

# *Learning From HIV and AIDS*

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*Introduction. Learning from HIV and  
AIDS: from multidisciplinary to  
interdisciplinarity*

GEORGE T. H. ELLISON WITH MELISSA PARKER  
AND CATHY CAMPBELL

This disease is not like any other . . . in the 20 years since the disease was recognised, more than 20 million people have died from it. Another 40 million are infected. New infections are occurring at the rate of 15,000 a day, and the rate is still increasing. Unless there is a significant change for the better almost all these people will die.

The Economist, July 11th 2002<sup>1</sup>

[A]t current infection rates, AIDS, the deadliest epidemic in human history, will kill 68 million people in the 45 most affected countries over the next 20 years . . . ”

Peter Piot, Executive Director of UNAIDS, writing in the  
New York Times in July 2002<sup>2</sup>

**‘Learning from HIV and AIDS’ – a multidisciplinary  
symposium of the UK BioSocial Society**

Mindful of the extraordinary contribution made by health professionals, academics, policy makers and the communities worst affected to understand and respond to HIV/AIDS, the UK BioSocial Society invited representatives from these groups to a multidisciplinary symposium held at the Institute of Education in May 2001. The sheer scale of the HIV/AIDS pandemic has resulted in unprecedented research activity, both theoretical and applied, and has led to a huge array of formal and informal publications (ranging from dedicated academic journals<sup>3</sup> and professional texts, to local newsletters and

global websites).<sup>4</sup> For the most part, however, these cover responses to HIV/AIDS – at the individual-, familial-, communal-, institutional-, national-, regional- and global-level. We therefore posed the question: ‘What have we learnt *from* HIV/AIDS?’ – as an extraordinary biological and social phenomenon in its own right, *and* as a subject for academic, professional and lay enquiry.<sup>5</sup> The symposium provided both an opportunity and a framework for academics, professionals, policy makers and advocates to reflect critically on what they had learnt from HIV/AIDS, and how these lessons might inform interdisciplinary and inter-professional collaboration – with a view to tackling *both* the biological *and* the social challenges posed by HIV/AIDS.<sup>6</sup> On the one hand, then, we hoped the symposium would explore what HIV/AIDS might tell us about the biological and social nature of human society, and the ways in which these two are inter-related. On the other hand, we hoped to map out the advances in technique, and developments in knowledge, which have emerged from studying HIV/AIDS – thereby exploring the relative merit of uni-disciplinary contributions versus multidisciplinary syntheses, and the potential for inter-disciplinary collaboration. To this end the symposium sought to draw together parallel and synergistic, as well as competing and contradictory, strands of professional and academic work. By examining what people from very different disciplines have *learnt* from their experience of HIV/AIDS, this *biosocial* approach aimed to transcend disciplinary boundaries and synthesise a more holistic account of what, collectively, has been learnt, and how different contexts and disciplinary approaches influence our understanding of the disease.

The collection of contributions in this volume is therefore intended to reach out to the BioSocial Society’s existing constituency of academics, professionals and students who are committed to a greater understanding of the interdependence of biological and social issues (through an *explicitly* inter-disciplinary, biosocial approach). It also aims to address a broader audience of community advocates, health care professionals and policy makers involved in HIV/AIDS-related representation, practice and decision-making – for whom a multidisciplinary synthesis might better illuminate the challenges they face. We were guided by the need to cover, in sufficient detail, the wide range of different *contexts* affected by HIV/AIDS, from the individual to the global. We also sought to organise these within a framework

that would facilitate comparisons across the different contexts *and* different disciplines involved, to promote an inter-disciplinary approach – an approach we felt was crucial to look beyond those issues or levels of analysis that are considered unique to any one discipline or field of expertise.

## **HIV/AIDS at the start of the twenty-first century**

HIV/AIDS causes immense suffering to millions of people. Recent figures published by UNAIDS (the joint United Nations programme on HIV/AIDS) show that HIV/AIDS has been diagnosed in every continent on the globe, yet its distribution is far from even. North America, for example, has 950 000 people living with HIV/AIDS and Western Europe 550 000, whilst in Australia and New Zealand the number infected stands at 15 000. By contrast, an estimated 28.5 million people are infected with HIV in sub-Saharan Africa, and 11 million African children are thought to have been orphaned by AIDS.<sup>7</sup> The figures emerging from Eastern Europe and Asia are not as high as those reported for sub-Saharan Africa and currently stand at one million in Eastern Europe and Central Asia, and 5.6 million in South and Southeast Asia. However, a substantial increase is predicted in many of these regions over the next 20 years, and it is possible that the prevalence of HIV/AIDS in countries such as India, China, the Ukraine and Russia will overtake that reported in parts of sub-Saharan Africa (for example, see Lau *et al.*, 2002).

