

Publish or perish: the case of HIV/AIDS
(Montego Bay, Jamaica)*

Ladies and gentlemen, every academic has heard the expression “publish or perish” and the connotation has been that academic survival depended on the ones ability to publish, hopefully original work. Many an academic has perished because he or she did not believe that this aspect of his or her responsibility should outweigh all the other contributions to a good society. I use the expression here in a different sense. I wish to emphasize that unless there is some collective approach to purveying information such that it changes the behavior of individuals and the social environment that conduces to the practices that lead to HIV infection, there is no doubt that large numbers of us will truly perish. The purveying of that information is a quintessential function of publishing.

But now let me thank Mr. Ian Randle for the invitation to address you, and I am indeed impressed to see an international forum in the Caribbean on publishing focused on an issue that is truly of global importance. I welcome the notion that a group as important as yours considers that it has a peculiar role to play in the efforts to control the HIV/AIDS epidemic. I understand that the Strategic Plan of the Caribbean Publishers Network (CAPNET) 2002 recognized the need for the industry to respond to the epidemic and this conference is a result of that commitment.

It is now a universal canon that this epidemic will not be controlled unless we involve the skills and knowledge of a wide range of social actors that traditionally have not been seen as instrumental for change in health. Your initiative is a good one and may have even more significant implications for your future work. You are focused on HIV now, but as sure as the night follows the day there will be other epidemics of infectious disease that will affect humankind and we need to have established a large and wide constituency of concern for the new health problems that the enhanced global interconnectedness is sure to visit upon us.

My major frame of reference will be the Caribbean, as that is the region I know best, but I am pleased to see participants from other parts of the world, especially those most affected by the epidemic. I am sure the idea is that by sharing experiences and discussing differences, there will be some benefit to all those in the world infected and affected by the virus, as indeed, all humankind is affected in one way or another.

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I make no apologies for repeating and emphasizing that at a fundamental level HIV/AIDS is a health problem. If the virus caused no one to be ill or die, it would not be a source of alarm. It is the impact of the ill health and the fact that determinants of that ill health are so wide and varied, that it is imperative to look for an approach that involves all sectors of society. The attention being paid to HIV/AIDS by actors outside the traditional health sector is also a clear indication of the importance of health to all aspects of human development and the need to address health issues with a range of instruments and approaches that are outside the competence of those traditionally trained to deal with manifestations of disease.

In any discussion of the relationship between publishing and HIV/AIDS one can explore the linkage from one or other direction and I am sure that the epidemic must in some way have an impact on publishing and publishers. At the most elementary level, those countries whose economies are being devastated by AIDS will not be a good market for published material. The depletion of human resources in those countries affects all professions and enterprises, so I would be surprised if publishing escaped. But today, I choose to be unidirectional and focus on how publishers and publishing may be involved in the control of the epidemic.

Considerable attention is paid to the role of the popular press in HIV/AIDS but I would make a distinction here between that medium and the scholarly publishing which is more represented at this conference. Everyone agrees that the media do have a role in the control of the epidemic^{1 2,3} They can be sustained advocates for the rights of persons living with HIV/AIDS and can convey the sense of urgency and immediacy that is often needed to spur action. Of course, the need to maintain public interest sometimes leads to over-dramatization of the issues and the kind of sensationalization that does not help to control the epidemic. They are able to reflect public attitudes because of the frequency and nature of their publications. Unfortunately, many of the public attitudes that are played out in the Caribbean stem from the kind of moral judgment that allows little sympathy or charity for persons with AIDS.

But before we examine the approaches to the control of the epidemic that might interest publishers, it is worthwhile describing some of its characteristics in the Caribbean.⁴ I do this more for the benefit of our visitors as I am sure the Caribbean people know these facts very well. The bald statistics show that there are about 500,000 persons living with HIV/AIDS in the wider Caribbean, of whom about 20% are in the CARICOM countries. The estimates range between 270,000 and 780,000. The adult prevalence rate is about 2.3%. I am imprecise about the numbers and the wide ranges given are an indication of one of our problems. Persons are unwilling or simply scared to come forward and be tested, partly because of the stigma and discrimination that attend the disease, the lack of confidentiality and the belief that in most cases the HIV positive state and the eventual progression to AIDS is a death sentence, given the unavailability of therapy in many countries.

¹ Stein J. HIV/AIDS and the media. The Centre for AIDS Development, Research and Evaluation (Cadre) Johannesburg, South Africa, April 2001.

