Both Medium and Message: HIV/AIDS, Information and Communication in Africa

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ABSTRACT

The African AIDS epidemic continues to pose severe public health and developmental problems for many African nations. A primary impediment in the fight against AIDS is a lack of information and communication about the disease. Information and communication, as well as information and communication technologies (ICT) hold vast potential to hinder the spread of the disease, as key elements of all aspects of HIV/AIDS strategies, including prevention, treatment and care and protection of human rights. They offer potential solutions to misinformation and myths, silence and denial, and stigma and discrimination against people living with HIV and AIDS (PLWHA). They are also key to a civil society response to the epidemic, enabling advocacy, mobilization, empowerment, participation and facilitating greater accountability. The non-technological and human enablers of communication and information offer comparatively abundant resources, and the participation of PLWHA and communities are critical to the success of AIDS strategies, depending on effective information and communication. This paper broadly examines the role of information and communication in the fight against AIDS on the African continent. Part One describes the nature and scale of, and responses to, the AIDS epidemic. Part Two describes the current status of ICT across the continent. Part Three explores the use of information and communication in the fight against HIV/AIDS, describes both national and international HIV/AIDS and ICT initiatives being conducted in various African countries, and identifies challenges and opportunities for civil society. Finally, the paper identifies guiding principles and recommendations for the future.

ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
CD-ROM	Compact Disc Read Only Memory
CIDA	Canadian International Development Agency
CSO	Civil Society Organization

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ICAD	Interagency Coalition on AIDS and Development
ICT	Information and Communication Technologies
HIV	Human Immunodeficiency Virus
NEPAD	New Partnership for African Development
NGO	Non-Governmental Organization
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission
STD	Sexually Transmitted Disease
TAC	Treatment Action Campaign
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Testing and Counseling

INTRODUCTION

During the eighties, American AIDS advocates co-opted the phrase "silence equals death" from the environmental movement to describe the danger of a lack of information and communication around HIV/AIDS. On a continent where generalized epidemics are the norm and infection rates continue to climb, the African AIDS epidemic embodies and amplifies the continuing truth of this statement. Here, a lack of information and a lack of voice continue to be primary causes of infection among the worst affected groups of women and youth.

More effective communication about the disease and greater flow of information are central to the success of AIDS strategies and to reducing vulnerability to HIV infection. Information and communication are sources of power in an epidemic characterized by a lack thereof: they confer the power to protect against infection, to influence decision makers, and to live lives of dignity and equality once infected. In a region often characterized by resource limitations and fragmented infrastructures, information and communication are two of the most critical and abundant resources available in the fight against HIV/AIDS. They are both the prerequisites and enablers of an effective response.

There is now considerable consensus that an effective response to the epidemic should be a comprehensive one, requiring prevention, treatment, and the protection of human rights. These elements are part of a continuum, with prevention enhanced by the availability of treatment, which in turn reduces the stigma of an illness perceived to be a death sentence. Effective prevention also relies on the reduction of vulnerability to infection, in high-risk groups like women and youth, through the protection of human rights and other means. Information and communication are central threads running

throughout this response, providing both form and content to prevention, treatment, and vulnerability reduction.

While resource limitations and infrastructural gaps hamper both extensive ICT connectivity and significant scaling up of a comprehensive response to HIV/AIDS, the African continent is rich in the human resources and initiative necessary to enable an effective response to HIV/AIDS. This is evidenced by successes in countries with falling infection rates like Uganda, Senegal, and Zambia, and in the multitude of civil society and community projects that are having tremendous local impact throughout the continent. These examples illustrate that in countries with massive infection rates and limited financial resources, strong leadership and the participation and involvement of all social and economic sectors – especially affected communities – are critical elements of an effective response to HIV/AIDS. This participation is largely dependent on the free flow of information and communication.

Nonetheless, significant obstacles to effectiveness remain: limited resources, stigmatization and discrimination of PLWHA, a lack of information to enable appropriate behavioral changes and to counter the dangerous social consequences of misinformation and myths about the disease, and continuing social and political silence and denial about the disease. There are also continuing political and legal battles over the ability of developing countries to take all measures necessary to procure and provide essential HIV/AIDS medicines. Information and communication offer potential solutions to many of these obstacles.

Information and communication (and the technologies that facilitate them) are also key elements of a civil society response to the epidemic, enabling advocacy, mobilization, and empowerment of PLWHA, women, and other vulnerable groups. ICT also increase democratic participation and provide greater accountability of national and international decision makers.

Technology vastly enables information and communication, which, in addition to offering an effective medium, are themselves sources of empowerment and human and economic development. ICT offer a multidirectional flow of information, as well as mechanisms of communication capable of assisting in the fight against AIDS in a variety of ways.

This paper broadly examines the role of information and communication in the fight against the AIDS epidemic on the African continent. The paper is intended to increase understanding of how information and communication offer key resources in relation to HIV/AIDS, and to suggest key actions that both AIDS CSOs and information and communication CSOs can take to assist in combating

HIV/AIDS. The paper's structure is as follows: Part One describes the nature and scale of, and responses to, the AIDS epidemic on the African continent. Part Two briefly describes ICT, Africa's information society and digital divide, and the current status of ICT across the continent. Part Three explores the use of information and communication and their technologies in the fight against HIV/AIDS, describes both national and international HIV/AIDS and ICT initiatives being conducted in various African countries, and identifies challenges and opportunities for civil society. Finally, the paper identifies guiding principles and recommendations for the future.

PART ONE: THE HIV/AIDS PANDEMIC IN AFRICA

Close to twenty million people around the world have died from AIDS since the epidemic first began,[1] and millions more are becoming ill and dying every year. Despite the global reach of the epidemic, the vast majority of infections are in sub-Saharan Africa. In 2004, 25.4 million people were living with HIV/AIDS in this region.[2] In 2003, approximately 4.8 million people became infected and 2.9 million people died.[3] In 2002, nearly eleven million children orphaned by AIDS were living in Sub-Saharan Africa.[4] The projected loss of life is enormous: in 2002, in response to HIV/AIDS the UN Population Division lowered earlier global population estimates for 2050 by two hundred million people.[5]

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[1] UNAIDS, *Report on the Global AIDS Epidemic*, at 23 (2004), *available at* http://www.unaids.org/wad2004/EPI_1204_pdf_en/EpiUpdate04_en.pdf (last visited Jan. 24, 2005) [hereinafter UNAIDS 2004].

[2] UNAIDS & World Health Organization, *AIDS Epidemic Update*, at 3 (2004), *available at* http://www.unaids.org/NetTools/Misc/DocInfo.aspx?href=http%3A%2F%2Fwww%2Eunaids%2Eorg%2Fwad2004%2FEPIupdate2004%5Fhtml%5Fen%2Fepi04%5F00%5Fen%2Ehtm (last visited Jan. 24, 2005) [hereinafter AIDS Epidemic Update].

[3] UNAIDS 2004, *supra* note 1, at 23.

[4] UNAIDS, *Report on the Global HIV/AIDS Epidemic*, at 23 (2002), *available at http://www.unaids.org/NetTools/Misc/DocInfo.aspx?href=http%3A%2F%2FGVA%2DDOC%2DOWL%2FWEBcontent%2FDocuments%2Fpub%2FGlobal%2DReports%2FBarcelona%2FBRGlobal%5FAIDS%5FReport%5Fen%2Epdf* (last visited Jan. 24, 2005) [hereinafter UNAIDS 2002].

[5] Press Release, UN Population Division, Below-Replacement Fertility Expected in 75 Percent of Developing Countries By Year 2050 According to UN Population Report (Feb. 26, 2003), http://www.un.org/News/Press/docs/2003/pop850.doc.htm (last visited Nov. 30, 2004).

High-prevalence countries are experiencing dramatic drops in life expectancy, the ill and the dying are overwhelming already strained public health services, and millions of children are being orphaned, often without adequate social safety nets. HIV/AIDS deepens household poverty, "threatens development, social cohesion, political stability, food security[,] and life expectancy[,] and imposes a devastating economic burden."[6]

Without effective reduction of its spread and impact, the epidemic will slash human and economic development on the continent, and undermine the aspirations – expressed in the Millennium Development Goals[7] and by the New Partnership for African Development (NEPAD) – to vault Africa forward into a renaissance of development and reduced poverty.[8] The unmet needs of the epidemic are a colossal crisis and challenge for African states and the international community. The urgency of the situation requires that all effective strategies be utilized to reduce infections and to care for those infected, orphaned, or otherwise affected by the disease. To do so demands "urgent and exceptional national, regional[,] and international action."[9]

As a prelude to the main discussion of the role of information and communication in combating HIV/AIDS, the following section sketches key features of the African epidemic, as well as the elements of and obstacles to an effective response.

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[6] "Declaration of Commitment on HIV/AIDS," G.A. Res. S-26/2, U.N. GAOR, 26th Special Sess., 8th plen. mtg,, Annex, Agenda Item 8, ¶ 8, U.N. Doc. A/RES/S-26/2 (2001), *available at* http://www.unaids.org/NetTools/Misc/DocInfo.aspx?LANG=en&href=http://gva-doc-owl/WEBcontent/Documents/pub/Publications/External-Documents/GAres26-2_en.pdf [hereinafter UNGASS].