One of the many consequences of the pandemic is that it has had a major impact on life expectancy among the world's poorer countries (Fee and Fox, 1989; Farmer, 1999). In Lesotho, for example, someone who turned 15 in the year 2000 had a 74% chance of becoming infected before her, or his, 50th birthday. Even in relatively prosperous Botswana, average life expectancy is thought to have dropped to 36 years – a level last seen more than 50 years ago. The impact of AIDS on life expectancy is also felt beyond Africa, albeit somewhat less dramatically. Haiti's life expectancy is currently almost six years less than it would have been without AIDS, and in Cambodia it is currently four years lower. South America has also been affected, in Guyana, for example, the probability of becoming HIV-positive

between the ages of 15 and 50 is 19% (or nearly 1 in 5; UNAIDS, 2002).

Unfortunately, biomedical and pharmaceutical responses have had a relatively small impact upon the pandemic. Attempts to develop vaccines, for example, have had limited success and these endeavours have probably been hindered by the allocation of relatively modest amounts of funding.<sup>8</sup> This research has also focused, almost exclusively, on strains of HIV predominating in the United States and Western Europe, rather than those posing the greatest threat globally (Barnett and Whiteside, 2002).

There has been more success in the development of antiretroviral drugs and these are prolonging thousands of lives in high-income countries (Babiker *et al.*, 2000) as well as a wealthy minority in low-income countries (Garnett *et al.*, 2002). However, these drugs continue to remain inaccessible to the majority of those infected by HIV. Thus, at the end of 2001, it was estimated that only 30 000 of the 28.5 million people living with HIV/AIDS in Africa had access to antiretroviral drugs (a mere tenth of one per cent; 0.1%: UNAIDS, 2002; see also: Cheek, 2001; Barnett and Whiteside, 2002; Campbell, 2003).

Prevention efforts have also been disappointing. They have tended to take one of two forms:

- (1) Efforts have been made to improve treatment for other sexually transmitted infections (STIs), which are thought to increase vulnerability to HIV infection (Wawer *et al.*, 1999; Grosskurth *et al.*, 2000). These efforts have been demonstrated to be effective in carefully monitored interventions (under the auspices of high profile research teams with substantial financial backing; see: Boily and Anderson, 1996; Boily *et al.*, 2000). But their positive results have been difficult to replicate in 'real-world' settings (e.g. Ellison *et al.*, 2001a). In many of the countries most affected by HIV/AIDS, public health systems are grossly under-funded, and lack the technical and human capacity to implement effective treatments for STIs. Furthermore, mainstream STI services often take little account of the fact that a high proportion of the population might understand sexual health and healing in very different ways to biomedical practitioners

(e.g. Nicoll *et al.*, 1993). Such differences can undermine the likelihood of appropriate or timely uptake of services and, thereafter, adherence to treatment and partner notification.

- (2) Efforts have been made to promote various forms of safer sexual behaviour – such as increasing the use of condoms. These efforts have also been singularly unsuccessful, often because they draw on individualised psychological, as opposed to more holistic, models of behaviour change. The former ‘target’ the individual as the locus of change and, more often than not, seek to improve individual knowledge of HIV transmission with a view to encouraging safer sexual behaviour. However, one study after another has highlighted the way in which conscious, individual control over sexual behaviour (and other health behaviours) is constrained by a host of factors over which individuals have little, if any, control (see Campbell, 2000). These range from unconscious needs for trust and intimacy, to wider social and economic factors such as poverty, migrant labour, the disempowerment of women (Campbell, 2003), and social conditioning within prevailing masculine norms (Delius and Glaser, 2002). The centrality of social and economic factors in shaping sexual behaviour (particularly commercial sex work: Day 1988; Gysels *et al.*, 2002) highlight the folly of thinking that decisions to adopt safer sexual behaviours are under the control of rational, individual choice (e.g. Sneed and Morisky, 1998).

Against this background of ineffective individual-level approaches, policies and programmes addressing HIV/AIDS have increasingly sought to locate efforts within the context of community development programmes. These range from general, community-strengthening initiatives (such as income generation projects and women’s support groups) to more specific attempts to promote local participation in the design, implementation (e.g. Campbell and Jovchelovitch, 2000), and evaluation (e.g. Ellison *et al.*, 2001b) of HIV-prevention efforts. Above all, they try to enhance the likelihood of people exercising personal control, at the *individual* level, over their health. However, research in this area suggests that even the best efforts of marginalised groups or disadvantaged communities, to improve their circumstances are

unlikely to succeed (let alone achieve their *optimal* impact) in the absence of support from more powerful stakeholders in both the public and private sectors, as well as from within the communities themselves (Gillies, 1998; Parker, 2001).

