more cost-effective to put the money into bed nets, immunization and dealing with childhood diseases.

The argument that the AIDS epidemic is not as big as expected is fallacious and should be treated as such. Indeed credit must be given to prevention programmes which responded to fears that the epidemic was out of control. UNAIDS was well aware of the changing epidemic. In its 2007 Annual Global Report, on the basis of better and updated data, UNAIDS concluded that the number of people infected with HIV was lower than previously feared, the global estimates declined from 40 million to 33 million. Linked to this was a confirmation that HIV had not, and would not spread uniformly.⁶

⁵ Note that Chin and Epstein’s criticism of UNAIDS, an organization with an uncertain mandate and a constituency of many different UN agencies which pull it in different directions, invests it with a power to affect the epidemic that the organization simply does not have. Failure to reach at-risk populations is less a fault of UNAIDS than it is of member states of the UN itself, particularly in Africa (see De Waal 2006).

⁶ Economists have sensible view. It is said when British economist John Maynard Keynes was asked by a parliamentarian how he reacted when ‘the facts’ change, he responded – ‘I change my mind. What do you do, sir?’

England accuses UNAIDS of creating and imposing ‘the biggest vertical programme in history’ which has eroded the public health sector (by diverting human resources), undermined government efficiency (with additional reporting requirements and poorly co-ordinated donor activities) and effectively removed national control over spending priorities. He proposes UNAIDS be shut down and money be withheld from the Global Fund until it joins sector-wide basket fund arrangements to combine donor and domestic funding (2008, p.1072). In his view, funding for health systems and funding for HIV amounts to a zero-sum game: ‘until we put HIV in its place, countries will not get the delivery systems they need’ (2007, p.1073).

The arguments and positions on AIDS exceptionalism can change. An editorial in *The Lancet Infectious Diseases* in August 2008 stated: ‘We consider HIV to be a challenge still deserving of an exceptional response. HIV/AIDS is a complex disaster and despite best efforts almost 7000 people still contract HIV every day’ (Lancet Infectious Disease 2008). Two months later *The Lancet* stated, ‘Our recent series on HIV prevention indicates that UNAIDS needs to place science at the centre of its policies and be evidence-driven. It is time to unwind the rhetoric, and reposition the response to HIV/AIDS as one of several important health challenges. A view beyond HIV/AIDS will reinforce plurality and justice, protecting minorities and thus wider majorities. UNAIDS needs to abandon AIDS exceptionalism.’ (Lancet 2008). In mid-2009 there were a series of meetings looking at global health initiatives and AIDS and health systems. These were organised by WHO with facilitation by *The Lancet* in various locations: (Venice 20-21st June); the World Bank (Washington 25-26th June); and the International AIDS Society (Cape Town 17th-18th July),⁷

The Period 2006 – 2009

- Medicalisation of epidemic continued with calls for ‘universal access’ by 2010.
- Evidence that the epidemic incidence had peaked and prevalence was stable.
- A number of influential books analysed the causes of the epidemic and responses to it, especially those of the international community and inferred that these should change.
- There were polemical calls against AIDS exceptionalism.

The situation in mid-2009

This paper was written for the aids2031 project and finalised in mid-2009. At this point, there are a number of overarching issues. It is apparent that the world has entered a severe sustained economic crisis.⁸ This crisis will have implications for the response to HIV and AIDS. An analogy is to compare it with a famine. In the face of famine children may die; be wasted - where a lack of food leads to malnourished and under-weight children; or the child may become stunted - where physical and mental development is impaired for life! Will the effect of the economic crisis on HIV/AIDS be one of stunting or wasting?

⁷ These will be reviewed in publications that emanate from the paper

⁸ The UNAIDS/World Bank Economics Reference Group (ERG) contributed to briefing notes for senior World Bank and UNAIDS leadership produced by UNAIDS economists and this section is drawn from these notes.

In November 2008 the IMF projected a fall in world economic growth from 5.0% in 2007 to just 2.2% in 2009.⁹ The European Commission indicated in January 2009 that the 16 countries using the Euro would see their economies shrink by 1.9% in 2009. As of May 2009, major donors had not given any official indication that total Official Development Assistance (ODA) contributions to HIV/AIDS programs would be cut. However, there is evidence (personal communication) that ODA budgets will be reduced and health spending and AIDS will be affected.

The global crisis means support for HIV/AIDS may not increase in 2010 and beyond. UNAIDS estimated, based on the country-defined targets, that low- and middle-income countries will require US\$ 25.1 billion (US\$ 18.9 billion–US\$ 30.5 billion) for AIDS in 2010. Of this, nearly US\$ 11.6 billion is for HIV prevention and US\$ 7 billion for treatment. (UNAIDS 2009 a). The major HIV/AIDS donors may be forced to reduce their commitments to keep their budget deficit at a manageable level. The global economic crisis will further affect domestic economies and migrant remittances increasing the burden especially in high prevalence, low income countries of Sub-Saharan Africa.

