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Edited by George Ellison, Melissa Parker and Catherine Campbell

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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 2002¹

[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 2002²

**‘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 journals³ and professional texts, to local newsletters and

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global websites).⁴ 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.⁵ 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.⁶ 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.⁷ 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

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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.⁸ 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

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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

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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

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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)⁹ among gay-identified men in London

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(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 zoonoses¹⁰ 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'¹¹ 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