[7] At the United Nation's Millennium Summit in September 2000, heads of state reaffirmed their commitment to working toward a world in which sustaining development and eliminating poverty would have the highest priority. See The World Bank Group, *Millennium Development Goals*, *at* http://www.developmentgoals.org/About_the_goals.htm (last updated Sept. 2004) [hereinafter *MDG*], under which all states undertook time-bound goals and targets with respect to poverty reduction and improved development.

[8] NEPAD is a program of action for the re-development of the African continent, conceived and developed by African leaders. The goals of NEPAD are to promote accelerated growth and sustainable development, to eradicate widespread and severe poverty, and to halt the marginalization of Africa in the globalization process. It provides goals and action plans in seven areas: political governance, economic governance, market access and agriculture, human development, infrastructure, science and technology, and environment and tourism. See NEPAD, *About Nepad – Nepad in Brief*, *at* http://www.nepad.org/en.html (last visited Dec. 1, 2004).

[9] UNGASS, *supra* note 6, at ¶ 8.

1. THE SIZE AND SPREAD OF HIV/AIDS IN AFRICA

HIV in Africa is primarily transmitted through sex, which is largely heterosexual.[10] A significant secondary cause of infections is mother to child transmission of the virus during labor or breastfeeding, with a small additional percentage caused by unsafe injection practices.[11]

Regional disparities in HIV prevalence are significant. Northern Africa has the lowest rates of infection on the continent, with adult infection rates maintaining at and under 2.6 percent.[12] In Sub-Saharan Africa in 2003, approximately twenty-nine million people were living with HIV/AIDS, including ten million young people aged fifteen to twenty-four, and three million children under fifteen.[13] More troublingly, the epidemic continues to grow there: in 2002 over seventy percent of new infections worldwide occurred in this region.[14]

Epidemics in Southern and Eastern Africa are generalized, affecting almost every segment of society.[15] In East Africa in 2001, rates were at or over five percent in Uganda, Ethiopia, Tanzania, Congo, Burundi, and Rwanda, and at fifteen percent in Kenya.[16] Ethiopia displays rapid increases in infection, with the 2002 estimate

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[10] Global HIV Prevention Working Group, *Access to HIV Prevention: Closing the Gap*, at 8 (2003), *available at* http://www.kff.org/hivaids/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=14225 (last visited Jan. 20, 2005) [hereinafter Global Working Group].

[11] *Id.*

[12] UNAIDS 2002, *supra* note 4, at 198 (indicating that Egypt is at less than 0.1 percent, Algeria and Morocco are at 0.1 percent, that Libyan Arab Jamahiriya is at 0.2 percent, and that Sudan is at 2.6 percent, but providing no information on prevalence rates for Tunisia).

[13] Global Working Group, *supra* note 10, at 7.

[14] Symposium, Monitoring the AIDS Pandemic (MAP), *The Status and Trends of the HIV/AIDS Epidemic in the World*, at 10 (2002), *available at* http://www.mapnetwork.org/docs/barcreport.doc (last visited Dec. 1, 2004) [hereinafter MAP].

[15] Global Working Group, *supra* note 10, at 7; *see also* TONY BARNETT & ALAN WHITESIDE, AIDS IN THE TWENTY-FIRST CENTURY: DISEASE AND GLOBALIZATION 98 (2002) (a generalized epidemic is one which has spread far beyond the original sub-populations with high-risk behavior, and in which prevalence among women attending urban antenatal clinics is five percent or more).

[16] UNAIDS 2002, *supra* note 4, at 190.

of 2.7 million infections expected to escalate to seven to ten million by the end of the decade.[17]

Although epidemics in West and Central Africa are comparatively less severe, they are still extremely high, and continue to grow. Rates in 2001 in Cote D'Ivoire, Sierra Leone, and Burkina Faso were over five percent, and in Cameroon and Central African Republic were over ten percent.[18] In 2002, there was also evidence of rapid HIV spread in the most populous country in Africa, Nigeria, which has the third largest African epidemic.[19] Nigeria's epidemic is projected to grow to ten to fifteen million people — approximately one-quarter of the adult population — by 2010.[20]

In 2001, there were also troubling increases in Angola among pregnant women attending antenatal clinics in the capital, Luanda.[21] This trend is distressing because Luanda is a refuge for tens of thousands of people displaced by war, which significantly increases vulnerability to infection by disrupting social and governance systems.[22] A similar trend may occur in the countries of the Great Lakes region, including Burundi, the Democratic Republic of Congo, and Rwanda.[23]

The countries in Southern Africa are the worst affected on the continent, with prevalence rates in 2001 of over ten percent in Malawi and Mozambique, over twenty percent in Namibia, Zambia and South Africa, and over thirty percent in Botswana, Zimbabwe, Swaziland, and Lesotho.[24] Regionally, Botswana has the highest population percentage of infections (38.8 percent of the population), but South

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[17] U.S. National Intelligence Council, *The Next Wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India and China* (Sept. 2002), *available at* http://www.cia.gov/nic/special_nextwaveHIV.html (last visited Dec. 1, 2004) [hereinafter Next Wave].

[18] UNAIDS 2002, *supra* note 4, at 190.

[19] MAP, *supra* note 14, at 11.

[20] Next Wave, *supra* note 17.

[21] UNAIDS 2002, *supra* note 4, at 27.

[22] *Id.*

[23] *Id.*

[24] *Id.* at 190.

Africa has the highest number of infected persons of at least five million.[25]

2. DEMOGRAPHICS AND DETERMINANTS OF THE AFRICAN AIDS EPIDEMIC

Despite these frightening numbers, the vast majority of people living with HIV/AIDS do not know they are infected. There is limited access to preventive services such as voluntary testing and counseling services and PMTCT, and little incentive to be tested given the pervasive stigma and discrimination associated with the disease and the lack of accessible treatment.

While a failure to engage in safe sex explains why the disease has spread, this failure does little to explain the social and economic determinants of such behavior. A lack of information continues to be a primary stumbling block, which together with several other factors limits the effectiveness of efforts to counter the spread and impact of the disease. These factors include stigma, discrimination, silence and denial about the disease, poverty, inequality, gender inequities, militarization, war, conflict, and sexually transmitted diseases. High mobility is another primary risk factor for infection, as seen in the extremely high infection rates among refugees, migrant workers, and truck drivers who operate along commercial routes. There are also extremely high rates of infection among sex workers in Africa, particularly those who work commercial transport routes.

2.1 WOMEN AND YOUNG PEOPLE ARE AT HIGHEST RISK IN THE REGION

In Sub-Saharan Africa, women account for fifty-seven percent of all HIV infections, and young women aged fifteen to twenty-four are three times more likely to be infected than young men of the same age.[26] These differential rates are largely explained by the gender inequities now understood to be "driving the epidemic in Sub-Saharan Africa, as women who lack economic independence, educational opportunities, and access to health information and services often have difficulty avoiding exposure to the virus."[27]

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[25] *Id.*

[26] AIDS Epidemic Update, *supra* note 2, at 7.

[27] Global Working Group, *supra* note 10, at 8.

The heightened risk of infection amongst women and girls is exacerbated by physiological vulnerability to infection, as well as limited access to prevention options and health services, legal disenfranchisement, diminished educational opportunities, sexual violence, sexual trafficking, and inter-generational sex.[28] Poverty is another risk factor for women, forcing many into sex work and "placing them at high risk of contracting HIV and transmitting the virus to their sex partners."[29]

The young are also at extraordinarily high risk of infection: in 2001, half of all new infections – over seven thousand daily – were found in young people.[30] This vulnerability is due to risky sexual behavior and a lack of access to HIV information and prevention services. Despite the generalized nature of the epidemic in countries across Sub-Saharan Africa, many young people in the region still do not know how to protect themselves from HIV. Reports on levels of accurate information among youth about HIV/AIDS are startling: in 2001, half of the teenage girls in sub-Saharan Africa did not realize that a healthy-looking person can be living with HIV/AIDS.[31]

In 2002, "in countries with generalized HIV epidemics, such as Cameroon, Central African Republic, Equatorial Guinea, Lesotho, and Sierra Leone, more than [eighty] per cent of young women aged [fifteen] to [twenty-four did] not have sufficient knowledge about HIV."[32] In Botswana, where one in three sexual partners has HIV, "[two-thirds] of young people in their last year of primary school...thought they could tell if someone was infected with HIV by looking at them. By secondary school, a fifth of the pupils still believed they could screen out risky partners by looks alone."[33]

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[28] *Id.* at 12.

[29] *Id.* at 8.

[30] UNAIDS, *Children and Young People in a World of AIDS*, at 2 (2001), *available at* http://www.unaids.org/NetTools/Misc/DocInfo.aspx?href=http%3A%2F%2FGVA%2DDOC%2DOWL%2FWEBcontent%2FDocuments%2Fpub%2FPublications%2FIRC%2Dpub02%2FJC656%2DChild%5FAids%5FEn%2Epdf (last visited Jan. 20, 2005).