There is now a widespread consensus that governments have a key role to play in the success of HIV-prevention programmes. Unfortunately, the relative ineffectiveness of biomedical, behavioural and community-level responses has been matched by the lukewarm response of many national governments to epidemics in their countries. At the symbolic level, HIV/AIDS is a meeting point for the taboo topics of sex, contagion and death (Altman, 1986). Moreover, at the early stages of local epidemics, HIV levels have often been concentrated amongst social groups that are already marginalised (such as commercial sex workers, injecting drug users, and men who have sex with men) – groups who often live or work in particularly ‘high risk’ situations. As a result, the disease has become highly stigmatised, with governments and powerful constituencies responding with, at best, confusion and, at worst, outright denial. The quality of government leadership, and the willingness of leaders to openly and unambiguously acknowledge the existence of national epidemics, has emerged as key to understanding why some low- to middle-income countries – including: Senegal (Gow, 2002) and Uganda (Parkhurst, 2001; 2002; Gow, 2002) in Africa; Cuba (Santana, 1997) in Central America; and Thailand (Rojanapithayakom and Hanenberg, 1996; Surasiengsunk *et al.*, 1997; Ford and Koetsawang, 1999) in Southeast Asia – have had some success in containing their epidemics, whilst others (including several wealthier countries) have not.

Despite the growing recognition that HIV/AIDS is fuelled by macrosocial factors, such as poverty and the disempowerment of women, this has done little to dissuade many governments from dragging their heels, or responding to the disease with incoherent and inconsistent policies. The challenge of bringing about social change to deeply rooted structural problems is complex, and requires sustained long-term strategies (e.g. Tawil *et al.*, 1995). It is tempting to conclude that some governments simply balk at the enormity of the challenge, and can only respond with confusion or denial (Fortin, 1990). Since the people most affected by HIV/AIDS are often those

with the least access to economic power or political influence it is, perhaps, hardly surprising that so many governments offer such a lukewarm response. In high-income countries, vocal groups of people living with HIV/AIDS (particularly from within the gay community; Epstein, 1996) have been a significant force in lobbying for greater attention to the needs and human rights of affected individuals. In low-income countries the pre-eminence of biomedical perspectives and the paucity of lay biomedical expertise have prevented a comparable lobby emerging (de Waal, 2002).

In many of the poorer countries in which HIV/AIDS predominates, and where people with AIDS have little or no access to medical care or treatment, responsibility for the care of the dying ultimately falls on the poorest households. In many cases the burden of caring for dying relatives strips households of both their assets and their principal bread-winners. Many such households simply dissolve as parents die, and children are sent away to be brought up by relatives or friends (Urassa *et al.*, 2001). Those that do not dissolve may be severely impoverished: as meagre savings are eaten up by medical expenses or funeral costs; as adults are forced to leave work, and children are forced to leave school, either through illness or to care for affected family members (Preble, 1990); and as precious assets, such as livestock, vehicles and land, are sold. In Zambia, for example, monthly disposable incomes fell by 80% in two-thirds of households where the father had died, while in Côte d'Ivoire, the income of HIV-affected households was *half* the average. In one province in South Africa, households used an average of 21 months' savings to pay for medical treatment and funeral costs, whilst in Thailand, 41% of AIDS-affected households had sold land, and 57% had completely used up all of their savings (UNAIDS, 2002). Already burdened and demoralised by poverty, and facing the additional expense of the coping with the disease, there is little likelihood that such households can or will mobilise to fight for their rights, or to demand appropriate government responses to their plight. Thus, in countries where governments do not take the initiative in responding to HIV/AIDS, and where the disease is often shrouded in stigma and denial, there is unlikely to be widespread popular pressure for change. In this way, at an individual and a social level, the enormity of AIDS and the burden of coping tend to get hidden in

the lives of ordinary families (Palloni and Lee, 1992). Despite this, the vast bulk of research and development into HIV/AIDS focuses solely on its *health* effects, with far less attention given to its impact on the welfare of households, communities and entire societies.

## **Multidisciplinary perspectives on learning from HIV/AIDS**

To examine what we have learnt from such research, this volume contains contributions from a wide range of academic and professional disciplines. It begins with a chapter that reflects on the biological origin and nature of HIV (Hutchinson). This describes how biologists have learnt much about the human immune system, the ecology of immunodeficiency viruses and the genetic characteristics which frame biologists' understanding of variation in virulence and susceptibility. It is followed by chapters on epidemiology (Ghani and Boily) and demography (Gregson) – two quantitative social sciences which have made substantial advances in data collection and analysis. Each of these chapters illustrate how methodological developments have enhanced their capacity to model the social patterning of the pandemic, and their ability to cope with the impact of HIV/AIDS on the quality of the data they use. Taking us from these, biomedically-focused, contributions to those from disciplines adopting ethnographic and other, essentially qualitative, approaches, Wood with Ellison provide a detailed narrative of the changing role of HIV clinical specialists treating HIV/AIDS in cosmopolitan and multicultural London. They reflect on both the extraordinary advances in combination drug therapies, and the contradictory social forces that limit their potential benefit. A review of the ways in which the HIV prevention literature tackles the social and contextual demands of the Ottawa Charter introduces the next chapter (Campbell and Cornish), which goes on to examine, through a social psychological framework, the contextual challenges facing community-led HIV prevention initiatives. Following on from this are two in-depth ethnographic chapters: the first of these discusses the growing popularity of 'backrooms' (where anonymised and unprotected sex takes place)<sup>9</sup> among gay-identified men in London

