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0521808669 - Learning from HIV and AIDS

Edited by George Ellison, Melissa Parker and Catherine Campbell

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Learning From HIV and AIDS

Different professional and academic disciplines have addressed the HIV/AIDS pandemic from a variety of perspectives, using different analytical approaches. By bringing these together in one volume, *Learning from HIV and AIDS* provides a more complete picture of this multi-faceted disease – from the biological and social factors which facilitate HIV transmission – to the powerful cultural and political forces which fuel the pandemic. Chapters from contributors working on the aetiology, treatment and prevention of HIV/AIDS identify how their work has helped predict the spread of HIV and has improved the survival of those infected. Yet interventions to reduce the spread of HIV have had limited success, and few HIV-infected individuals have access to combination drug therapies. Written for students and researchers, and taking a multidisciplinary perspective, this book demonstrates that progress in developing effective and acceptable interventions can only be achieved through interdisciplinary collaboration between the biological, medical and social sciences.

GEORGE ELLISON is Professor of Public Health and Director of the Institute of Primary Care and Public Health at South Bank University, London. His work on HIV/AIDS includes a randomised controlled trial to promote partner notification for sexually transmitted infections in Alexandra, and participatory workshops on the critical appraisal of educational interventions for HIV prevention throughout southern Africa.

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Foreword

If men could learn from history, what lessons it might teach us! But party and passion blind our eyes, and the light which experience gives is a lantern on the stern, which shines on the waves behind us!

Samuel Taylor Coleridge, *Table Talk*

Learning from HIV and AIDS is proving every bit as problematic as Coleridge characterised history as a teacher. HIV of course poses its own particular challenges. National responses have had to address a disease that is primarily spread by unprotected sex, around which open discussion is often clouded by prejudice, denial, ignorance and misconception. These have all facilitated the spread of HIV/AIDS, and impeded the pace of national political responses. Approaches to HIV/AIDS which seek to promote learning relevant to policy responses for prevention, care and impact, are therefore urgently required at national, regional and global levels. This volume is a valuable contribution to that agenda.

As the new millennium unfolds, the HIV/AIDS pandemic continues to spread apace in many parts of the world. These are generally the places that can least afford the increased burdens of suffering and deprivation the disease brings about, and those that typically lack the capacities required to mount an effective prevention and care response. The poverty-reduction development prospects of much of Eastern and Southern Africa are seriously challenged by a high prevalence of HIV in the general population – threatening hard won gains in: human development; life expectancy; and education. Meanwhile, HIV continues to spread in West Africa.

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Despite extraordinary advances in virological and epidemiological techniques (as the chapters by Hutchinson, and Ghani and Boily describe), the science of HIV/AIDS impact analysis and impact mitigation is still relatively new (as evident in the chapters by Gregson, and de Waal). Nonetheless, it is already very clear that in the worst affected countries, no aspect of life is likely to be *unaffected*, be it the family, livelihood, gender relations, governance or food security. With the virus extending its reach into the highly populated countries of Asia (particularly India and China), and rapidly gaining ground in Eastern Europe, our collective well-being across the globe will undoubtedly be affected by the success or failure of what UNAIDS calls the “drastically expanded, global prevention effort” that is urgently required (UNAIDS, 2002a).

In the absence of a vaccine or cure, tackling HIV/AIDS will continue to rely on prevention. The prevention of HIV transmission is heavily dependent on effective learning translated into action to reduce risk *and* vulnerability to infection (UNAIDS, 2002b). Policies and programmes based on learning from HIV and AIDS are, at this time, arguably our best hope for ‘reducing HIV infections among 15 to 24-year-olds by 25% in the most affected countries by 2005 and, globally by 2010’ – perhaps *the* key target agreed by 189 countries in the United Nations General Assembly Special Session’s ‘Declaration of Commitment on HIV/AIDS’ (UNAIDS, 2001). Such learning needs to underpin national strategic responses and needs to occur at different levels, including: the social; the institutional; and the individual.