[31] *Id.*

[32] UNAIDS, UNICEF, WHO, *Young People and HIV/AIDS: Opportunity in Crisis*, at 13 (2002), *available at* http://www.unaids.org/NetTools/Misc/DocInfo.aspx?href=http%3A%2F%2Fgva%2Ddoc%2Dowl%2FWEBcontent%2FDocuments%2Fpub%2FTopics%2FYoung%2DPeople%2FYoungpeopleHIVAIDS%5Fen%2Epdf (last visited Jan. 20, 2005).

[33] *Id.*

"Surveys from [forty] countries indicate that more than [fifty] per cent of young people aged [fifteen] to [twenty-four] harbour serious misconceptions about how HIV/AIDS is transmitted." Such misconceptions vary from one culture to another, regarding "both on how HIV is spread (by mosquito bites or witchcraft, for example) and on how it can be avoided (by eating a certain fish, for example, or having sex with a virgin)."[34] "Virgin rape" of young boys and girls, and even infants, is a particularly abhorrent offshoot of these myths and misinformation; however, this myth very infrequently accounts for the extent of child and infant rapes occurring.[35]

2.2 STIGMA, SILENCE, DENIAL AND HUMAN RIGHTS VIOLATIONS

In all regions and at all times, HIV/AIDS has been characterized by pervasive prejudice and stigma. People infected – or thought to be so – have routinely experienced social and political isolation and marginalization, and have often been abandoned and expelled by families and communities, or subjected to intimidation and violence. This prejudice has been a direct cause of pervasive human rights violations against PLWHA, particularly in the form of systemic discrimination and breaches of privacy rights. Although some countries now provide explicit legal protection for PLWHA,[36] there is ongoing discrimination against PLWHA, including in health care and employment.[37]

This stigma and discrimination has complex and multiple causes. UNAIDS reports that the stigma is:

> triggered by many forces, including lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment, irresponsible media reporting on the epidemic, the fact

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[34] *Id.*

[35] *The "Virgin Myth" and Child Rape*, 33 MEDICAL RESEARCH COUNCIL NEWS No. 2, (Apr. 2002), *at* http://www.mrc.ac.za/mrcnews/april2002/virgin.htm (last visited Dec. 2, 2004).

[36] See, e.g., Fatima Rahiman for AIDS Law Project, *Regional Audit on HIV/AIDS, Human Rights and Other Relevant Issues*, at 8 (2000), for a discussion of explicit legal protections for PLWHA in South Africa, *available at* http://dedi20a.your-server.co.za/alp/images/upload/HIV.AIDS%20Audit.doc (last visited Feb. 7, 2005).

[37] Peter Aggleton & Richard Parker for UNAIDS, *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination* at 11 (2002), *available at* http://www.dec.org/pdf_docs/PNACP852.pdf (last visited Jan. 20, 2005).

> that AIDS is incurable, social fears about sexuality, fears relating to illness and death, and fears about illicit drugs and injecting drug use.[38]

The stigma attached to the disease, and the direct negative consequences attached to being HIV positive, perpetuate a persistent social and often political silence about and denial of HIV/AIDS. In high-prevalence developing countries, silence and denial are deepened by the fear of being ill without accessible and effective health care. In this atmosphere, people are unlikely to be receptive to prevention messages, and have little incentive to be tested.

Silence and denial considerably limit effective availability of communication and information about the disease amongst the individuals and communities most at risk. This is exacerbated when national, community, and religious leaders and policy-makers collude with social silence and denial, and deny both the existence of the problem and the fact that it requires urgent action.[39] The silencing effect is such that those infected "feel guilty and ashamed, unable to express their views[,] and fearful that they will not be taken seriously."[40] Fear of being openly HIV positive is particularly damaging to efforts to normalize the consequences of infection, and significantly limits the participation of PLWHA in AIDS programs.

In these and other ways, silence and denial pose tremendous obstacles to mounting an effective response to the epidemic by limiting prevention, treatment, and impact alleviation, and increasing vulnerability to infection. In addition to legal protections and strong leadership, the free flow of information and communication is critical to overcoming the constrictive vise which silence, denial, and discrimination place on appropriate responses to the epidemic.

This is to say nothing of the *kind* of information and communication that would effectively ensure behavioral change within discriminatory and stigmatizing social and political contexts. The nature of health information and communication and methods of dissemination are clearly critical to their success in achieving behavioral changes. This paper does not, however, focus on this issue, but instead delves more intensively into the broader discussion of the

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[38] *Id.* at 5.

[39] *Id.*

[40] *Id.*

role that information and communication can play in combating HIV/AIDS in Africa.

3. REGIONAL AND GLOBAL COMMITMENTS AND CONSENSUS ON AN EFFECTIVE RESPONSE TO THE EPIDEMIC

In recognition of the gravity of the global and particularly African epidemic, there have been a number of regional and global declarations and commitments to taking greater and more effective action on HIV/AIDS.

At the United Nations Millennium Summit in September 2000, heads of state and governments pledged to halt and begin to reverse the spread of HIV/AIDS by 2015.[41] This commitment was echoed on the African continent in April 2001, when members of the Organisation of African Unity signed the *Abuja Declaration on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases*. In the declaration, HIV/AIDS was declared a state of emergency on the continent, and countries committed to take personal responsibility and to provide leadership in the fight against HIV/AIDS, setting specific goals such as allocating at least fifteen percent of annual budgets to the improvement of the health sector.[42]

These commitments reached their global zenith in June 2001, when the member states of the United Nations General Assembly met in a Special Session (UNGASS) on HIV/AIDS. One hundred and forty two countries adopted a declaration to "secure a global commitment to enhancing coordination and intensification of national, regional[,] and international efforts to combat [HIV/AIDS] in a comprehensive manner."[43]

The UNGASS declaration reflects several new understandings about the epidemic. First, an effective response will be a comprehensive one, and effective prevention relies in fundamental ways on the availability of treatment and care. Second, the declaration recognizes the need for targeted interventions aimed at all high-risk groups, especially young people and women. Third, the declaration recognizes that the effectiveness of HIV/AIDS prevention and

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[41] *MDG*, *supra* note 7.

[42] *Abuja Declaration on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases* at 4-5 (2001), *available at* http://www.un.org/ga/aids/pdf/abuja_declaration.pdf (last visited Jan. 20, 2005).

[43] UNGASS, *supra* note 6, ¶ 1.

treatment programs also relies on addressing underlying causes of the epidemic, especially gender inequality, as well as poverty, lack of information, and vulnerability to human rights violations. Fourth, the declaration reflects the growing recognition that community mobilization is the core strategy on which successful campaigns against HIV/AIDS have been built, with PLWHA participation being a crucial component. This kind of mobilization is dependent upon "eliminating stigma, developing partnerships between social and government actors, and systematically involving communities and individuals infected and affected by HIV/AIDS."[44]

Notably, countries party to the declaration committed to time-bound targets and goals in all primary areas of importance in the epidemic, including: leadership, prevention, support and treatment, human rights, reducing vulnerability, attending to orphans, alleviating social and economic impact, attending to HIV/AIDS in conflict and disaster affected regions, increasing available resources, and research and development.[45]

Some of these targets included ensuring that at least ninety percent of young people aged fifteen to twenty-four have access to information, education, and services necessary to develop the life skills needed to reduce their vulnerability to HIV by the year 2005, raising this level to ninety-five percent by 2010, empowering women as an essential part of reducing vulnerability to HIV, and, by 2003, effecting national strategies to strengthen health-care systems and address factors affecting the provision of HIV-related drugs, including antiretroviral drugs.[46]

4. THERE IS HOPE, BUT THE AFRICAN AND GLOBAL RESPONSE REMAINS INSUFFICIENT

There are stories of success and hope emerging from African countries like Uganda, Senegal, and Zambia, which illustrate the potential for governments, communities, and individuals to take positive and effective action against the epidemic. Uganda is the first African country to have restrained a serious HIV/AIDS epidemic, with

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[44] UNAIDS 2002, *supra* note 4, at 16.

[45] UNGASS, *supra* note 6.

[46] UNGASS, *supra* note 6, ¶¶ 53, 55.

declining HIV prevalence seen since the early 1990s.[47] More recently, Zambia has seen decreases in HIV prevalence among fifteen to twenty-nine year old urban women.[48] In addition, "urban men and women [are] reporting less sexual activity, fewer multiple partners[,] and more consistent use of condoms."[49]

Despite these isolated successes, new HIV infections continue to occur in almost all countries, and the impact of the epidemic on individuals, families, communities, and regions continues to grow. This increase is hardly surprising given the limited scale of prevention, and even more limited scale of treatment on the continent. It is reported that mass media awareness programs in Africa reach only forty-three percent of people at risk.[50]

There are particularly troubling indications that current HIV/AIDS programs are failing among the highest-risk groups in the epidemic. In 2003, "more than one-half of all young people (ages [fifteen to twenty-four]) in more than a dozen countries (primarily African) [had] never heard of AIDS or [had] serious misconceptions about how HIV is transmitted."[51] "Only [eight percent] of out-of-school youth and a little more than [one-third of in-school youth [had] access to prevention programs."[52] The remainder of prevention priorities were being met in similarly limited fashions: "[f]ewer than one in [twelve] sex workers and their clients [were being] targeted by behavioral programs;" only fourteen percent of people in need of STD treatment could obtain it; and only six percent of people who wanted VCT had access to it.[53]

Access to HIV/AIDS treatment throughout Africa is even more severely limited than access to STD treatment or VCT: until approximately 2003, less than one percent of people with HIV/AIDS had access to antiretroviral medicines, and less than five percent had

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[47] *Id.* at 24 (showing that HIV prevalence among pregnant women in Kampala fell for eight years in a row - from 29.5 percent in 1992 to 11.25 percent in 2000).