(Parker), and considers the social and political implications of these for anthropologists seeking to contribute to HIV prevention strategies; the second focuses on HIV/AIDS in Botswana (Heald), where biomedical explanations about the nature of HIV/AIDS conflict with indigenous knowledge to render biomedical programmes ineffective, if not counter-productive. The final chapter analyses the use of three different idioms ('plague', 'war' and 'sin') to represent HIV/AIDS in public and political discourse, and the effects these have on the role of governance and politics in responses to national epidemics (de Waal). The volume concludes with a postscript (Marks with Ellison), which reflects on historical work on previous epidemics, and on the first phases of the HIV/AIDS pandemic, to place in historical context each of the 'lessons' from the disciplines represented in this volume.

From these summaries, it is clear that all of these disciplines have learnt valuable lessons from HIV/AIDS. It is also clear that the biological nature and social impact of the disease have influenced each discipline's particular focus. This has led to a recognition, by biologists, that zoonoses<sup>10</sup> still pose a serious threat to human health, and that these threats might increase as a result of changes in social structures and social mobility – changes which bring humans into closer contact with wild reservoirs of disease and with one another, thereby facilitating the transfer of pathogens, from non-human primates (in the case of HIV) to humans, and from one human being to another (Hutchinson). For the quantitative social sciences, HIV/AIDS has led to renewed interest in the development of epidemiological techniques for studying infectious, as opposed to non-communicable, diseases (Ghani and Boily), and to a switch in demographic preoccupations from declining fertility to increasing mortality (Gregson). HIV clinical specialists have developed new social skills for use in the provision of palliative care, and in networking across health, welfare and legal agencies, to help provide for their patients' clinical *and* social needs (Wood with Ellison). Psychological research has taken on a broader view, looking beyond individual determinants of behaviour to the contextual and structural factors that condition individual responses and autonomy (Campbell and Cornish). The ethnographic approaches favoured by anthropologists have been used to explore the 'lived experience' of both the disease, and the socio-cultural attitudes which

sustain the transmission of HIV – including research undertaken amongst those who accept the explanations offered by biomedical science (Parker) *and* those who do not (Heald). Finally, political science has drawn on comparative analyses of African countries at similar risk of HIV/AIDS, but with very different levels of disease, to provide stronger evidence that differences in policy and governance are responsible for intensifying *and* attenuating national HIV/AIDS epidemics (de Waal).

However, it is also clear that the very different approaches, and the very different tools, used by each of these disciplines determine not only the sorts of questions they ask and the sorts of explanations they provide, but also the sorts of lessons they have learnt. Thus, Hutchinson's focus on the use of new genetic technologies to identify the phylogenetic origin(s) and molecular biology of HIV, concludes by suggesting that differences in virulence amongst different HIV strains, and differences in susceptibility amongst different human populations, might be genetically determined. Ghani and Boily describe how advances in epidemiological modelling techniques (particularly using the prevalence of AIDS, to perform 'back-calculations'<sup>11</sup> of asymptomatic HIV prevalence) – developed to predict the spread of HIV – might also be used to predict the likely impact of different types of interventions. Likewise, Gregson describes how demographers have drawn on existing expertise, in researching the social and behavioural determinants of fertility, to develop radically different life tables for those countries worst affected. Wood with Ellison describe how biomedical advances in treating HIV/AIDS (particularly combination drug therapies) have revealed important social and economic barriers to presentation for care and adherence to therapy – barriers which clinicians have found difficult, if not impossible, to challenge. In a similar vein, and following their review of the role that context and structure play in HIV prevention, Campbell and Cornish conclude that community-led prevention initiatives are undermined when they are unable to address powerful *external* structures or fail to engage *internal* constituencies with the power to enact change. After examining why backroom sex is both irresistible yet damaging to gay-identified men, Parker argues that concerted efforts are urgently required to challenge these venues as acceptable and

legitimate expressions of gay culture.<sup>12</sup> Heald demonstrates why biomedical knowledge on HIV/AIDS is neither ‘neutral’ nor ‘culture-free’, and explains why HIV prevention programmes must be based within local understanding of disease causality. Finally, de Waal draws upon the political characteristics of African regimes with comparatively successful HIV/AIDS policies, to assert that HIV/AIDS needs to be seen as a *political* threat, and thereby *politicised*, to ensure prevention is ‘mainstreamed’ at the heart of political power structures.<sup>13</sup>