While successes have been made in a number of countries in reducing HIV infection rates (most notably in Thailand, Uganda and Brazil) either these are, as yet, insufficiently understood, or the lessons thereof have yet to be appropriately applied elsewhere. The unrelenting progress of the pandemic across the globe suggests a repetitive pattern of responses that are ‘too little, too late’ – a pattern which implies that there remains insufficient investment in identifying which measures are effective in prevention, care and impact mitigation. Indeed, there are those (most notably Barnett and Whiteside, 2001) who argue that the consequences of the HIV/AIDS epidemic have not been properly considered by *any* agency. Perhaps this is not surprising, given that we are still learning about the social and economic impacts of the Black Death in medieval England (e.g. Platt, 1997). Yet this time lag should serve as a stark warning of the challenges facing a fuller understanding of ourselves in our own

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time. Whilst, as Marks with Ellison argue (in their postscript to this volume), historians have an important role to play in developing this understanding – of the lived experiences of the epidemic within historical *and* contemporary contexts – we cannot afford to wait until the light from Coleridge's lantern illuminates these. In addressing the new and increasingly pervasive threat of HIV/AIDS, there is no alternative but to address the contemporary factors and vested interests which cloud our understanding.

Fortunately, the need to learn more about local HIV/AIDS epidemics, and the pandemic itself, is wholeheartedly accepted by UNAIDS and its co-sponsors. Indeed, one of the most explicit expositions of the need to promote learning as a basis for policy and action is contained in UNESCO's strategy for HIV/AIDS preventive education (UNESCO, 2001). Much is still not known about the disease – there remain many gaps in our knowledge and these have profound implications for our capacity to act. The recently finalised five year Evaluation of UNAIDS (UNAIDS, 2002c) concludes that a lack of data (let alone analysis) is itself a major contributory factor in impeding community initiatives and the scaling up of responses. It suggests that, with a few recent exceptions, there is little evidence of impact on changes in behaviour, or any clear understanding of the contextual factors which limit behaviour change.

This volume of articles usefully contributes to this debate and highlights several key areas where research is urgently needed. In their introduction, Ellison with Parker and Campbell discuss the importance of moving from multi-disciplinary syntheses to dedicated inter-disciplinary work – a change in research culture they see as crucial to understanding the biological, social *and* political complexity of HIV/AIDS. Inter-disciplinary approaches are required to understand the relationships between the different levels at which HIV/AIDS operates, and to support the development of effective, complex, multi-level, multi-sectoral interventions. This view draws on the relative ebullience of those contributors from disciplines that have benefited from technological and methodological advances, and have thereby contributed most to what we *do* know about the biological nature, transmission, impact and treatment of HIV/AIDS (particularly chapters by Hutchinson, Ghani and Boily, Gregson and, to some extent, Wood with Ellison) – ebullience that is qualified by those concerned with the diverse experience of individuals and communities affected by HIV/AIDS and the complex challenges

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facing health promotion (Campbell and Cornish, and Parker), health ‘education’ (Heald) and governance (de Waal). Campbell and Cornish make a strong case for further conceptual and empirical work to learn more about those factors (including social and community processes) that promote or constrain prevention programmes. In part, this is an area of work that has suffered from what Parker and Heald consider a reluctance (if not a failure) on the part of anthropologists to contribute to effective prevention programmes, despite their insightful critique of acontextual biomedical approaches.

In their postscript to the volume, Marks with Ellison seek to place the HIV/AIDS pandemic in both contemporary and historical context, but warn that historians are unused to providing radical or pragmatic advice until they gain a coherent view of events – i.e. by which time events have taken on a life of their own. Indeed, De Waal cautions us about what we might expect to learn from history, as HIV/AIDS appears to fit no historical pattern. In this he re-affirms the view that there is as yet no proven model of what works in HIV prevention – responses have been, and remain, largely a matter of trial and error, and have resulted only in what he calls an ‘untheorised consensus’ on what HIV/AIDS programmes *should* (and not *could*) be doing. Worse, de Waal believes that this consensus shies away from controversy and some of the more contested policy terrain, thereby trapping what he calls ‘the AIDS industry’ in ‘a cycle of ineffectiveness’. He proposes two pre-conditions for successful national responses: first, that they be founded on rigorous public health science; second, that they be framed by the real potentialities of governance. Citing Ugandan experience, he argues that understanding the political threat of HIV/AIDS is likely to be the most critical factor in motivating government responses, and that developments in this arena are likely to present the best opportunities for an effective national response.