[48] *Id.* at 26 (showing declines from 28.3 percent in 1996 to 24.1 percent in 1999).

[49] *Id.*

[50] Global Working Group, *supra* note 10, at 10.

[51] *Id.*

[52] *Id.* at 9.

[53] *Id.*

access to treatments for opportunistic infections.[54] Although recent years have seen dramatic price reductions, the drugs remain prohibitively expensive for many developing countries. By late 2004, access to HIV/AIDS treatment had increased to approximately eight percent largely due to reduced drug prices and increased technical and financial assistance.[55] While African countries are increasingly moving towards introducing these drugs into their public health sectors, broader access than current levels will take many years to achieve given medicine prices, limited resources, and infrastructural limitations within public health sectors.

A lack of affordable treatment is not only a tremendous injustice, but an obstacle to an effective response to the epidemic. Treatment is one of the greatest possible incentives for people to be tested, thereby bringing them into contact with preventive messages and services.

These deficiencies in a comprehensive response are only partially explained by a lack of resources. Despite commitments to the contrary, many nations have simply failed to prioritize the epidemic as the emergency it is, and leadership and political will — which are not resource intensive commodities — remain insufficient.

However, an effective response is not the sole responsibility of government, nor is it entirely dependent on resources. All members of society bear some responsibility, including the media, communities, the private sector, religious leaders, and public sector employees such as health care workers and educators. In particular, civil society and PLWHA organizations play a critical role in driving appropriate AIDS policies and programs. AIDS advocacy among PLWHA and human rights groups has always been a fundamental element of the fight against HIV/AIDS, depending for success upon the enforcement of legal protections, the effective use of mass media, and the mobilization of communities, PLWHA, and all civil society to ensure that governments and other relevant sectors act accountably and responsibly in response to the AIDS epidemic.

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[54] World Health Organization, Progress Report for 3x5: Progress in Numbers, at 11 (2004), available at WHO http://www.who.int/3by5/en/numbers.pdf (last visited February 7, 2004).

[55] *Id.*

PART TWO: THE INFORMATION SOCIETY, INFORMATION AND COMMUNICATION TECHNOLOGIES, AND THE AFRICAN DIGITAL DIVIDE

Within roughly the same time period of the HIV/AIDS epidemic's explosive growth in Africa, there have been similarly dramatic changes to the nature of global communication and informational availability. The world has connected electronically through telephone networks, the Internet, email, and globalized mass media, and vast stores of information and knowledge are now electronically accessible. This transition to an Information Society has significant implications for all aspects of life, including social and economic development, as well as politics, law, and accountability both within and between states. This transition has the potential to play an important role in the fight against HIV and AIDS.

The following section elaborates on the primary forms of information and communication technology, and describes the information society, the digital divide, and the current status of ICT in Africa. This sets the stage for the discussion that follows regarding the role of information, communication, and ICT in the fight against HIV/AIDS in Africa.

1. INFORMATION AND COMMUNICATION TECHNOLOGIES

ICT is the abbreviation commonly used to refer to information and communication technologies. While it often refers to "the new generation [of] information technology spawned by the merger of computers and telecommunications,"[56] it also encompasses traditional broadcasting media such as radio and television. ICT can therefore be defined as "any information and communication technology involved in enabling the capture, processing, storage, transmission[,] and communication of information through electronic means."[57]

Major ICT include telephone and fax, broadcast technologies such as radio and television, multimedia such as video and CD-ROMs, computers, Internet connections, email, distance learning technologies, telecenters, videoconferencing, telemedicine, and electronic networks.

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[56] Alexander G. Flor, *ICT and Poverty: The Indisputable Link*, at 3 (2001), *available at* http://www.worldbank.org/html/extdr/offrep/eap/eapprem/infoalexan.pdf (last visited Dec. 2, 2004).

[57] D S Bateson Consulting, Inc., *Health, HIV/AIDS and Information and Communication Technologies: A Needs Assessment*, at 7 (2002), *at* http://www.voxiva.net/objects/pdfs/health_hiv-aids_ict_report.pdf (last visited Dec. 3, 2004).

Except for radio, television, video, and CD-ROMs, all are reliant on telephone connections, although emerging satellite technologies are introducing new methods of connectivity.

2. THE INFORMATION SOCIETY

This explosion of information and communication technologies has enabled greater information accessibility and global communication than ever seen before in history. Manuel Castells describes this technological revolution, centered on information technologies, as "reshaping, at accelerated pace, the material basis of society."[58] Information has become a raw material to drive social and economic development, and ICT are crucial to enable societies to participate effectively in this global information society. The global economy is now characterized by the rapid flow and exchange of information, communication, and capital.

The result of these developments has been to transform economic and social structures and relations,[59] "as well as the socio-cultural strata of nations around the world."[60] While it has long been accepted that ICT are a key engine for economic performance and growth, more recently ICT have been accepted as effective tools to advance human development. Thus the information society promises a "knowledge-based society, yielding untold dividends for education, health, development, democracy and much more."[61]

3. THE DIGITAL DIVIDE

However the vast majority of people in the world remain untouched by this revolution. The technological advancement at the heart of the information society has largely bypassed Africa, and this

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[58] MANUEL CASTELLS, THE INFORMATION AGE: ECONOMY, SOCIETY AND CULTURE: VOL. 1: THE RISE OF THE NETWORK SOCIETY 1 (1996).

[59] World Summit on the Information Society, *Basic Information – Frequently Asked Questions (FAQ) – What is the information society?*, *at* http://www.itu.int/wsis/basic/faqs.asp (last visited Dec. 3, 2004).

[60] Audrey N. Selian, ITU, *ICTs in Support of Human Rights, Democracy and Good Governance*, at 5 (2002), *available at* http://www.itu.int/osg/spu/wsis-themes/humanrights/ICTs%20and%20HR.pdf (last visited Jan. 21, 2005).

[61] CRIS, *Communication Rights in the Information Society: The CRIS Campaign: Whose Information Society?*, *at* http://www.wacc.org.uk/modules.php?name=News&file=print&sid=788 (last visited Jan.. 21, 2005).

inequity in access to the opportunities presented by the digital revolution has become known as the digital divide. Given the close association between ICT and economic development, the divide threatens to widen the current development gap between the wealthy and the poor, both within and between countries.

The digital divide

> refers to the gap between individuals, households, businesses[,] and geographic areas at different socio-economic levels with regard both to their opportunities to access information and communication technologies (ICTs) and to their use of the Internet for a wide variety of activities.[62]

This divide reflects various differences among and within countries which affect the ability of individuals and businesses to access the Internet.[63] Although the demarcations largely refer to distinctions between rich and poor countries, data suggests a growing digital divide within the OECD (Organisation for Economic Co-operation and Development) area.[64] This suggests that access to ICT is not determined simply by a country's level of development, but that other social, cultural, and economic factors may also determine the extent of access to ICT.

While access to basic telecommunications infrastructures is fundamental, important "readiness" indicators appear to be "computer availability – and potentially the availability of alternative access through TVs or mobile phones – and Internet access."[65] Among households, the digital divide appears to depend primarily on income and education, although "[o]ther variables, such as household size and type, age, gender, racial and linguistic backgrounds[,] and location also play an important role."[66] Access to technology is therefore only one (albeit critical) variable within the broader spectrum of factors that

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[62] Organisation for Economic Co-operation and Development, *Understanding the Digital Divide*, at 5 (2001), *available at* http://www.oecd.org/dataoecd/38/57/1888451.pdf (last visited Dec. 3, 2004) [hereinafter OECD 2001].

[63] *Id.*

[64] Organisation for Economic Co-operation and Development, *Local Access Pricing and E-commerce*, at 7 (2000), *available at* http://www.oecd.org/dataoecd/9/63/27129228.pdf (last visited Dec. 3, 2004).

[65] OECD 2001, *supra* note 62, at 5.

[66] *Id.*

may influence access to ICT. For the Internet in particular, use "involves a complex chain of personal abilities and access to technical resources, many of which are related to income."[67] Moreover, "effective usage is to a certain degree dependent on education, which is in turn dependent on income."[68] While education provides basic reading and writing skills which may determine one's ability to use ICT such as the Internet, education may also influence other psychological factors which affect access. For instance, "the belief in one's capabilities to organize and execute courses of Internet actions...is a potentially important factor in efforts to close the digital divide that separates experienced Internet users from novices."[69]

From the perspective of the digital divide in Africa, this paper will focus on the primary determinant of technological access in addressing efforts to bridge this divide with respect to HIV/AIDS.