² Media & HIV/AIDS in east and Southern Africa: A resource book. Ed. ST Kwame Boafo, Paris Unesco, 2000. http://www.unesco.org/webworld/publications/media_aids

³ See Press Release SG/2098 AIDS/97 Media leaders from around globe expand response to UN's call to fight AIDS epidemic. <http://www.un.org/News/Press/docs/2005/sg2098.doc.htm>

⁴ HIV/AIDS Working Paper for the Caribbean Commission on Health and Development

The epidemic is not abating and projections for the Caribbean estimate that by the end of this decade, compared with the figures for the year 2000, there will have been an increase of 21% in the number of persons living with HIV/AIDS. The optimistic scenario is that there will be wider availability of therapy as currently occurs in countries like Barbados and the Bahamas. Thus we will see a greater number of survivors and AIDS may be on the way to becoming another chronic disease to be controlled by regular medication. On the other hand, the prediction is that the number of new infections will continue to rise, so we will have an ever increasing pool of individuals needing treatment. The economic and social consequences of that scenario are grim, with significant negative macro and microeconomic consequences for our countries. We see the epidemic taking a disproportionately greater toll on the young in the most productive time of life and it is a major cause for alarm that the young females represent the group with the most rapidly increasing prevalence. The mode of transmission is predominantly heterosexual except in Cuba where homosexual transmission prevails.

But these statistics do not tell the full story of the social dimensions of the epidemic and the questions that society has to answer in trying to control it. Does the increasing prevalence in young girls reflect the gender discrimination in the society? Will the rampant homophobia that characterizes most of our societies impede the passage of modern laws that seek to abolish discrimination for purposes of work, and the decriminalization of homosexuality? Given the clear evidence of transmission in correctional facilities, will the laws ever be changed such that condoms can be made available there? Will the attitude to prostitution change, and will prostitutes agree to band together to protect themselves from being infected? On one occasion, in referring to the possibility of prostitutes grouping together for mutual protection, I introduced the story from the Greek play *Lysistrata* to demonstrate the power of women's groups. You will recall that in that play the women banded together to stop the war by withholding sex from the men. I was chastised for yet again placing the burden of control on women and relieving men of responsibility for safe sex. Will our societies fail to appreciate the need for accepting sexuality as intrinsic to being human and accept the need to instruct the young in this area, understanding that sexual development is as much a reality as is physical and spiritual development? Information has a role to play in the answer to all of these.

There is no doubt that the control of the epidemic requires the treatment of individuals as well as the treatment of populations, either of which may or may not be affected, but both of whom are at risk. The methods and approaches to the two groups are fundamentally different. The treatment of individuals centers on persons who are already ill, as well as preventing them becoming infected in the first place. We have drugs and care of various types for the former. In the case of populations we deal mainly with the prevention of illness and the attention is focused on the changes needed in societal behavior and the changing of societal norms that facilitate the spread of the epidemic. Unfortunately, the tendency is to focus on the individuals, both for treatment and behavioral change, often with an approach that smacks of victimization, instead of examining the societal milieu that facilitates or impedes individual change. This is not to depreciate the notion of individual agency, but to place equal if not more emphasis in this forum on environmental influence.

Some of the challenges to control the epidemic were addressed recently by a distinguished group of Caribbean experts.⁵ They highlighted stigma and discrimination as obstacles to HIV prevention. Another challenge was posed thus:

“One challenge confronting the Caribbean region is to gain a better understanding of the current scope and magnitude of its HIV epidemics and the underlying factors that contribute to their continued escalation. With this, it is important to ascertain the factors necessary for slowing down the progression of the HIV epidemic and, more aggressively, for reversing its impact”. They also identified as a challenge the need for “systematically documenting and gathering data and information”.

In the final analysis, it is information that leads both to individual change as well as to moving those levers that shift society and it is in this context that I see publishers and publishing playing a fundamental role and responding to the challenges that have been articulated. The simplistic answer to whether the publisher has a role is “yes” and it is equally simplistic to say that all that is needed is to produce material that contains important information and everything will be well. However, there is considerably more to be considered in defining a role for publishers.