Given their very different foci it is, perhaps, unsurprising that different disciplines come up with such different explanations and different answers. Those reliant on individual-level quantitative data, even when (as in epidemiology and demography) these data are used to identify groups and processes at a *population-* or *sub-population-*level, inevitably produce individual-level answers – such as improvements in knowledge (about HIV/AIDS, its prevention and treatment), attitudes (particularly self-efficacy; Bandura, 1996) and behaviour (i.e. safer sexual practices or prompt presentation for, and adherence to, treatment). The contributions reflecting on these (Ghani and Boily, and Gregson), and related biomedical disciplines (Hutchinson), also have a tendency to focus on the *methodological* constraints and innovations that they have identified from studying HIV/AIDS (such as the development and application of new techniques for identifying the origin, and for measuring and predicting both the spread and the impact, of the disease). In contrast, contributors from those social and political sciences favouring ethnographic and qualitative approaches draw upon *existing* techniques to explore, contextualise and reflect upon the lived experience of HIV/AIDS in very particular settings. These chapters all present detailed case studies of their own research (Campbell and Cornish, Parker, and Heald) or detailed analyses of socio-political processes (de Waal), to demonstrate the powerful role that *structure* and *context* play in conditioning and restricting the behavioural choices available to individuals and groups alike. The experiences of HIV clinical specialists (Wood with Ellison) fit somewhere between these two extremes: on the one hand they have experienced the dramatic impact of treatments developed through empirical biomedical research; on the other they have been frustrated by their powerlessness to overcome the social constraints their patients face. The

ability of clinicians to *treat* HIV/AIDS and prevent transmission has therefore been offset by social policies and social attitudes that undermine the *care* they are able to provide. Despite the much vaunted future benefits of genetic technologies (in the design and production of HIV vaccines, for example: Hutchinson), their potential efficacy remains hotly debated (Ghani and Boily) – *and* still some way off (Moore and Anderson, 1994; Laurence, 1997; Boily *et al.*, 1999). There also appears to be little *clinical* benefit in the classification of the ‘core groups’ favoured by epidemiology and demography. Instead, HIV clinical specialists rely on individualised care to support the medical *and* social needs of their patients (Wood with Ellison) – an approach which seems more in-tune with the contextualised, in-depth and actor-orientated approaches preferred by the contributions from social psychology, anthropology and political science (i.e. Campbell and Cornish, Parker, Heald, and de Waal). Clearly, treating the ‘whole patient’ (i.e. both their medical *and* social needs) requires an holistic approach – one that reaches across professional, disciplinary and methodological boundaries to consider both the generic and the particular (Moatti and Souteyrand, 2000). In this sense, the contributions to this volume display a lamentable lack of synergy between different disciplines, and a tendency for disdain for those who see themselves as central to mobilising research and policy on HIV/AIDS from those who see themselves at the periphery (whether involuntarily or willingly).

### **Multidisciplinary perspectives on inter-disciplinary responses to HIV/AIDS**

Even with regard to this issue, ‘inter-disciplinarity’, there are fundamental differences in perspective amongst contributors from the different disciplines represented in this volume. Hutchinson describes how collaboration between different disciplines (albeit the biological disciplines of medical science, molecular biology, genetics and zoology) was required to ‘map’ the possible phylogenetic and geographical origins of HIV, and how future collaboration with social scientists will be needed to identify the changes in social structures and social mobility responsible for newly emerging zoonoses. Ghani and Boily

describe how modelling the transmission of HIV required a more detailed understanding of sexual behaviour and sexual mixing – information which required collaboration with (amongst others) demographers who, as Gregson describes, were somewhat sceptical of early pessimistic epidemiological predictions. Both of these contributions recognise the need for a more detailed and sensitive understanding of social processes – particularly those which influence how individual choices (such as whether to have children) might be altered by, or might change in response to, the pandemic. Indeed, Gregson pays tribute to the important role that demographers with a training in other disciplines (including anthropology) have played, and the importance of small-scale in-depth longitudinal studies to inform a more detailed understanding of the social dynamics of HIV/AIDS. Both he and Ghani and Boily<sup>14</sup> acknowledge the limitations of the quantitative questionnaire surveys on which their disciplines rely – particularly for identifying subtle differences in behavioural, socio-cultural and structural factors responsible for differences in HIV prevalence in ostensibly ‘similar’ populations.<sup>15</sup> Thus, for the most part, these contributors feel their disciplines are *already* engaged in collaborative multidisciplinary work (though not entirely integrated, *inter-disciplinary* work). They also seem to recognise the value of future collaboration, and acknowledge the need for the very different insights such collaboration might bring. By contrast, contributors from disciplines preferring ethnographic and other, essentially qualitative, methods seem to view themselves as excluded – either because they are not welcome to collaborate or because their methods and values are incompatible with collaboration on equal terms (by which they often mean, *their* terms). This view is compounded by their detailed critique of superficial biomedical approaches (and simplistic discourse; de Waal) – a critique for which these disciplines’ pre-occupation ‘with in-depth reflection on the particular’ makes them particularly adept at identifying contextual constraints to prosaic biomedical interventions (Campbell and Cornish, Parker, and Heald). As such, their inherent lack of respect for dominant biomedical paradigms – albeit a ‘healthy’ disrespect, which fosters their critical insights of ‘other’ – might appear to undermine, if not contradict, their stated desire for more integrated and holistic interventions. This apparent contradiction does