The vulnerability of individual countries can be assessed in relation to the size of the existing total HIV expenditure in proportion to the size of the national economy, the ‘HIV spending burden’, and the degree of aid dependency for the HIV programme. Countries can be arranged into four categories, with high or low HIV spending burden, and high or low aid dependency. Countries with high spending burden and low aid dependency (such as Botswana) will be vulnerable to the extent that their economies are affected by the downturn. Countries with high spending burdens and high aid dependency (such as Haiti, Mozambique or Rwanda) will be critically vulnerable to cuts in international aid. Where countries (Honduras, Ghana or Indonesia) have a low spending burden in relation to their income and low aid dependency, there is scope to reprioritise within the national budget. This fits with AIDS exceptionalism in these settings.

Treatment in the resource-poor world will require major additional funding. There have been significant gains: an estimated four million people are getting drugs, and consequently mortality has fallen. These programmes need to expand further. Only about 40 percent of those who need treatment in middle- and low-income countries are getting it; the number of people needing drugs will continue to rise each year; and those who have been on treatment for longer periods of time require more expensive second-line regimens.

Recent research presented to the UNAIDS World Bank Economics Reference Group (Case and Paxson 2009) finds an erosion of health services which is highly correlated with increases in AIDS prevalence. This work uses Demographic and Health Survey data for 14 African countries. The implications of this are still being analysed, and point to AIDS exceptionalism.

Should AIDS be treated as exceptional?

The answer is simple (with some caveats). In some settings it must be, in others it should not be. Three factors that determine this AIDS exceptionality are:

- The level of prevalence
- The demographic dynamics of the country
- Availability and domestic affordability of treatments.

⁹ IMF, World Economic Outlook Update, November 2008

Prevalence levels

Most at risk populations and low prevalence countries

In all developed countries and most developing countries with low prevalence (less than three percent), AIDS can be normalized and treated as a public health issue. Where drugs are available this will be given further impetus as it can be regarded as a long-term chronic disease. In these settings, it will be located largely on the margins of society and in specific populations. These groups are known as the 'most at risk populations' (MARPs) and include, for example, injecting drug users, men who have sex with men, commercial sex workers, and male prisoners. It should be noted these groups also exist in high prevalence countries, for example in Senegal, adult prevalence in 2006 was less than 1% but in 2004 (the latest year for which there are data) among men who have sex with men it was over 25%. (UNAIDS 2009 c)

AIDS is also found in marginal populations who do not obviously fall into the MARP category. In 2008 a report showed the HIV epidemic was sizable in Washington D.C. The Director of HIV/AIDS Administration said: 'Our rates are higher than West Africa. They're on par with Uganda and some parts of Kenya.'¹⁰ The epidemic here is disproportionately affecting African-Americans. In the Canadian province of Saskatchewan, the Chief Medical Health Officer interviewed on CBC on 23rd March warned of 'a major public health crisis' because the rate of HIV infection was accelerating, and was more than double the national average. The largest single group being affected were young aboriginal women in inner-city Regina and Saskatoon where 60 percent of cases are transmitted through injecting drug use. (Whiteside 2009).

It can be argued that for these groups, AIDS is exceptional. Nationally the need is to normalize and destigmatise the disease and address the actions that put people at risk. In 85 UN member countries, sex between adults of the same gender is criminalised and 10 countries the state has the ability to impose the death penalty. In many countries injecting drug use and sex work are criminalised. These groups are generally inaccessible to government Ministries of Health and services are often provided by non-governmental organisations. (Zaheer et al. 2009)

In some settings AIDS funding is being misdirected. In Ghana prevalence among sex workers is 78 percent and they account for 76 percent of transmission sources, yet 99.2 percent of funding is targeted at the general population. The MARP's needs may be exceptional, but this does not make the issue exceptional in a national context, unless there is clear evidence of spread beyond these groups. In these settings, AIDS should be regarded as one health issues, while recognizing the particular vulnerability of those most affected and at risk and the stigma attached to the disease.

In developing countries with low prevalence, there should be continual monitoring to ensure that there are no significant outbreaks, this is part of the standard health sector portfolio. Given the long-wave nature of the epidemic, monitoring is relatively easy.

