Human Development

Democratizing HIV Communication

Information and communication are the key assets within the global knowledge economy. Economic growth, market access, and the ability to manage risk correlate directly with the rapidity and breadth of information access and the availability of appropriate communication channels (Stiglitz, econlib.org). It would be helpful for economists recognizing the value of information and genuine two-way communication to argue for its importance within the fight against HIV/AIDS, particularly to donors intent on proving "bang for buck." We know that despite the optimistic buzz around the potential of new information and communication technologies, "the global gap between have-nots, and know and know-nots deepens" (Human Development Report 1999). The same applies to knowledge and communication on AIDS. There remain serious divides and disconnects between those creating AIDS information and agendas and those silently affected. Using parallels with the role of information in broader society, this article makes a start at showing how the media can democratize, illuminate and energize the response to the pandemic.

Empowering by information

The Biennial 15th International AIDS Conference in Thailand, 2004 centers, around the theme "Access For All". "Access" is not only about AIDS care, treatment and prevention services. Access for all should encompass access to information, and access to platforms to air views and health priorities, particularly those of the most affected. Those working for an independent, critical and responsive media on AIDS hopefully will adopt and rally behind this slogan.

Development economists write of the "information rich" and the "information poor" (Zielinski 2001). The pattern of HIV distribution neatly echoes the distribution of information and communication access. It is the communities most disenfranchised with the information society that bear the brunt of the AIDS epidemic, including the poor, the displaced, sex-workers, young women, migrants, and others. The patterns of poor health, and poor information opportunity are often the result of more fundamental social and political economic inequities. "AIDS moves through the fracture points of society" (Farmer 1992), consistently affecting those already disadvantaged through inequitable gender,
social, or economic relations. Media and communication can bridge these divides. The ability to communicate, to create and receive information, and to share perspectives is central to advocacy, activism, and civil society participation.

The relationship between AIDS and information access is not entirely straightforward. The highly networked, such as business elites, politicians, and others prosperous within the information economy, are often also heavily affected by AIDS. But partly through access to information and the right to speak out, HIV amongst these groups remains less prevalent, and less immediately associated with disease and fatality. The early fight for rights, treatment, care, and prevention of AIDS amongst the gay community in the north shows how communication can mitigate the impact of the epidemic.

Mobilizing civil society

A common question in health policy circles is “how can we mobilize civil society?” Too often the answer centers only on pushing out information. The more appropriate question for health policymakers would be “how do we enable civil society to mobilize us?” This is particularly true in countries with weak infrastructure, poor governance, stifled media, and meager resources. And part of the answer to this question is to support media capacity, growth, and freedom to engage with AIDS (Carrington 2002).

In countries facing, or about to face, the brunt of the AIDS pandemic, the media is changing fast. Privatization, globalization, and deregulation of the media industries have transformed the informational landscape. This media information revolution increasingly provides opportunities for a multitude of perspectives to be aired. These changes are characterized by multiple sources of information, including growing numbers of local radio stations and print publications. These are increasingly privately owned in countries once dominated by the state media. There is television in places where there was none before, with multiple, usually commercial channels where once there was only one. The new technologies of the Internet and mobile telephony are also changing how people communicate. In place of limited information coming from a few authoritative sources, many messages are now passed between growing numbers of individuals and organizations in increasingly networked societies. It has become far more difficult to target information and fewer sources are automatically accepted as authoritative.

Just as within broader economic terms, businesses, governments and other institutions depend not only upon hearing but also on being heard for their success (Branscomb 1994), so too do those within the information economy around HIV/AIDS. Placing HIV within an information economy allows us to draw upon and leverage the resources of economic discourse. More importantly, it lays out within a simple, apolitical logic the importance of bottom-up communication, as well as top-down information dissemination. This information economy features have-nots and have-nots, the empowered and the disempowered. It features a currency of life saving information and a monopoly on who produces and transmits it. The Bush administration’s approach to AIDS prevention, focusing around abstinence, is a useful case in point. To what extent did this U.S. policy direction sublimate a domestic agenda to enable southern voices to emerge? How would this be read in terms of an AIDS information economy of haves and have-nots? Other donors, the UN and civil society are often also culpable of paying insufficient attention to the importance of empowerment of the voices of those most affected.

Donors, international NGOs, the UN, and others in the forefront of the response are unlikely to be wittingly seeking to control the discourse that shapes the response to HIV/AIDS. Yet in the battle to generate and disseminate AIDS messages and agendas, those high-disease burdened countries and communities at the receiving end are too rarely and insufficiently empowered to speak out on this issue (Scalway 2003). Where those most affected can use media and other communication channels to demand better services, life-saving drugs, and basic rights in relation to health, remarkable successes can follow. The work of the Treatment Access Campaign in South Africa is a notable example.

Creating networks

Networking the AIDS community involves creating connections across some of the political, social, and gender inequalities that fuel the epidemic (Panos/UNFPA 2001). There is potential for the changes
in the contemporary media environments to make this happen through greater pluralism, access to information, and democratization. But these changes also bring about a highly advertising-driven and commercial media, often prone to sensationalism. There has been an explosion of radio stations in many developing countries and an associated upsurge in talk radio. Discussion programs, phone-ins and other talk-based formats are increasingly popular and provide some of the most powerful examples of development programming. This format brings greater equity to the production of knowledge and understanding about HIV/AIDS. Stories told by HIV positive people, sympathetically treated on a radio program, can arguably have far more effect than more conventional communication messages, and there are many examples of this happening (see Soul City example on www.comminit.com).

Community media, particularly community radio and the telecenter movement, offer useful entry points for this horizontal or bottom-up communication, but still receive little support within the context of HIV/AIDS. Partly because of ease of start-up, and ease of access, online communities offer a range of horizontal communication models amongst special interest groups, yet they are only starting to connect those who were hitherto out of touch. Africa only accounts for one percent of Internet usage for example. Empowering more marginalized groups living with HIV, particularly the rural poor, to enter into private dialogue or public debate about the response remains an imposing challenge. Despite traditional and faith-based community networks, innovations such as neighborhood health committees (Zambia Integrated Health Project 2004), and increasing access to broadcast media, the majority of those currently living with HIV may never have the means to meaningfully air their views to their publics and to their policymakers.

The “Access for All” theme needs to be seized upon by those working with AIDS and communication. Access to information, access to public debate, and access to a media that can speak for, to and across communities are all good rallying calls. All of us working with or for the media could usefully apply this slogan to bringing the communities most affected by HIV/AIDS into the discourses that determine the response.

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References