4. THE STATUS OF ICT IN AFRICA

The reasons for the African digital divide are diverse. The NEPAD initiative sums them up as follows: "poor ICT infrastructure, combined with weak policy and regulatory frameworks and limited human resources, has resulted in inadequate access to affordable telephones, broadcasting, computers and the Internet."[70]

Of the approximately 816 million people in Africa, it was estimated in 2001 that only: 1 in 4 had a radio: 205 million 1 in 13 had a television: 62 million 1 in 130 had a computer: 5.9 million 1 in 160 used the Internet: 5 million[71]

[67] Johannes M. Bauer et al., *Internet Access in the European Union and in the United States*, 19 TELEMATICS AND INFORMATICS 117, 122 (2002).

[68] *Id.*

[69] Matthew S. Eastin & Robert LaRose, *Internet Self-Efficacy and the Psychology of the Digital Divide*, 6 J. OF COMPUTER-MEDIATED COMMUNICATION (Sept. 2000), *available at* http://www.ascusc.org/jcmc/vol6/issue1/eastin.html.

[70] NEPAD, *Bridging the Infrastructure Gap: Bridging the Digital Divide: Investing in Information and Communication Technologies*, ¶ 106, *at* http://www.nepad.org/documents/30.pdf (last visited Dec. 3, 2004).

[71] Mike Jensen, *The African Internet – A Status Report*, *at* http://www3.wn.apc.org/africa/afstat.htm (last updated July 2002). The figures and information in this section are drawn extensively from this source, and are not individually referenced.

In 2002, radio was by far the dominant mass medium in Africa with twenty-five percent of Africans owning radio sets. Existing radio transmitter networks were estimated to cover over sixty percent of the African sub-continent. Community broadcasting was also slowly taking off in the region, with a growing number of community radio licensees in Ghana, Mali, Niger, Uganda, and South Africa.[72]

Television was far more limited at 7.6 percent. National television coverage was largely confined to major towns, and some countries did not yet have their own national television broadcaster: even relatively well-developed Botswana did not launch its own broadcaster until 2002. There were increasing numbers of commercial stations, but their news and information output was "often either a re-broadcast of the national (state-controlled) broadcaster's news, or that of an international broadcaster or news agency. Local news and current affairs, especially that focusing on events outside of the capital, [was] rarely broadcast."[73]

There is extremely limited individual ownership of personal computers and Internet connections: in 2002, 0.8 percent of people had computers, and 0.6 percent used the Internet (a figure which encompasses the fact that there are usually three users per dialup Internet account).[74]

There are encouraging trends of growth in Internet usage, with rapid growth in most urban areas in Africa, and current availability in every capital city. However the vast majority of Internet subscribers are located in Northern Africa and South Africa, with a smattering of subscribers in the remaining forty nine Sub-Saharan African countries.[75] Although higher Internet use tends to be associated with more developed economies and infrastructures as in Northern Africa and South Africa, countries like Senegal and Cape Verde have higher connectivity levels than their gross domestic product per capita would suggest.[76]

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[72] *Id.*

[73] *Id.*

[74] *Id.*

[75] *Id.* (indicating that by mid-2002 there were 1.7 million dialup Internet subscribers in Africa, with 1.2 million in Northern Africa and South Africa, and 500,000 in the remaining forty-nine Sub-Saharan countries).

[76] *Id.*

The overall fixed line teledensity is extremely limited, with only one in one hundred people in Africa, or one percent, having telephones.[77] Infrastructure is focused in capital cities: "[i]n over [fifteen] countries in Africa, including Cote d'Ivoire, Ghana[,] and Uganda, over [seventy] percent of the lines are still located in the largest city."[78] There is, however, a high level of variability between countries and regions, even within the sub-Sahara. In 2002, the countries of the Sahel and Central Africa had the least phone lines: Mali, Congo, Niger, and Chad had one phone line for every two hundred to five hundred people. Northern Africa and South Africa had a teledensity of about one in thirteen, and West and East African coastal countries had teledensities varying from one in fifty to one in one hundred. Countries with teledensity above one in fifty were Botswana, Cape Verde, Gabon, Mauritius, Mayotte, Namibia, Sao Tome, Senegal, and Swaziland.[79]

There has also been very rapid growth in mobile cellular telephony in Africa: there are currently over eighty networks in forty-four countries. Estimates are of about fifty-three million users in Africa (with approximately nineteen million in South Africa).[80] Access is mainly offered in capital cities, but also in some secondary towns and along major truck routes.

Throughout Africa, ICT connectivity, use, and ownership are skewed towards urban areas, with ICT users in cities and towns vastly outnumbering rural users. While these figures illustrate limited ICT access, they do not represent all users, as many people listen to the same radio or television at the same time. This large scale sharing of information resources is a dominant feature of the African media landscape, with readership of a single newspaper often being more than ten people.

Public access services are very much in demand due to the relatively small number of people who can afford a phone line. As a result, in many countries there are rapidly growing numbers of telecenters, kiosks, cybercafés, and other forms of public Internet

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[77] NEPAD, *supra* note 70, at 2.

[78] Jensen, *supra* note 71.

[79] *Id.*

[80] Cellular Online, *Cellular Operators in Africa*, *at* http://www.cellular.co.za/africa-cellsystems.html; Cellular Online, *Latest African Mobile and Cellular Statistics*, *at* http://www.cellular.co.za/stats/stats-africa.htm; Cellular Online, *Statistics of Cellular in South Africa*, *at* http://www.cellular.co.za/cellular_south_africa.htm (last visited Dec. 3, 2004).

access, such as computers added to community phone shops, schools, police stations, and clinics. One of the best known examples is Senegal, which has over ten thousand commercially run public phone bureaus. While most public access centers are in urban areas, a growing number are being established in rural and remote locations, and offer access to the Internet and other more advanced ICT services.[81]

PART THREE: INFORMATION AND COMMUNICATION IN THE FIGHT AGAINST HIV/AIDS

Effective communication of valid and appropriate information is the specific remedy for infection rates attributable to a lack of information, and for many of the social ills associated with misinformation and myths about the epidemic.[82] Information can confer the capacity to act appropriately, whether by protecting oneself from infection or taking steps to influence decision makers. Information is the source of considerable personal and social power, with the capacity to shift some of the power differentials at the heart of the epidemic. This brings to mind Marshall McLuhan's famous observation in relation to mass media, that "the medium is the message."[83] McLuhan suggested that use of new technologies to disseminate information (the message) could lead to social change, and that we should also see the medium (mass media) as a force capable of exerting social change irrespective of its content.[84] While communication is the medium for conveying important HIV/AIDS-related information, as an activity that negates the silence that surrounds HIV/AIDS, it is also the message itself.

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[81] Jensen, *supra* note 71.

[82] As already noted, information and communication may depend for their effectiveness upon their content, as well as the social context in which they are received. See, for instance, the brief discussion in this paper at the end of Part Three, section 7.1.

[83] MARSHALL MCLUHAN, UNDERSTANDING MEDIA: THE EXTENSIONS OF MAN 7 (1964).

[84] *Id.* ("In a culture like ours, long accustomed to splitting and dividing all things as a means of control, it is sometimes a bit of a shock to be reminded that, in operational and practical fact, the medium is the message. This is merely to say that the personal and social consequences of any medium – that is, of any extension of ourselves – result from the new scale that is introduced into our affairs by each extension of ourselves, or by any new technology.").

Information and communication, technologically-enabled or not, are clearly at the heart of effective AIDS programs. While information is the basic component of safer sex messages, effective prevention relies critically on overcoming obstacles posed by: misinformation and myths about the disease, silence and denial, stigma and discrimination, and limited knowledge about HIV/AIDS prevention services, including voluntary counseling and testing (VCT) and measures to prevent mother to child transmission of HIV (PMTCT).

Information and communication facilitate the empowerment and reduction of vulnerability of PLWHA, women, and other susceptible groups that form fundamental parts of the fight against AIDS. Reducing vulnerability includes providing an enabling and protective legal environment, which protects people's (and especially women's) rights to equality and non-discrimination.

Yet the need for a more effective flow of information and communication regarding HIV/AIDS extends to all facets of the disease, as well as appropriate responses to it, which include enabling treatment and support, epidemiological and health research, and reduction of vulnerability to infection. The intimate connection between health and access to information is reflected in international human rights law, which views access to health related information and education as an underlying determinant of health.[85]

Information and communication are also powerful tools for AIDS service organizations, human rights advocates, and PWLHA organizations, which use information and communication to enable advocacy, mobilization, networking, and capacity-building. Information and communication play critical roles in addressing some of the political factors that limit effective responses, by facilitating greater transparency and monitoring of government through civil society and mass media reporting, and by encouraging increased democratic participation. Information and communication offer valuable tools to hold countries to their political and legal commitments to HIV/AIDS, expressed internationally, regionally, and nationally.