¹⁰ This was incorrect as adult HIV prevalence in is 5.4 per cent in Uganda and between 7.1 and 8.3 percent in Kenya, but it was a good sound bite. Sources <http://www.unaids.org/en/CountryResponses/Countries/kenya.asp> and <http://www.unaids.org/en/CountryResponses/Countries/uganda.asp> accessed 04/04/09

UNAIDS has three important roles

Firstly, it has a crucial and continued task in surveillance and must interpret and act on changes in the location or direction of the epidemic. Secondly, it must be an advocate for marginal groups and correctly targeted funding; it should track funding to ensure it is used efficiently and effectively. Thirdly, UNAIDS should function as an information broker, producing the best possible information and packaging it in accessible ways. Especially in resource-poor countries information needs to be distilled and policy implications identified.

Mid range prevalence 3 – 10 percent

For countries with prevalence of over three and less than 10 percent, the exceptionality 'rule' will be a function of prevalence and wealth, except as stated above for the MARPs. This is simple: where people are able to access treatment, then we don't regard AIDS as exceptional. There is one caveat, the extent to which domestic funding is available. In a situation where treatment is dependent on outside resources, and people are getting more spent on them than the per capita health expenditure, then AIDS is still exceptional. The reasons are that such people are favoured over others and there is a dependency on international largesse.

High Prevalence Countries

AIDS **must** be treated as exceptional in countries with high prevalence, over 10 percent. In the absence of treatment, HIV- infected people experience episodes of illness that lead to death, and demographic consequences are huge. If treatment is provided then consequences will be averted (for example parents live longer leading to less orphaning) and delayed. All effects flow from these illnesses and deaths or from the decisions relating to provision of treatment, its cost and financing.

Demographic dynamics

The Former Soviet Countries

Demographic dynamics are important since the epidemic may be small, but have a disproportionate impact because of who is infected. The prime examples are some of the countries of the former Soviet Union where AIDS exacerbates an already troubled demographic situation of low total fertility rates and declining populations. Ukraine has one of the worst epidemics in the region with an adult prevalence of 1.6 percent. While this might seem low, it is mainly located among young male injecting drug users, and these individuals are, in the Ukrainian context, 'scarce'. According to UNDP the population growth rate was -0.1 percent per annum between 1975 and 2005 and was projected to be -0.8 between 2005 and 2015 (UNDP 2007/2009). AIDS exacerbates an already troubling demographic situation, with low total fertility rates and a declining population. By 2030, the median age of the Russian population will be over 40. By 2015, there will be just four workers for every three non-workers, with most of the non-working-age population being elderly. In these settings the consequences of AIDS are exceptional.

Mortality and its consequences

AIDS is always exceptional in countries with high prevalence due to the increased in mortality and/or the challenges of providing treatment. Effects flow from these illnesses and deaths and the decisions relating to provision of treatment and its cost and financing. The demographic consequences of declining life expectancy, changes in the size and structure of the population, and increased orphaning make the consequences long-lasting and socially impoverishing. Untreated AIDS means amplified mortality, especially among those aged 20 to 49; rising infant and child mortality; falling life expectancy; changes in the population size, growth, and structure; and a growth in the numbers of orphans. The scale of the impact depends on the location, size, and age of the epidemic and the underlying demographics of a country.

Adult mortality ¹¹ rises as a result of AIDS. In Botswana, in 2002 the crude death rate was estimated at 28.6 per 1,000, without AIDS it would have been a mere 4.8. For Tanzania, the 2002 figures are: without AIDS 12.1, with AIDS 17.3. Two key development indicators are infant and child mortality both of which rise due to AIDS. In the absence of interventions, children born to infected mothers have about a 30% chance of being infected. Infected children will inevitably if not treated, fall ill and die. Mortality among infected mothers has an adverse impact on child survival. Child mortality rates show the greatest increase in Botswana: in 2002, the rate was estimated at 107.1 per 1000, without AIDS it would have been only 30.6. By 2010, it is projected to be 122.9 instead of falling to 22.8. (US Bureau of the Census 2004). This has a huge impact on the chances of achieving the Millennium Development Goals and undermines a nations' very existence.

Life expectancy plummets in high prevalence countries. In 2003, the UN Population Division estimated that in the seven worst affected countries AIDS would reduce life expectancy by 43 percent between 2010 and 2015. Without therapy, by 2010, life expectancy could be just 26.7 years in Botswana and 27.1 years in Mozambique. (US Bureau of the Census, 2004). The data don't show what this catastrophic decline in life expectancy will actually mean for these societies, nor have academics and politicians engaged with this issue.

AIDS has the potential to reduce populations. Some 2.8 million, mostly young adults, are dying from AIDS every year. In the worst affected countries the mortality is considerable: UNAIDS estimates that in 2005 South Africa had 320,000 deaths from AIDS, Nigeria 220,000, and Zimbabwe 180,000. The deaths are cumulative: by 2015, some 6 million South Africans may well have died of AIDS – 13% of the population, and they are from the age groups most essential for the nation's economic and social viability.