This volume presents a number of key challenges for development practitioners working in the field of HIV/AIDS and for the development agencies which employ them:

- Much has been learnt *about* HIV/AIDS but we have yet to learn *from* the pandemic. On the one hand there is no room for complacency, while on the other the potential benefits of

successfully engaging with HIV/AIDS extend far beyond issues of medicine or even public health – to more effective and holistic solutions for tackling global inequality and for promoting effective, ethical governance.

- HIV/AIDS is a complex, multi-factoral issue requiring comprehensive and holistic responses. It requires development professionals to develop an ability to be able to understand different types of knowledge (both ‘scientific’ and ‘social’), and their associated discourses. This implies greater, not less, HIV/AIDS-related specialisation of those involved in policy dialogue and formulation – for which specific inter-disciplinary training is required, involving the establishment of strong links within and between different sectors, professions and academic disciplines. A stronger emphasis is required with regard to prioritising evidence-informed policy and practice. This implies developing specific knowledge management capacity for policy development.
- HIV/AIDS is both a social development *and* a political issue. Much more effort is required to ensure that social development perspectives, and research (including that from anthropology, sociology and social psychology), are included at the forefront of policy and programme development. Support for national responses requires rather more sophisticated political analysis than has generally been employed to-date.

How, then, might we best maximise opportunities for learning at all levels, and how do we ensure that the lessons learnt properly inform policy dialogue and formulation, planning and implementation? Institutionally, this surely requires that bureaucracies put a higher value on policy-relevant research. In particular, increased attention needs to be paid to learning about what factors promote or inhibit HIV prevention – to ensure that formulation and implementation are informed by a comprehensive understanding of what’s happening, what’s possible *and* what works. It is essential to recognise the crucially important contribution that academic communities, in particular universities and research institutes, have to play in addressing HIV/AIDS at national, regional and global levels. Attention needs to be paid to ensuring that national and regional HIV/AIDS research capacity is strengthened through the allocation of

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funding to policy-relevant research and building up institutional capacity in the countries and regions worst affected. Promoting higher education links (North-South and South-South) to combat HIV/AIDS is likely to be highly effective in this regard.

Hitherto, a predominantly biomedical response has severely limited the effectiveness of national HIV prevention programmes. Recognising that responses to address HIV/AIDS effectively are frequently compromised by turf wars across sectoral, departmental and disciplinary boundaries requires investing in approaches to foster greater coherence and collaboration. In particular, it is essential that we identify and address institutional, disciplinary and personal impediments to learning about *and* from HIV/AIDS. This will also require empowering non-medical ‘lay specialists’ to fulfil their roles, with adequate resources and appropriate prioritisation for their unique expertise. Finally, it is important that we recognise how development agendas may be driven as much by ideology as evidential considerations. Bilateral development policy is, to a greater or lesser extent, enmeshed in foreign policy considerations and thereby inherently politicised. Openness of government is more likely to correlate with an approach to development and HIV/AIDS that is more conducive to objective analysis and evidence-based policies.

The increased level of resourcing that is becoming available to governments from the Global Fund for AIDS, TB and Malaria (GFATM), multi-lateral (World Bank MAP) funds, and bilateral sources comes at a time when the evidence-base for what works is weak and capacities to formulate, implement and evaluate remain under-developed, particularly in many of the worst-affected and *at-risk* countries. Against this background, investment in national and international capacity to support evidence-informed policy formulation and implementation has to be a high priority. Appropriate emphasis needs to be given to knowledge development *and* knowledge management, and to developing adequate monitoring and evaluation capacity, if we are to promote multi- and inter-disciplinary research. Without strengthening accountability there is the real risk that funds will be mis-allocated, and that the current window of opportunity to address the pandemic will be missed – so that historians of the future will be charged with explaining why a preventable disease spread so perniciously and at such a cost...

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