Legally protected freedoms of expression and privacy are therefore critical instruments to a society's informational accessibility and free communication. In this regard, ICT offer a freedom of informational access and expression that may exceed permissible social, political, and legal boundaries. The Internet, email, discussion groups, and chat

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[85] *General Comment 14*, Committee on Economic, Social and Cultural Rights, 22nd Sess., ¶ 11 U.N. Doc. E/C.12/2000/4 (2000), *available at* http://www1.umn.edu/humanrts/gencomm/escgencom14.htm (last visited Dec. 4, 2004).

rooms offer free expression and communication on topics that are otherwise taboo to people who are otherwise silenced. This is borne out by an independent gender assessment study conducted in schools in Senegal, Mauritania, Uganda, and Ghana which found that school girls primarily used the Internet to research information that is banned or taboo in their cultures. The Internet was seen as a "safe partner" that could provide "the information we need to adapt to this modern world." [86] ICT like the Internet also offer alternative methods of communication in repressive regimes that limit free speech. As one Zimbabwean delegate to a UN Commission for Africa meeting indicated: "ICTs means [*sic*] government cannot monopolise information on governance...[t]here is more oppression of journalists in my country. But the authorities cannot shut down every Internet user."[87]

The broadcasting technologies of radio and television are the most prevalent forms of ICT in Africa, and are the primary vehicles both for transmitting information about prevention and treatment services to large sectors of the population, and for reducing the silence, stigma, myths, and misconceptions associated with the disease. Personal computers, Internet access, and email have very low prevalence in most of Africa, but offer extremely valuable tools for education, communication, and expansive access to relevant information and knowledge. The Internet, CD-ROMS, digital libraries, and electronic databases offer access to unlimited sources of information, with particular benefits for health care workers, AIDS advocates, and national decision makers. PLWHA, communities, and CSOs are important enablers of information and communication, particularly where technology and infrastructures are limited.

The ability to connect to information and communication structures, electronic or otherwise, does not only confer knowledge; effective use of connectivity is now itself a form of political power with the capacity to affect social change. In the new information society, "[b]ecause information and communication circulate primarily through the diversified, yet comprehensive media system, politics

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[86] Dr. Coumba Mar Gadio, *Exploring the Gender Impacts of World Links in Some Selected Participating African Countries: A Qualitative Approach*, at 10 (2001), *available at* http://world-links.org/english/assets/gender_study_v2.pdf (last visited Jan. 21, 2005).

[87] UN Integrated Regional Information Networks, *Still Waiting for the Information Revolution* (May 15, 2003), *available at* http://allafrica.com/stories/printable/200305150744.html (last visited Dec. 4, 2004).

becomes increasingly played out in the space of media," and this media includes computer-mediated communication networks.[88]

There are considerable examples from across the African continent of the innovative use of information and communication in various aspects of the fight against HIV/AIDS. The following sections elaborate on how information, communication, and ICT are being used in relation to various aspects of the HIV/AIDS epidemic, including prevention, health care, population research and epidemiology, advocacy and mobilization, treatment access, networking and empowerment of AIDS-focused NGOs and PLWHA, and increased governance and accountability.

1. PREVENTION

Given the predominance of HIV among young people, and the startling figures showing knowledge gaps regarding HIV/AIDS, AIDS prevention strategies should include interventions targeted at this group. In addition, general prevention strategies must focus specifically on other high-risk groups, including women, sex workers, men who have sex with men, truck drivers, refugees, and migrant workers. Such strategies include prevention messages (regarding safer sex, anti-discrimination, and accurate information about HIV/AIDS), as well as prevention services (PMTCT and VCT). This section focuses on school based education and mass media campaigns as two primary mechanisms for effectively using ICT.

1.1 SCHOOL BASED EDUCATION

Education and life skills training in schools are fundamental parts of effecting appropriate behavioral changes among youth. UNAIDS suggests that national AIDS programs should aim to provide one hundred percent of schoolchildren with AIDS education addressing effective prevention, non-discrimination, and care and support for people with HIV/AIDS.[89] Such education has been shown to help young people delay sex and avoid risky behavior when they become sexually active.[90]

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[88] CASTELLS, *supra* note 58, at 476.

[89] UNAIDS, *School Based Interventions and Services*, in SUMMARY BOOKLET OF BEST PRACTICES, at 173 (1999), *available at* http://www.umich.edu/~spp638/Coursepack/prog-bestpractices.pdf (last visited Dec. 4, 2004).

[90] *Id.*

While this may seem fairly obvious, children and young people are often denied AIDS education in schools due to religious or social sensitivities to sexuality and HIV/AIDS. Moreover, the availability of information does not guarantee its application: "[i]n some places, schools may teach information on AIDS but not the behavioural skills needed for prevention and support."[91]

UNAIDS indicates that maximum effectiveness requires: partnerships between policy-makers, religious and community leaders, parents, and teachers in formulating sound policies on AIDS education; use of curricula adapted to local culture and circumstances; focusing on life skills rather than biomedical information; teaching students to analyze and respond to social norms and to understand which norms are potentially harmful and which protect their health and well-being; and training of teachers and peer educators.[92] UNAIDS also recommends that HIV prevention and health promotion programs should be started for children at the earliest possible age, and before the initiation of sexual activity, ideally with age-appropriate programs at the primary school level.[93]

In this realm, education is clearly not technologically dependent, requiring in many cases only appropriate teacher knowledge and skills. However, ICT offers a medium popular within youth culture, as well as individual empowerment, with social and economic development as a potential offshoot. Technologies like digital and satellite broadcasting are also being used to enable access to AIDS information in remote or rural areas where teacher skills and knowledge are low, and where access to technology is highly limited.

This trend is evidenced by a World Bank initiative called World Links that is establishing Internet learning centers in schools and community learning centers in several African countries, including Ghana, South Africa, Uganda, Zimbabwe, Botswana, Kenya, and Zambia. The project provides participating students and teachers with online educational modules, addressing topics like basic facts about HIV/AIDS, social action, prevention, and myths and misunderstandings about HIV/AIDS.[94] The project specifically aims to

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[91] *Id.*

[92] *Id.*

[93] *Id.*

[94] Anthony Bloome, *Fighting the Insidious Killer: African Teenagers Battle HIV/AIDS Through ICT*, DEVELOPMENT OUTREACH (Spring 2002) *at* http://www1.worldbank.org/devoutreach/spring02/article.asp?id=160 (last visited Dec. 4, 2004).

reach rural youth by basing three-quarters of its Internet Learning Centres outside of capital cities and using mobile van telecenters and satellite technology.[95]

1.2 MASS MEDIA CAMPAIGNS

Mass media and social marketing using popular culture are able both to convey important information protecting against HIV/AIDS and to dispel myths and stigma. Mass media campaigns use television, radio, Internet websites, online discussion groups, print media, and school and other youth-based education for maximum effect.

The relative prevalence of radio and television in Africa makes these technologies key for disseminating information on reducing vulnerability to AIDS. Experience from South Africa, where media penetration of radio and television is extremely high, shows that social marketing using mass media could be highly effective means of disseminating HIV/AIDS information.[96]

A South African project called loveLife seeks to substantially reduce the HIV infection rate among young South Africans – and to establish at the same time a new model for effective HIV prevention among young people.[97] The key components of loveLife's approach are nationwide media campaigns, including youth-focused television and radio programming, weekly youth newssheets, and billboards and taxis that promote sexual responsibility and direct young people to counseling and clinical services. loveLife runs service and support programs, including a network of youth centers that provide HIV prevention services, and accessible adolescent health services in public clinics nationwide. loveLife also works with over one hundred community-based organizations known as loveLife franchise-holders. Rural areas are accessed with loveTrains that visit towns and villages

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[95] *Id.*

[96] Nancy Coulson, *Developments in the Use of Mass Media at the National Level for HIV/AIDS Prevention in South Africa*, at 1 (2002), *available at* http://www.comminit.com/pdf/HIV-AIDS_south_africa_campaigns_report.pdf (last visited Dec. 4, 2004) (indicating that ninety-nine percent of people have access to radio and seventy-five percent have access to television).

[97] loveLife, *at* http://www.lovelife.org.za/corporate/index.html (last visited Dec. 20, 2004). (loveLife is a partnership between the South African government, over one hundred community-based organizations, U.S. foundations, and the corporate sector).

across South Africa's rail network, and loveTOURS run through a traveling radio broadcasting unit.[98]

A primary feature of loveLife is its combination of well-established public health approaches with innovative marketing techniques, reaching young people by:

> [s]peaking in language that young people relate to and understand[,] [u]sing a tone of optimism, rather than relying on scare tactics – which have little credibility with youth[, and] [h]arnessing the power and influence of South African's youth culture, including television, music, and sports to promote healthy living.[99]

A survey of South African youth between the ages of fifteen and twenty-four found that eighty-five percent of young South Africans say they have heard of loveLife, and approximately two-thirds report making behavioral changes as a result of HIV/AIDS awareness.[100] Nonetheless, despite the relatively high saturation of radio and television in South Africa in comparison to other African countries, a recent South African study found that people living in poorer households and in rural areas have low exposure to broadcast and print media.[101] In the predominantly poorer countries of Africa that have even lower prevalence of radio and television, HIV/AIDS information and communication initiatives should be aimed broadly at overcoming the large gaps in informational availability and accessibility faced especially both by poor and rural communities, and by women and girls.