Population growth decreases through premature deaths; a reduction in fertility; and changing sexual behaviours. In most settings, AIDS simply means a population will grow more slowly. In Thailand, growth is expected to be 1% per annum rather than 1.1%; in India and China, the impact will be negligible as the populations are so large and the epidemic is, relatively, so small. In other countries, AIDS will actually cause populations to decline. The Bureau of the Census estimated Botswana's growth rate in 2002 to be -0.2% per annum instead of 2.3%. In South Africa, the growth rate is projected to be -1.4%, in Swaziland -0.4%, and in Lesotho and Mozambique -0.2%. The impact of this on the national psyche, economy, and social welfare systems will be drastic.

¹¹ The importance of increased maternal mortality has not been fully addressed

The structural impact of the disease is considerable since it is working age people (and parents) who die. The dependency ratio changes placing demands on the government and society to provide education for the children, and health and social support for both the young and the elderly. Conventional dependency ratio calculations assume adults are productive, AIDS without treatment means significant numbers are chronically sick and properly belong in the 'dependants' category. The gender balance will change. In heterosexually driven epidemics, more women will die than men and do so at younger ages. Men aged between 35 and 54 will outnumber women.

Orphaning is a core issue. Globally, orphan numbers were declining, and despite the onset of AIDS this trend has been sustained in Asia, Latin America, and the Caribbean. In Sub-Saharan Africa numbers of orphans have grown dramatically. AIDS orphans increased from fewer than one million in 1990 to 12 million in 2005. In 2003, 12.3% of all children in sub-Saharan Africa were orphans (in Asia it was 7.3% of children, and 6.2% in Latin America and the Caribbean). Children orphaned by AIDS have different experiences and bear additional burdens to those orphaned by other causes. Parents die after prolonged illness, both parents may be infected and if taken in by grandparents the children face the prospect of losing elderly caregivers through age and illness.

The demographic impacts of AIDS in high prevalence countries mean it must be regarded as exceptional. Governments face demographic consequences never seen before and will have to grapple with how best to respond.

The role of treatment and donor dependency

Provision of therapy is a global success story. In low- and middle-income countries the number on treatment rose from about 300 000 in 2002 to 3 million in 2007. In Africa only about 35 percent of those who need the drugs are getting them. Once treatment begins the medication must be taken for life. The drugs are expensive, beyond the reach of most poor people. Patients will, after a period of time, need to move from first-line treatment (current cost \$92 per patient per year for the drugs alone) to second-line treatment (\$1214). This must be seen in the context of per capita public health expenditure, (\$431 per person per year in Botswana but only \$41 in Lesotho and \$14 in Mozambique) (World Bank 2009).

International aid is crucial, literally keeping people alive. The poorer the country and the greater the disease burden, the more they will be dependent on such assistance. This gives rise to another form of exceptionality – cost and dependency. We need to assess the proportion of the budget going to treatment and ask if it is appropriate and sustainable, both domestically and internationally. Governments need to ask themselves how they feel about having their sovereignty, in the sense of controlling whether their citizens are alive, in the hands of others. This international dependency has been documented by Over (2007 and 2008), who examined it from an international entitlement point of view, asking if a global welfare paradigm is appropriate. Given the current economic crisis this question becomes even more pertinent.

The UNAIDS Action Agenda.

In May 2009 UNAIDS published its action agenda for 2009 – 2011. There are eight priorities.

- Prevent mothers from dying and babies from becoming infected with HIV;
- Ensure that people living with HIV receive treatment;
- Prevent people living with HIV from dying of tuberculosis;
- Remove punitive laws, policies, practices, stigma and discrimination that block effective responses to AIDS;
- Protect drug users from becoming infected with HIV;
- Empower young people to protect themselves from HIV;
- Enhance social protection for people affected by HIV; and
- Stop violence against women and girls. (UNAIDS 2009 b)

When the first draft paper was prepared I suggested UNAIDS must continue what it has been doing, only better. The agenda states: ‘In order to address these (priority) areas effectively, the Secretariat and the Cosponsors will support cross-cutting strategies and institutional delivery mechanisms that build on what we know works and will take steps for change where we need to work differently and work better’. (UNAIDS, 2009 b p8).¹²

Prevention is key on the agenda. On treatment, the guidelines are critical, as is advocacy for increased resources. The debates over of vertical versus horizontal programmes (or indeed as has even been suggested, diagonal) for AIDS treatment are vexing. Solutions need to be tailored to the situation in a country. Resources will not be sufficient, choices will have to be made. The best possible use of money is fundamental, but exactly what that is will vary from country to country.