not go entirely un-noticed in each of their contributions, yet they all (Campbell and Cornish; Parker; Heald) offer insights into what Campbell and Cornish call ‘disappointing’, and what Heald characterises as ‘unhappy’, experiences of social scientists working within biomedically-driven interventions. These insights are worth revisiting here.

Biomedically-focused interventions often provide little scope for contributions from ethnographic or qualitative research, preferring shallower quantitative descriptions of the people, places and processes involved – descriptions which take up a large part of the literature in this area (which Campbell and Cornish review). In those instances where participatory and contextually-sensitive interventions for HIV prevention have been undertaken in full collaboration with qualitative social scientists, these are often undermined by insensitive biomedical approaches elsewhere (as Campbell and Cornish describe; see also: Sumartojo, 2000; Tawil *et al.*, 1995). From Parker’s perspective, anthropologists typically prefer to ‘go it alone’, undertaking long-term fieldwork using participant observation unencumbered by the constraints of narrowly-defined biomedical interventions. Indeed, the detailed and complex data generated by such fieldwork has inevitably led to a certain amount of derision for the construction of ‘black box’ epidemiological categories – such as ‘high risk’, ‘low risk’ and ‘core group’.<sup>16</sup> These categories often involve gross over-simplifications and are vulnerable to an implicit bias towards targeting marginalised groups (such as commercial sex workers), as opposed to more powerful constituencies (such as sex workers’ clients).<sup>17</sup> In the process, the idiom ‘core group’ stigmatises those who are already marginalised, and distracts attention away from others ‘at risk’ (Glick Schiller *et al.*, 1994). Some even argue that categorisation specifically produces data which, unlike qualitative analyses, are open to misrepresentation (Parker) – but as we shall see, ethnographic anthropological research is also open to misinterpretation and misuse (particularly by those from other disciplines).

Heald points out that the ‘absence of anthropology’ goes against WHO recommendations for biomedical interventions based on local knowledge and collaboration with alternative sources of health care

(such as ‘traditional healers’) – recommendations which anthropologists are well-equipped to address. She sees HIV/AIDS as dominated by a biomedical focus that views ‘science’, ‘scientific facts’ and ‘scientific technologies’ as ‘neutral’ and ‘culture-free’. Yet this is something that truly reflective social scientists (*and* reflective biomedical scientists) know to be false, even for their own, most grounded work (Glick Schiller *et al.*, 1994; and as Heald herself concedes). Like Parker, Heald believes that anthropologists have been reluctant to engage in quantitative and ‘generalisable’ biomedical approaches that seek to enumerate, rather than explore, the manifestation of HIV/AIDS. She sees the pragmatic methods of much biomedical work as incompatible with anthropological approaches, and their data inappropriate for anthropological analysis. Moreover, Heald suggests that what is entirely orthodox to anthropology can be utterly ‘heretical’ to biomedical science, and vice versa – voicing particular concern over the misuse of anthropological research to support the construction, and stigmatisation, of ‘core groups’ (as we alluded to in the previous paragraph).<sup>18</sup>

Underpinning Heald’s concerns, and those voiced by Campbell and Cornish and by Parker, is what appears to be a widespread belief that the quantitative natural and social sciences engaged in biomedical research are wilfully ignorant of the contribution that reflective social science might make. Indeed, de Waal seems to view biomedical disciplines as bastions of the status quo, in which their views are pre-eminent (if not *entirely* infallible) in the eyes of policymakers, while their research receives the lion’s share of the research funds available. Nonetheless, Heald concedes that anthropology in particular, and reflective social science in general, bears some of the responsibility for failing to collaborate on grounds of self-interest: anthropologists prefer ‘pure’ over ‘applied’ research, so that contributing to pragmatic, ‘real world’ HIV/AIDS programmes can be seen as an unpromising topic for anthropological enquiry. As such, these disciplines have, for the most part, remained on the periphery – or *identify* with the freedoms the periphery permits (Frankenberg, 2001) – as barely audible critics of the policies and programmes undertaken by others.