I will deal more substantively with the positive benefit of published information, but information can both help and hurt. I have to recognize the harm that published information did in the early days of the epidemic, and the case of HIV/AIDS is as good an example as any as how data published by authoritative sources can have deleterious effects. Haitians were unjustly pilloried at the beginning of the epidemic. Various publications indicated that Haitians were more prone to infection and adduced that being Haitian was a risk factor for acquiring the disease. One paper in the prestigious *Annals of Internal Medicine* that described what we now know to be AIDS in a group of Haitians ended with the damning comment; “The fact that it (the disease) has occurred in a specific subpopulation is of epidemiologic significance.”⁶ One researcher from the US Centers for Disease Control is alleged to have said that AIDS sufferers belonged to a “4-H” club—Haitians, hookers, heroin users and homosexuals.⁷ Such is the power of the published word that these assertions not only stigmatized Haitians unfairly, but are said to have had a serious negative impact on their tourist industry.

There are several other publications that have subsequently been shown to be in error. One such established that the epidemic had no economic impact in Africa.⁸ In these examples the publisher was the conduit for false information, the validity of which must have been accepted because of the authority of the source. This shows the vulnerability of the publisher, who although taking all possible steps to ensure accuracy, can sometimes be led astray. The only solace is that there is no absoluteness about the truth as even Pilate would ask.

⁵ Strengthening the Caribbean Regional Response to the HIV Epidemic. Report of the Caribbean Technical Expert Group Meeting on HIV Prevention and Gender. Jamaica, 2004

⁶ PitchenikAE et al. Opportunistic infections and Kaposi’s sarcoma among Haitians: Evidence of a new acquired immunodeficiency state. *Annals of Internal Medicine*.98;277-284:1983

⁷ The Eighties Club. The AIDS Epidemic. <http://eightiesclub.tripod.com/id321.htm>

⁸ The economics of HIV and AIDS,. The case of South and South East Asia. Eds D Bloom and P Godwin. Oxford University Press 1997

But let us fast forward to today and examine the role you individually and as a group may play in the efforts to control the epidemic. I like the description which says that⁹

“The essence of professional publishing is that it identifies, verifies, shapes, packages and distributes the procedures and research developments in the world’s professions. The accumulation and refinement of this knowledge, through the ages, has facilitated the processes and construction of the infrastructure of civilization itself.”

I see the publishing process as assuming a responsibility for adding critical value to the material that is collected and submitted. This value is added through the process of careful editing, careful scrutiny of the accuracy of the material and so packaging, printing and marketing the product so that it has an effect. You will say that professional pride makes you do those things routinely as a part of your normal activities with any kind of material, so what is special about HIV/AIDS.

I believe that the special nature of your work in HIV/AIDS will derive from the social responsibility of publishers to be a part of the solution to this problem. One of the expected outcomes of this conference is that *“Publishers will become sensitized to the epidemic, its social and economic implications and their corporate responsibility in the face of the global plague”*.

The instrument of information you wield is so powerful and the epidemic of such seriousness that you cannot escape that responsibility. I see this social and corporate responsibility played out in several ways. I confess some trepidation in attempting this as when I entered Google and looked for the social role of publishers, I found 4.9 million entries. This must mean that there can be no doubt as to this role.

I see the role in terms of what and how you publish. It is clear that there are many facets to the problem, some of which are very sensitive indeed. I see you taking the decision not to avoid issues because they are sensitive and may evoke strong responses from various factions in society. I see you deliberately mining those issues that represent the factors that contribute to the escalation of the epidemic. I see you publishing scholarly material on matters like sexuality and the rationale for the homophobia that exists in the Caribbean. I see you exploring the anthropological issues that surround the perceptions or reality of male masculinity and the manner in which it is so expressed that it may affect HIV transmission. I see you addressing these issues as meriting scholarly discourse and abjuring the lurid presentations that sensationalize serious matters.

But the responsibility extends beyond what you publish. I posit that the responsibility makes for a more aggressive approach to obtaining publishable material in these fields. Is it inappropriate for you to seek out those persons who work in these fields and commission work from them? I know that much work on serious social issues tends to be consigned to the grey literature and not have the benefit of the rigorous process that you publishers employ as a normal

⁹ Dill JF. The creative role of the professional or STM publisher. International Publishers Association
<http://www.ipa-uie.org/trainings/dill.html>

part of your craft. So I am suggesting that you do not wait to be asked and courted, but acknowledge that the gravity of the issues require a more positive and direct approach to the sources.