Conclusion

AIDS should be treated differently from other diseases. It is indeed exceptional in some settings. In some places it is a crisis, but also a long-term development issue. There is no cure and treatments are expensive. In poor countries, the cost of treating one AIDS patient is many times the average expenditure on health. Even if money were no object, there are human resource constraints. Although science has made strides, vaccines, microbicides and a cure are ephemeral. AIDS is having a devastating impact in some places.

AIDS is a preventable disease and we need to advocate for what works while acting as the conscience to ensure MARPs and marginal groups are considered. Focus on treatment has distracted us from prevention.

¹² The document states with regard to crosscutting issues, we will: bring AIDS planning and action into national development policy and broader accountability frameworks; optimize UN support for applications to, and programme implementation of, the Global Fund to Fight AIDS, Tuberculosis and Malaria; improve country-by-country strategic information generation, analysis and use, including through the mobilization of novel sources; assess and realign the management of technical assistance programmes; develop shared messages for sustained political commitment, leadership development and advocacy; and broaden and strengthen engagement with communities, civil society and networks of people living with HIV at all levels of the response.

In an excellent essay Bowtell (2007) writes: ‘There is no constituency for HIV prevention that can remotely rival that advocating care, treatment and research. The care and treatment coalition determine priorities; convene conferences and influence politicians, donors and the public debate about the allocation of scarce resources. Everyone with HIV and AIDS has, by definition, an urgent need for support. They will always have the first call on funding because they can demonstrate need. ... In politics, numbers count. Politicians and bureaucrats ignore numbers and need at their peril. Responding to the multifaceted and urgent need for care and treatment is more pressing than the spending time and money on prevention. By its nature, those advocating prevention find very few seats (at) the top table, although the constituency of those at risk of HIV infection is far larger than those who require treatment. The social and economic benefits of these young people not contracting HIV are obvious but the political benefits are negligible. The urgent has trumped the important and generated a peculiar but real moral hazard’.

Speaking in 2007 at the pathogenesis conference in Sydney, leading scientist Dr Anthony Fauci, said eloquently: ‘For every one person that you put in therapy, six new people get infected. So we're losing that game, the numbers game.’ This is unsustainable. Public health tells us prevention is better than cure.

The fact that AIDS is preventable gives UNAIDS a key role, advocating for and developing prevention tools that will work. It must be an advocate for prevention. Aids2031 must see this as a core area and look at how to advocate and programme for it. Finding the tipping points to make AIDS prevention work is the challenge in hyperepidemic countries.

AIDS is a long-wave event which requires mitigation. It is primarily a sexually transmitted infection affecting young adults. The spread is silent and the long incubation period means the virus has infected many people before illnesses manifest and the threat is apparent. British scientist, Professor Roy Anderson modelled the course of the epidemic and estimated it will take 130 years to work through the global population. (Barnett and Whiteside 2002).

This is why aids2031 is such an important initiative. In 2031, 22 years hence, there will be people infected today living on treatment. There will be many children who have grown up without parents. The demographic, social and political consequences will still be working themselves through many badly affected nations – the very ones where AIDS has to be treated as exceptional. The goal must be to engage scientists and social scientists in long-term thinking and ensure political leadership takes the ideas and lessons on board.

I concluded in a recent publication that: ‘The debate between normalization and exceptionalism is sterile. AIDS is exceptional and needs to be treated as such. But the measures needed to deal with the schisms and fractures that give rise to the epidemic are long term. Preventing AIDS means equitable development: providing education, health, employment opportunities, and social support. These are development goals, and not (just) about HIV/AIDS’. (Whiteside, 2008). The AIDS response can not happen in isolation, it is part of the development agenda. In places where the MDG’s are missed by the widest margins AIDS will have been responsible.

Preparing this paper for *aids2031* and especially reviewing the origins of exceptionalism and the push against it has confirmed my view. AIDS is exceptional. The idea that exceptionalism is somehow wrong is an oversimplification of an issue. Globally UNAIDS has a role in advocating

for people on the margins everywhere. It needs to ensure global surveillance, and especially to monitor the situation in low prevalence countries. The lack of emphasis on prevention is critical and this must be one of UNAIDS key functions.

AIDS activists face a number of difficult questions. Why we do not give more priority to prevention? What is the cost of treatment and how it will be maintained? And how should issues of sustainability and national sovereignty be considered?¹³

¹³ These are addressed in the appendix, areas for further research.