To consider the relative merits of the contributions made by quantitative biomedical and reflective social sciences to the treatment and prevention of HIV/AIDS, it might help to consider the experiences of HIV clinical specialists – in many respects the professional arm of biomedical HIV/AIDS research. To this end, Wood with Ellison illustrate how biomedical advances in treatment (particularly Highly Active Antiretroviral Therapy – HAART) transformed the nature of clinical care for HIV patients – albeit in those contexts where well-resourced services were able to introduce HAART to those who needed it (Garnett *et al.*, 2002). They describe how the HIV Unit at London’s North Middlesex Hospital changed from a centre providing palliative care to terminally ill patients, to one in which selecting the most appropriate combination therapies for HIV-positive patients was the principal activity (alongside the introduction of effective pharmacological, surgical and nutritional interventions to prevent the vertical transmission of HIV from mother to baby). Ostensibly, clinicians were the principal professional beneficiaries of the biomedical focus of most HIV/AIDS research activity. Yet, ironically, these therapeutic benefits threw into sharp relief the importance of social and structural barriers to presentation for care and adherence to therapy – barriers which severely constrain the impact of combination therapy. HIV clinical specialists have developed a number of important social skills in an effort to overcome these barriers, such as: tailoring advice and support to match each individual patient’s circumstances and needs; acting as advocates on their patients’ behalf; using an inter-professional approach to network with welfare agencies; and engaging with external stakeholders (such as religious leaders) to enlist their support in changing socio-cultural attitudes to the disease. Notwithstanding these skills, the most salient lesson clinicians have learnt is their limited ability to influence external barriers to treatment and adherence.<sup>19</sup> In particular, Wood with Ellison single out the way in which clinicians have less and less authority to challenge some of the most important policies affecting HIV patients in their care – such as those enacted by the UK’s National Asylum Seekers’ Service.

It seems as if the influence of biomedical disciplines on HIV/AIDS policy evaporates as soon as these seek to address issues with wider social, economic and political ramifications. This is further evidence

that at least some aspects of social policy formulation seem implicitly resistant to, or reluctant to engage with, contributions from social scientists – or, for that matter, from biomedical scientists attempting to tackle social factors that impinge on technological advances.

## **Learning political lessons from HIV/AIDS**

Heald argues that HIV/AIDS has, from the outset, been a highly politicised disease – not least in North America and Western Europe where (as we mentioned earlier in this introduction) the concentration of the disease within the gay community led to HIV/AIDS being adopted as a cause célèbre, intimately connected to gay rights (Epstein, 1996). In these contexts, lay AIDS activists successfully promoted non-medical expertise as equivalent, if not superior, to biomedical knowledge, and in so doing won the right to be consulted and included by ‘experts’ developing HIV/AIDS policy and research agendas.<sup>20</sup> This was an unprecedented event, more profound perhaps than the role of the women’s movement in recapturing reproduction and pregnancy from medical specialities dominated by men (Oakley, 2000). Yet the success of the gay community in lobbying for representation, alongside effective *and* acceptable interventions, has not been replicated by the disempowered communities who bear the brunt of the disease in Africa.<sup>21</sup> Worse, Parker contends that powerful players within the gay community in North America and Western Europe have consistently overlooked, or refused to acknowledge, those aspects of contemporary gay sexual cultures (particularly the use of backrooms and other settings where anonymised, unprotected sex takes place) which directly impinge on HIV transmission. Indeed, the principal benefit of biomedical HIV/AIDS research, HAART, appears to sustain unsafe sexual behaviour in these venues precisely because it halts the onset of AIDS (and renders HIV ‘safe[r]’: Setbon, 2000). The reluctance to address the risks backrooms pose appears to reflect a political commitment, on the part of gay HIV/AIDS activists, to respect all aspects of homosexual cultures – activists who were often also involved in the long, and hard-won, battle to have homosexuality accepted by ‘mainstream society’ (de Waal). Yet Parker

points out that cultural sensitivity and respect should not, and has not, dissuaded society as a whole (i.e. ‘gay’ *and* ‘mainstream’) from challenging ‘cultured’ practices elsewhere (such as female genital circumcision/mutilation: Parker, 1996). She also argues that it is unlikely that backrooms facilitating anonymous *heterosexual* (as opposed to *homosexual*) transmission of HIV would be tolerated. There is certainly some evidence to suggest that the enforcement of seemingly draconian health-legislation, however unpopular to begin with, can ultimately succeed in transforming cultural values and social norms (e.g. drink-driving and smoke-free public spaces).