2. POPULATION RESEARCH AND EPIDEMIOLOGY

African countries face challenges in securing accurate information on HIV/AIDS from the field, especially when they have inadequate or fragmented health systems that limit the ability to "conduct effective

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[98] *Id.*

[99] *Id.*

[100] Reproductive Health Research Unit, *HIV and Sexual Behavior Among Young South Africans: A National Survey of 15-24 Year Olds*, at 2 (2004), *available at* http://www.lovelife.org.za/kids/Leaflet.pdf (last visited Jan. 22, 2005).

[101] NELSON MANDELA/HSRC STUDY OF HIV/AIDS 92 (Human Sciences Research Council Publishers 2002), *available at* http://www.hsrcpublishers.co.za/e-books/HIV%20Report.pdf (last visited Dec. 20, 2004) [hereinafter HSRC].

epidemiological work and other basic research contributing to evidence-based decision making."[102] ICT offer "access to information, applications to analyze data[,] and tools to communicate," which can help overcome some of these limitations.[103]

The iESSP 2 Project is working on integrating epidemiological surveillance in West Africa. The project is part of the Nationwide Health Information Systems of six West African countries: Benin, Burkina Faso, Cote d'Ivoire, Guinea, Mali, and Niger. It is targeted at improving health conditions through sustainable and efficient reinforcement of West African endemoepidemic control mechanisms, and strengthening their epidemiological surveillance capabilities. The project also aims to improve the skills and abilities of professionals by reinforcing acquired knowledge and experience through continued use of new information technology solutions and the creation of a website allowing data exchange.[104]

Epidemiological information using ICT is also being gathered from the private sector. In 2003, the massive South African mining corporation AngloGold rolled out a comprehensive AIDS reporting tool, using a health care information system "to analyse the impact of AIDS on healthcare costs, giving drill-down information on disease profiles and medical and facilities usage, enabling the mining group to estimate the cost impact of Aids and allowing it to project future cost impacts."[105]

3. EDUCATION OF HEALTH CARE WORKERS

Information and communication ownership and technologies enable various aspects of AIDS related health care, including training health care workers to deal with HIV/AIDS in a knowledgeable and non-discriminatory fashion. ICT are being used to improve access to information, education, and communication for health workers,

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[102] D S Bateson Consulting, Inc., *supra* note 57, at 41.

[103] *Id.*

[104] Center for International Cooperation, Health and Development, *Integrated Epidemiological Surveillance Support Project, Phase 2 (2003-2008), at* http://132.203.52.55/ang/index3b.html (last visited Jan. 22, 2005).

[105] ITWeb, *South Africa: AngloGold Rolls Out IT Against Aids* (April 29, 2003), *at* http://www.africapulse.org.za/index.php?articleid=1195&action=viewarticle (last visited Dec. 4, 2004).

especially in community and rural settings, using CD-ROMs, Internet, email discussion groups, and distance learning technologies.

The Internet offers almost unlimited access to journals and databases, information sharing with other health care professionals, and access to information with relevant local content and language.[106] Websites and CD-ROMs also enable access to information from conferences, major projects, and collections of documents in clearing-houses.[107] There is a tremendous amount of online information for HIV/AIDS-related health care. General and medical information is available on AIDS-specific websites such as UNAIDS, the Africa HIV/AIDS Research Database, or The Body. A key medical online resource is the Physicians' Research Network, which provides the latest information on research, diagnosis, and management of HIV and AIDS. The Network provides summaries of clinical presentations by leading researchers and clinicians, as well as featured reports on major clinical and scientific meetings in the U.S. and, when possible, internationally. The PRN Notebook is distributed free of charge to interested healthcare providers and researchers worldwide.[108]

While Internet and distance learning technologies may be costly or require infrastructure where there is none, computers and CD-ROMs are a "cost effective way to get journals, guidelines, education and training material in a manner less dependent on a weak infrastructure."[109] CD-ROMs are relatively cheap and accessible, and offer solutions to the education and improved information access of health care workers in community and rural facilities with limited resources and connectivity. Teaching-aids at Low Cost (TALC) is a scheme that seeks to facilitate the training of health care professionals using cheap ICT, including through the provision of urgently needed free health information to developing countries using CD-ROMs.[110]

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[106] D S Bateson Consulting, Inc., *supra* note 57, at 41.

[107] Development Gateway, *The Expanding Role of ICTs in HIV/AIDS Program Design and Implementation* (October 29, 2002), *at* http://topics.developmentgateway.org/hiv/sdm/previewDocument.do~activeDocumentId=366014 (last visited Dec. 4, 2004) (interviewing Dr. Malcolm Bryant, Medical Director of SatelLife).

[108] *See, e.g.*, UNAIDS, *at* www.unaids.org; Africa HIV/AIDS Research Database, *at* http://www.wangonet.org/Hard/AboutHARD/About_HARD.htm; The Body, *at* http://www.thebody.com/index.shtml; Physicians' Research Network, *at* http://www.prn.org/prn_cntnt/about.htm (last visited Dec. 4, 2004).

[109] D S Bateson Consulting, Inc., *supra* note 57, at 3.

[110] TALC, *at* http://www.talcuk.org/ (last visited Dec. 4, 2004).

Similarly, handheld computers are proving to be a useful and viable technology in rural settings for data collection, information dissemination, and access to medical reference materials.[111] An appraisal of a SatelLife PDA project in Ghana, Kenya, and Uganda illustrates that handheld computers offer both enormous potential for improving access to services and specific utility in rural healthcare settings.[112]

Email publications and discussion groups are another significant source of HIV/AIDS-related information. HealthNet News AIDS and other newsletters bring research and guidelines to health care workers in developing countries. HealthNet News AIDS is published twice a month and distributed by email within developing countries only. It targets physicians and contains copyrighted material drawn from peer-reviewed journals. It is mailed to 513 individual users in fifty-one developing countries, who share each issue with up to ten other readers.[113]

Another resource targeting health care workers is the Program for the Collaboration Against AIDS and Related Epidemics (ProCAARE), a discussion forum with the goal of providing:

> a forum for dialogue among clinical and public health physicians, nurses, researchers, policy makers, program managers, and other interested health practitioners both in the developing and industrialized world who are engaged in the fight against AIDS. Discussion centres on the continuum of biomedical and care issues covering such topics as prevention, access to drugs, home and institutional care, education, and epidemiology. ProCAARE ensures that the health professional in the developing world can communicate and exchange information on HIV/AIDS with colleagues around the world. A special focus of ProCAARE is to stimulate and support communication within the region among colleagues who share similar challenges and concerns.[114]

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[111] Bridges.Org, *Evaluation of the SATELLIFE PDA Project, 2002: Testing the Use of Handheld Computers in Ghana, Uganda and Kenya*, at ii (2003), *available at* http://www.bridges.org/satellife/evaluation_pda_project_28_February_2003.pdf (last visited Dec. 4, 2004).

[112] *Id.*

[113] Holly Ladd, *SatelLife: HIV/AIDS Related IT Programming*, Presentation before ICT Against HIV/AIDS Coalition, slide 8 (undated), *available at* http://www.sdnp.undp.org/ictaids/satellife_undp_HIV_ICT.ppt (last visited Jan.22, 2005).

[114] *Id.* ProCAARE, *at* http://www.procaare.org/about.php (last visited Dec. 4, 2004) (ProCAARE is a partnership between SATELLIFE, the Harvard AIDS Institute/Harvard School of Public Health, and Health and Development Networks).

Moderators for the group support the network by supplying summaries of current and relevant research findings and other material of interest.[115]

Other email discussion groups like AFRO-NETS[116] and AF-AIDS[117] are important avenues for government officials, health care workers, researchers, and advocates to connect with each other and to access current research and best practices. The IP-Health list of the U.S. Consumer Project on Technology[118] is an excellent resource on the latest developments, research, and informal views in the treatment access world.

The Internet and CD-ROMs enable distance education for health care workers, with digital satellite radio emerging in a similar role.[119] One example of such an initiative is the U.S.-based Johns Hopkins University, which makes available multimedia tutorials on the care of women with HIV, either online or as CD-ROMs. They are "designed to equip physicians, faculty[,] and healthcare trainers in limited-resource settings with the technical knowledge they need to provide high quality healthcare services to women with HIV/AIDS and to train other healthcare providers."[120]

There are several examples of initiatives aimed at supplementing existing health care with various ICT. The Enhancing Care Initiative supports local AIDS care teams in a range of developing countries including Senegal and South Africa. It provides Internet support including email, group discussions, shared document editing, a documents database, chat features, and a group calendar. This provides team members and affiliates with a virtual research community for archiving and sharing the latest knowledge about HIV and AIDS care.[121]

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[115] *Id.*

[116] See AFRO-NETS, *at* http://www.afronets.org (last visited Jan. 22, 2005).

[117] See AF-AIDS, *at* http://archives.healthdev.net/af-aids/ (last visited Jan. 22, 2005).

[118] See IP-Health, *at* http://www.cptech.org/ip/health/ (last visited Jan. 22, 2005).

[119] Development Gateway, *supra* note 104.

[120] JHPIEGO, JHPIEGO Expands into Area of HIV/AIDS (May 2002), *at* http://www.reproline.jhu.edu/English/6read/6issues/6jtn/v5/tn0204hiv.htm (last visited Jan. 22, 2005).