References

- Alexandra, Anna. 2001, *Pregnant Women and the Testing of HIV-Infections: Can the Practice of Coercive Testing Be Supported by Public Health Concerns When Weighed Against the Privacy Interests of Those Tested. Experience of Canada, Russian Federation and the United States*, Unpublished Master of Law Thesis, University of Toronto.
- Barnett Tony & Whiteside, Alan. 2002, *AIDS in the Twenty-First Century: Disease and Globalisation*. Basingstoke: Palgrave.
- Barnett, Tony & Whiteside, Alan. 1999. HIV/AIDS and Development: Case Studies and a Conceptual Framework. *European Journal of Development Research*, 11(2), pp.220-234.
- Barnett, Tony. 2008. Unpalatable Truths. *The Lancet*. 372(9635), p.282.
- Bayer, Ronald & Fairchild, Amy. 2006. Changing the Paradigm for HIV Testing – The End of Exceptionalism, *New England Journal of Medicine* (355)7, pp.647-649.
- Bayer, Ronald. 1999. Clinical progress and the future of HIV Exceptionalism. *Archives of Internal Medicine*. 159, pp.1042–1048.
- Bayer, Ronald. 1994. HIV Exceptionalism Revisited. *AIDS & Public Policy Journal*. Spring, p.16.
- Bayer, Ronald, 1991, Sounding Board: Public Health Policy and the AIDS Epidemic: An End to HIV Exceptionalism?, *New England Journal of Medicine* (324) 21 pp.1500-1505.
- Behrman, Greg. 2004. *The Invisible People: How the U.S. Has Slept Through the Global AIDS Pandemic, the Greatest Humanitarian Catastrophe of Our Time*. New York: Simon and Schuster.
- Bonell, Chris. 2006. Normalized Management of HIV Prevention Services in an Advanced Liberal NHS in the 1990s, *Critical Public Health*. (16)2, pp.89-97.
- Bowtell B. 2007. Applying the paradox of prevention: Eradicate HIV, *Griffith Review* 17
- Brown, Tim. 2000. AIDS, Risk and Social Governance. *Social Science and Medicine*, 50, pp.1273-1284.
- Casarett David J & Lantos, John D. 1998. Have We treated AIDS Too Well? Rationing and the Future of AIDS Exceptionalism. *Annals of Internal Medicine* 128(9), pp756 – 759.
- Case, Anne and Christina Paxson, ‘The Impact of the AIDS pandemic on health services in Africa: Evidence from Demographic Health Services, Paper presented to the ERG Meeting April 2009 (will be available on <http://www.heard.org.za/world-bank-unaid-erg.html>)
- Chin, James, 2006. *The AIDS Pandemic*. Oxford: Radcliffe Publishing.
- Connel, Erin, & Hunt, Alan. 2006. Sexual Ideology and Sexual Physiology in the Discourses of Sex Advice Literature. *The Canadian Journal of Human Sexuality*. 15(1), pp.23-45.
- Danziner, Renée. 1998. HIV Testing and HIV Prevention in Sweden. *British Medical Journal*, 316, pp. 293-295.

- De Cock, Kevin & Johnson, Anne M. 1998. From Exceptionalism to Normalization: a reappraisal of attitudes and Practice around HIV Testing. *British Medical Journal*, 316, pp. 290-293.
- De Lay, P. and K. De Cock. 2007. 'UNAIDS Rejects Claims of Exaggeration and Bias', *Nature*, 448: 251, 19 July.
- De Lay, P. Greener, R. and J Izazola, 2007. Are we spending too much on HIV?, *British Medical Journal*, 334 (345).
- De Waal, Alex. 2006. *AIDS and Power: Why there is no Political Crisis – Yet*. New York: Palgrave Macmillan Ltd.
- Elbe, Stefan. 2005. AIDS, Security, Biopolitics. *International Relations*, 19(4), pp.403-419.
- England, R. 2007a. 'Are we spending too much on HIV?', *British Medical Journal*, 334 (7589) 344.
- England, R. 2007b. 'The Dangers of Disease-Specific Programs for Developing Countries', *British Medical Journal*, 335: 565
- England, R. 2008. 'Writing is on the wall for UNAIDS', *British Medical Journal*, 336: 1072.
- Epstein, Helen. 2007, *The Invisible Cure: Africa, the West, and the Fight Against AIDS*. New York: Farrar, Straus and Giroux.
- Fee, Elizabeth & Krieger, Nancy. 1993. Public Health Then and Now: Understanding AIDS; Historical Interpretations and the Limits of Biomedical Individualism. *American Journal of Public Health*. 83(10), pp.1477-1486.
- Gagnon, Marilou & Holmes, David. 2008. Governing Masses: Routine HIV Testing as a Counteroffensive in the War Against HIV-AIDS. *Policy, Politics and Nursing Practice*, 9(4), pp.264-273.
- Gillespie, S., Kadiyala, S., and R. Greener. 2007. 'Is poverty or wealth driving HIV transmission?', *AIDS*, 21, Supplement 7: s5-s16.
- Gore, Al, 2000, Remarks prepared for delivery by Vice President Al Gore to the UN Security Council, 10 January 2000 sourced; <http://www.thebody.com/content/policy/art22.html> [accessed 25 May 2009].
- Gould, W. T. S. 2005. Vulnerability and HIV/AIDS in Africa: From Demography to Development, Population. *Space and Place*, 11, pp.473-484.
- Gruskin, S., Hendricks, A. & Tomasevski, K. 1996. Human rights and responses to HIV/AIDS. In: Mann, J. & Tarantola, D.J.M., eds. *AIDS in the world II*. New York, Oxford University Press.
- Heald, Suzette. 2006. Abstain or Die: The Development of HIV/AIDS Policy in Botswana. *Journal of Biosocial Science*, 38, pp.29-41.
- Herek, Gregory M. 1999. Aids and Stigma. *American Behavioral Scientist*. 42(7), pp.1106-1116.
- Hunter, Mark. 2009. Providing Love. In Cole, J. and Thomas, L.M. (eds) *Love in Africa*, University of Chicago Press.