The importance of recognising the role of politics and political governance in failing to provide either the will or the means for effective HIV prevention – over and above any role(s) that social and individual factors might play – is the topic considered by the penultimate contributor to this volume. De Waal notes that, despite their concern for the particular over the generic, a pre-occupation with the ‘contextual’ conditioning of social experience, and a tendency to embrace uncertainty and eschew illusions of ‘order’, the reflective social sciences have reached an extraordinary level of ‘un-theorised’ consensus with biomedical science over what ‘an HIV/AIDS programme’ might look like:

it should be founded on voluntary counselling and testing, education (preferably by peers), provision of condoms, efforts to overcome denial, stigma and discrimination, and care and treatment for people living with HIV and AIDS. Prevention of mother-to-child transmission of HIV and treatment of STIs are also prominent. It is, overwhelmingly, a model of voluntarism and community participation. (p. 254)

Yet de Waal points out that since this draws on an ‘NGO [non-governmental organisation] model of public action’, which strives to be as palatable (if not as ‘uncontroversial’) as possible, it fails to confront powerful and overarching social, economic and political structures. Just as the medicalised idiom of HIV/AIDS as a latter day ‘plague’ isolates prevention programmes within the ‘health [ministry] ghetto’, de Waal argues that community-based HIV/AIDS programmes can be ‘prisoner[s] of political circumstance, and as a

result, may be trapped in a cycle of ineffectiveness' (p. 255). Moreover, he warns that those who elevate structure and context above all else are often preoccupied with utopian political ideals which encourage the notion that decisive action on HIV/AIDS should be deferred until *after* a more egalitarian social dispensation has been achieved. By failing to acknowledge the immediate economic and political *consequences* of the pandemic, which are likely to further delay (if not destroy any capacity for) progress towards any such dispensation, an emphasis on structure and context distracts attention away from dealing with the disease at precisely the moment when action is required as a *prerequisite* for structural and political reform. In this way, a focus on structure and context can, paradoxically, undermine the action required to protect the capacity for change – particularly since the marginalised groups most affected by HIV/AIDS are likely to be further disenfranchised by the disease itself, and by its associated stigma. At a national level, this feeds into what Gregson describes as the *political* stigma of HIV/AIDS, where a high prevalence of disease is interpreted as evidence of inept or incompetent governance – an interpretation which might explain political interference in demographic studies in those countries where HIV prevention programmes have been particularly unsuccessful. It might also explain the belated, panic-stricken response to HIV/AIDS in Africa from international agencies and Western governments. This, Heald maintains, currently involves funding '*anything*' remotely related to HIV/AIDS whilst ignoring, for the most part, the public services most in need of support. Contemporary Western and international concerns with the impact of the African epidemic on economic and political security, both regionally and globally, certainly appear disingenuous, if not indicative of blatant self-interest (Heald). Yet de Waal suggests these concerns might indicate that policy makers, hitherto unconvinced by ethnographic accounts of the circumstances that place the disempowered at greatest risk, or even by epidemiological and demographic projections of the huge scale of the pandemic, have finally grasped that HIV/AIDS poses an inherently *political* (and not simply a medical or socio-demographic) threat, requiring *political* and *politicised* action.

## **Learning from HIV and AIDS – looking ahead to inter-disciplinary approaches**

Why are disciplines within, or closely connected to, the biomedical sciences seen as more central to HIV/AIDS? Why are some disciplines from the social sciences (such as demography and epidemiology) more readily engaged with mainstream biomedical science? Is this due to the biological nature of the topics they examine (i.e. reproduction and health), or is it because they are dominated by quantitative and positivist methodological approaches that are more accessible and persuasive to those trained in the natural and medical sciences? These quantitative social sciences aim to provide accurate projections of future events, and to determine the effectiveness and efficiency of preventive and therapeutic interventions – practical objectives that do not necessarily require a full understanding of ‘how’ and ‘why’ such predictions (or, for that matter, interventions) work. For example, the chapters by Ghani and Boily and by Gregson both acknowledge that the development of predictive epidemiological and demographic models relied on crude estimates of key variables (such as survey-based measures of the behavioural characteristics which determine HIV transmission, and incomplete or poor quality vital registration data). Although these models were instructive, providing an insight into the spread of the disease which turned out to be remarkably accurate, their lack of precision remains one of the principal criticisms levelled by those social sciences that prefer in-depth ethnographic and qualitative approaches. This criticism seems somewhat misplaced, given that the latter (i.e. reflective social scientists) are peculiarly comfortable with uncertainty. Instead it seems to originate from their commitment to exploring the complex interplay of individual, cultural and structural factors in very particular circumstances. Clearly there is room for *both* their approach and more positivist quantitative analyses. Indeed, Campbell and Cornish’s review of research tackling the social and contextual dimensions of HIV prevention found studies that had used individual-level quantitative, *and* contextualised qualitative, descriptions of behaviour (although very few that had used, or integrated, both). Nonetheless, their chapter concludes with a case study demonstrating the importance