The fact that so many of you are gathered here means that there is interest in the area. I have sometimes wondered if one could make a distinction in terms of interest between the for-profit commercial publishers and those who do not publish for profit. The former might target those populations that can afford their products, which in some circumstances may not be the group with the highest rate of infection. The not for profit publishers which by and large belong to organizations of civil society or institutions, might see themselves targeting the rest of the society, including the poorer segments which in the case of HIV is the group most likely to be infected. But in reality this is a false separation and the interests of both groups should merge, given the extent to which the epidemic is now affecting all segments of the society in one way or another.

I would prefer to see all scholarly publishing as one, and rather try to segment the target audiences for your products. I see you continuing to target the education sector and providing instructional material for several levels. I was privileged to be present at a launch of the book by Kelly and Bain on Education and HIV/AIDS in the Caribbean, published by Ian Randle.¹⁰ But there is much more to be done.

I was intrigued to read an excellent review by Michael Morrissey on the response of the education sector to the epidemic.¹¹ He makes the point that the education sector had until recently been unresponsive, but there was evidence of a recent change. In another very perceptive analysis of the Health and Family Life Education approach he noted that there had been little progress at the school level and Teachers' Colleges "*had not changed their training curriculum to reflect the need for HFLE.*" And please note the following comment. "*Commercial publishers of learning materials –the litmus test of school demand-had not published any instructional materials for HFLE or HIV/AIDS.* Publishers are the litmus test of the extent to which the education sector takes seriously its role in HIV/AIDS! This must be an enormous responsibility. I would not underestimate the difficulty of this task as the recent furor over what aspects of sexuality should be taught to children has demonstrated. But in addition there is need for scholarly work on education and HIV/AIDS and I hope that the recently created University chair in this area will spur the production of material that should be published.

Of course material will be needed in the health sector, and I see this going beyond the mere description of the disease and its manifestations. I would include material on the determinants of the illness and the social conditions that make for its spread and impede its control. There is a growing body of literature on the economics of HIV/AIDS which shows how badly we underestimated the economic consequences of the decrease in life expectancy that is projected if the epidemic does not abate. Other sectors will also need material. The tourism sector is all important in the Caribbean and the principals as well as the workers need to understand their roles in the prevention of the disease. Labor is a fertile field and the labor

¹⁰ Education and HIV/AIDS in the Caribbean. MJ Kelly and B Bain Ian Randle , Kingston and Miami

¹¹ Morrissey M. Response of the education sector in the Commonwealth Caribbean to the HIV/AIDS epidemic: A preliminary overview. International Labor Office, Geneva, April 2005.

institutions have already become painfully aware of the relation of HIV to business and the extent to which its control is a workplace issue. We plan to hold a major Caribbean consultation on business and HIV/AIDS in October in which we will stress not only the standard philanthropic approach of business to HIV, but try to emphasize that there are skills which business possesses and are uniquely theirs that can be brought to bear on the epidemic.

There is proper emphasis on the production of accurate, relevant materials by the publishers, but I would not wish you to neglect that other role of the publisher in ensuring that the materials do get to the places in which they will do the most good. It is essential that you pay attention to the marketing aspect of your trade, and I would single out the policy makers and senior managers in the Caribbean for targeting. There has been a very positive demonstration of resolve by the leading politicians of the region, but this interest must be fanned and kept alive. Senior officials in all the sectors must understand that the control of the epidemic is everybody's business. Thus the material must not only be published, but it must be marketed and advertised through the channels you know so well.

Finally, let me refer to the aspect of cooperation in publishing in the field of HIV/AIDS. If you accept that there is a shared social responsibility, and given the fact that the epidemic is global, then there is logic to international cooperation. One usually thinks of international cooperation in terms of nation states cooperating among themselves to pursue some common aim. But with the growth of state pluralism, we recognize many actors within the state and we extend the notion of international cooperation to joint action among them. There is much to learn from the diversity of the milieus in which HIV/AIDS exists, but there is one commonality. In no society, at least in no democratic society will one effect sustainable change without the effective use of information.

Mr. Chairman, I encountered another very good definition of publishing in an advertisement for a postgraduate degree in Publishing Studies.¹² It said:

"Publishing is an industry of the intellect that requires clear, critically trained thinkers of high caliber equipped with transferable skills of analysis, perception and presentation".

I am sure these skills are here in abundance and I trust that you will employ in grappling with the role that you should, can and must play in the efforts to control this modern plague.

I thank you.

¹² MA in Publishing Studies Department of Journalism, City University, London.
<http://www.city.ac.uk/journalism/courses/postgrad/publishing>