- IMF. 2008. World Economic Outlook Update: Rapidly Weakening Prospects Call for New Policy Stimulus. [Online] Available at: <http://www.imf.org/external/pubs/ft/weo/2008/update/03/index.htm> [Accessed 3 April 2009].
- Jansen, L. A. 2005. HIV Exceptionalism, CD4+ cell Testing, and Conscientious Subversion. *Journal of Medical Ethics*, 31, pp.322-326.
- Knight Lindsay. 2008, *UNAIDS the First 10 Years*, UNAIDS, Geneva
- Lancet Infectious Diseases, Does HIV/AIDS still require an exceptional response? *The Lancet Infectious Disease*, 8(8), p. 457.
- Lancet, Who should be the next Executive Director of UNAIDS? *The Lancet*, 372(9647), p.1359.
- Lazzarini, Zita. 2001. What Lessons can We Learn from the Exceptionalism Debate (Finally)? *Journal of Law, Medicine and Ethics*, 29, pp.149-151.
- Levine, Ruth; Woods, Ngaire; Kuczynski, Danielle & Sridhar, Devi. 2009. *UNAIDS Preparing for the Future*. Report of the UNAIDS Leadership Transition Working Group, Centre for Global Development, Washington D.C.
- Lewis, S. and P. Donovan. 2007. 'Time for a Change?', *Nature*, 447: 531-2, May.
- Mann, Jonathan M. 1992. Malcom Morris Memorial Lecture: AIDS in the 1990s: a Global Analysis, *Health*, pp.143-148.
- Mishra, V., Bignami-Van Assche, S., Greener, R., Vaessen, M., Hony, R., Ghys, P., Ties Boerma, J., Van Assche, A., Khan, S., and Rutstein, S. (2007). HIV Infection does not disproportionately affect the poorer in Sub-Saharan Africa. *AIDS*, 21 (supplement 7), s17-s28.
- Mistry, Neeraj. 2008. HIV exclusion does not mitigate risk. *Lancet Infectious Diseases*, Volume 8, Issue 3. pages 147-148, March 2008.
- Over, M: AIDS Treatment as an International Entitlement: Are We Ready for a Global Welfare Paradigm? Blog, September 28, 2007. Washington: Center for Global Development. Available from: http://blogs.cgdev.org/globalhealth/2007/09/aids_treatment_as_an.php
- Over, M: 2008. 'Prevention Failure: The Ballooning Entitlement Burden of US Global AIDS Treatment Spending and What to Do About It', Centre for Global Development, Working Paper no.144, April 2008.
- Piot, Peter. 2006. AIDS: from Crisis Management to Sustained Strategic Response. *The Lancet*, 368, pp.526-530.
- Piot, Peter & Aggleton, P. 1998. The Global Epidemic. *AIDS Care*, 10 Supplement 2, pp.s201-s208.
- Pisani, Elizabeth. 2008, *The Wisdom of Whores: Bureaucrats, Brothels and the Business of AIDS*. London: Granta.
- Poku, Nana K & Whiteside, Alan. Eds., 2004. *The Political Economy of AIDS in Africa*, Aldershot : Ashgate Publishing.

- Roehr, Bob. 2008. The Invisible Epidemic: Lack of recognition of homosexuality in many countries is hampering efforts to reduce HIV transmission among men who have sex with men. *British Medical Journal*, 337, pp.1262-1264.
- Rosenbrock, Rolf; Dubois-Arber, Françoise; Moers, Martin; Pinell, Patrice; Schaeffer, Doris & Michel Setbon. 2000. The Normalization of AIDS in Western European Countries. *Social Science and Medicine*, 50, pp.1607-1629.
- Setbon, Michel. 2000. La normalization paradoxale du SIDA. *Revue française de sociologie*, 41-1, pp.61-78.
- Sharp, Michael. 2007. The Effect of Genetic Determinism and Exceptionalism on Law and Policy. *Health Law Review*, 15(3), pp.16-18.
- Shilts, Randy. 1987. *And the Band Played On: Politics, People, and the AIDS Epidemic*, 20th Year Anniversary Edition, New York: St. Martin's Press
- Stillwaggon, Eileen. 2006. *AIDS and the ecology of poverty*. New York: Oxford University Press US.
- Thomas, Felicity; Haour-Knipe, Mary and Aggleton, Peter. 2009. *Sexuality, Mobility and AIDS*. (London:Routledge). (Mark Hunter)
- UNAIDS, 2009 (a). *What Countries Need: Investments for 2010 targets*, UNAIDS Geneva
- UNAIDS, 2009 (b), *Joint Action for Results UNAIDS Outcome Framework 2009–2011*, UNAIDS Geneva
- UNAIDS 2009(c). <http://www.unaids.org/en/CountryResponses/Countries/senegal.asp>
UNAIDS Geneva
- U.S. National Intelligence Council. 2000. *The Global Infectious Disease Threat and Its Implications for the United States*. Washington D.C. NIC [Internet] Available at: http://www.dni.gov/nic/PDF_GIF_otherprod/infectiousdisease/infectiousdiseases.pdf [Accessed 3 April 2009].
- UN-ECOSOC (Economic and Social Council of the United Nations) resolution (1994/24) 1994/24. Joint and co-sponsored United Nations programme on human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS). 44th plenary meeting 26 July 1994 [Online] Available at: <http://www.un.org/documents/ecosoc/res/1994/eres1994-24.htm> [Accessed 3 April 2009].
- UN Security Council 2000 available at <http://daccessdds.un.org/doc/UNDOC/GEN/N00/536/02/PDF/N0053602.pdf?OpenElement> [accessed 25 May 2009].
- UNDP. 2007/2008. 2007/2008. Human Development Report. [Online] Available at: <http://hdrstats.undp.org/indicators/39.html> [Accessed 3 April 2009].
- US Bureau of the Census. 2004. *The AIDS Pandemic in the 21st Century*. U.S. Government Printing Office, Washington, DC. [Internet] Available at: <http://www.census.gov/prod/2004pubs/wp02-2.pdf> (Accessed 3 April 2009).

Whiteside, Alan. 2008. HIV/AIDS: a very short introduction. Oxford; New York : Oxford University Press.

Whiteside, Alan. 2009. Let's not be complacent about AIDS - it's still killing us. *The Globe and Mail*, April 2 [Online] Available at: <http://www.theglobeandmail.com/servlet/story/RTGAM.20090401.wcoaid02/BNStory/specialComment/home> (Accessed 3 April 2009).

World Bank expenditure on public health expenditure compiled from web accessed 5th April 2009, permanent url <http://go.worldbank.org/3KMGKYPN90>

Wynia, Matthew K. 2006. Routine Screening: Informed Consent, Stigma and the Waning of HIV Exceptionalism. *The American Journal of Bioethics*, 6(4) pp.5-8.

Zaheer, Hasan A, Sarah Hawkes, Kent Buse and Michael O'Dwyer STIs and HIV in Pakistan: from analysis to action *Sexually Transmitted Infections* 2009;85

Appendix I

Areas for further research

Activism, institutionalizing leadership and advocacy movements.

This includes the experience of mainstreaming global initiatives (for example, gender, green revolution, climate change etc). This will require more thought and talking to people engaged in these areas.

Governance/Stewardship

At the international level the role of UNAIDS and its role in relation to the Global Fund, WHO, UNDP, the World Bank and other partners needs to be assessed. At the country level the cost of the disease commitment of governments and willingness to yield sovereignty need attention.

Social drivers of the epidemic

These areas continue to need work. The Hyperepidemic group of 2031 has a paper on this by Hein Marias, still in early draft form. If we understand the drivers we will have a clearer idea of how to stop the epidemic, but then we need to recognize we may choose not to do so. This needs more thought not necessarily research.

Financial and delivery issues

How much money is actually committed, how does it flow and how can national governments and donors be held accountable? We need clearer accessible data. This is a not research issue but data and political issue.