[121] See Enhancing Care Initiative, *at* http://www.eci.harvard.edu/intranet/ (last visited Jan. 30, 2005) (coordinated by the Harvard AIDS Institute in collaboration with the François-

4. INFORMATION AND COMMUNICATION AS CRITICAL ELEMENTS OF ADVOCACY: THE TREATMENT ACCESS STRUGGLE

The Internet, email, discussion groups, and mass media are proving to be crucial tools for national and international advocacy, as exemplified in the treatment access campaigns waged in African countries and internationally. They enable the large-scale social mobilization that has played a key role in these campaigns, as well as effective communication regarding key legal and political battles.

The Internet serves multiple functions for organizations fighting for human rights, including:

> email lobbying of elected representatives, public officials, and policy elites; networking with related associations and organizations; mobilizing organizers, activists and members using action alerts, newsletters and emails; raising funds and recruiting supporters; and communicating their message to the public via the traditional news media.[122]

Mass media in particular has played an important role by generating the negative publicity surrounding actions which obstruct developing country access to medicines. Media coverage — backed by broad civil society protests — has decisively altered the outcomes of several of these disputes. This coverage was evident when, in response to the U.S. government having placed South Africa on its trade watch list — a step preceding sanctions — for its amendment of its Medicines Act in 1997, AIDS activists staged public protests against then-Vice President Gore during his campaign for the U.S. presidency. The adverse media attention, and its feared impact on Gore's political future, led to the withdrawal of South Africa from the list. It also resulted in an official change in U.S. policy regarding Sub-Saharan African country efforts to access HIV/AIDS drugs.[123]

Xavier Bagnoud Center for Health and Human Rights and the Department of Population and International Health at the Harvard School of Public Health).

[122] Selian, *supra* note 60, at 33 (footnote omitted).

[123] Sonya Ross, *Gore Faces S. Africa AIDS Dilemma*, THE ASSOCIATED PRESS, June 30, 1999, *available at* http://www.aegis.com/news/ap/1999/ap990616.html; see, for example, the US executive order of 29 May 2000, which directed the U.S. government to refrain from seeking the revocation or revision of laws or policies in Sub-Saharan countries to promote access to HIV/AIDS pharmaceuticals and medical technologies. *See* Exec. Order No. 13155, 65 Fed. Reg. 30,521 (29 May 2000).

Similarly, when thirty-nine pharmaceutical companies sued the South African government to prevent the promulgation of the 1997 Medicines Act, intensive international media attention was focused on the case, and extensive public protests were conducted around the world. With negative publicity mounting, and their public profile plummeting, the pharmaceutical companies withdrew their case.[124]

These instances illustrate the capacity for public opinion – expressed through demonstrations, media coverage, and the Internet – to alter the behavior of key decision-makers, both public and private, towards more favorable outcomes for developing countries. Success relies on publicizing the actions of those who seek to limit developing country access to medicines, and ICT such as discussion groups and email newsletters play critical roles in this regard. They have enabled African AIDS groups to ensure that information about government intransigence, legal and political actions of foreign governments, and pharmaceutical companies, has a wide global audience through discussion groups, email newsletters, and the mass media.

ICT also offer the chance to reduce informational asymmetries that hamper appropriate and effective action by governments and civil society aimed at accessing lower priced medicines and diagnostics around the world. Informational availability is facilitated by international organizations like UNAIDS, the World Health Organization, and the United Nations Children's Fund, as well as the international NGO Medicins sans Frontieres, who publish up to date information on the sources and prices of antiretroviral medicines and diagnostics, as well as a list of manufacturers.[125] This publication is explicitly intended to overcome the information asymmetries which developing country governments and NGOs face in their attempts to procure medicines and diagnostics. It recognizes that the absence of price information is one of the barriers to access to drugs in countries with limited resources.[126] Thus,

> [e]ven where affordable alternatives exist, many decision-makers do not have the information they need to identify those

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[124] CPTech, *Court Case Between 39 Pharmaceutical Firms and the South African Government, at* http://www.cptech.org/ip/health/sa/pharma-v-sa.html (last visited Dec. 4, 2004).

[125] UNICEF, UNAIDS, WHO & Médecins Sans Frontières, *Sources and Prices of Selected Medicines and Diagnostics for People Living with HIV/AIDS*, at 11, 26 (2004), *available at* http://www.unicef.org/aids/files/SP_report_2004.pdf (last visited Dec. 4, 2004).

[126] *Id.* at 1.

> manufacturers that can supply these medicines....Without this information, there is a risk that low-income countries may be paying more than needed to obtain essential medicines.[127]

Activism by African PLWHA and advocates has played a critical role in these battles. In particular, the South African Treatment Action Campaign (TAC) has waged extremely successful legal and political battles, using mass media and ICT to disseminate their message broadly, as well as to mobilize national and international civil society. Its website contains details of campaigns, electronic versions of legal documents used in various cases, and links to other treatment access organizations around the world. The organization sends out newsletters to members, the public, and the media detailing its activities, presenting new developments and research, and calling for actions and support where appropriate. The organization also conducts widely publicized demonstrations and protests to bring attention to the South African government's delays and refusals to implement national HIV/AIDS treatment policies.[128]

TAC extensively promotes treatment awareness and literacy among South Africans, targets pharmaceutical companies to reduce drug prices, and sustains pressure on the government to fulfil its HIV/AIDS obligations. A key objective is to build a mass membership, currently standing at ten thousand people in seventy branches across the country.[129] The group's advocacy also relies on building networks and alliances with various civil society groups and sectors, nationally, regionally, and internationally. TAC has initiated an African network of AIDS Treatment Groups (Pan-African Treatment Access Movement) with activists from twenty-one African countries. It also works extensively with treatment access groups across the world. TAC has been actively involved in litigation, including the Pharmaceutical Manufacturers Association case referred to *supra*, a suit to force the government to provide comprehensive PMTCT, and most recently a claim at the competitions commission

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[127] UNICEF, UNAIDS, WHO & Médecins Sans Frontières, *Sources and Prices of Selected Medicines and Diagnostics for People Living with HIV/AIDS*, at 1 (2003), *available at* http://www.who.int/medicines/organization/par/ipc/sources-prices.pdf (last viewed Jan. 22, 2005).

[128] See TAC, *at* http://www.tac.org.za (last visited Dec. 4, 2004).

[129] Ofeibea Quist-Arcton, *Mbeki Still in Denial Says HIV Treatment Activist* (May 29, 2003), *at* http://allafrica.com/stories/200305290027.html (last visited Dec. 4, 2004).

against two pharmaceutical companies alleging excessive pricing of antiretroviral medicines.[130]

5. NETWORKING AND CAPACITY-BUILDING FOR AIDS GROUPS

As the treatment access movement exemplifies, use and ownership of ICT are primary mechanisms of the networking required for effective mobilization. ICT offer unprecedented opportunities for national and international networking by connecting communities and NGOs around the world to enable information-sharing, education, and the transfer of skills.

ICT are also excellent means of strengthening the capacity of AIDS NGOs across the African continent. They enable the "twinning" of African organizations with AIDS and human rights organizations elsewhere in the world in order to "enhance skills in human rights fact finding and documentation[,] share practical prevention materials and innovative intervention strategies[,]...[and] learn more about publicity and media work, campaigning, mobilizing legal support[,] and reporting for domestic and international audiences."[131]

6. GOVERNMENT ACCOUNTABILITY FOR AIDS

The free flow of information and communication offers greater transparency in national policy and decision-making on AIDS, as well as more effective governance: "[g]ood governance depends on the availability of adequate knowledge and information resources. Decision makers need this to make good decisions. The general public needs this to participate in the decision-making process and follow the implementation of agreed decisions."[132] ICT are enabling even remote NGOs and communities to publicize human rights violations widely,

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[130] *See Minister of Health and Others v. Treatment Action Campaign and Others*, 2002 (10 BCLR 1033 (CC); *see also* TAC, *supra* note 126.

[131] Inter-agency Coalition on AIDS and Development (ICAD) and the Communication Initiative (CI) for the Canadian International Development Agency (CIDA), *Twinning Against AIDS: A Report and Proposal for Using Information and Communication Technologies to Improve the Sharing of Information, Skills and Experience Between Organisations Responding to the HIV/AIDS Crisis*, at 2 (2002) *available at* http://www.comminit.com/pdf/twinning_against_AIDS_Final_Report.pdf (last visited Dec. 5, 2004) [hereinafter ICAD and CIDA].

[132] UN Integrated Regional Information Networks, *supra* note 84 (quoting K.Y. Amoako, Executive Secretary to the UN Economic Commission for Africa).

as well as national and local policy and program failures, thereby increasing accountability.

ICT also offer "[e]mpowerment of stakeholders, consultation[,] and bottom up inputs into policy formulation."[133] For example, in 2001 the Nigeria AIDS e-forum held a six month open electronic conference on key HIV issues in Nigeria, intended to mobilize stakeholders' input into the national response to the HIV/AIDS epidemic in Nigeria. The discussions were intended to guide the National Action Committee on AIDS (NACA) as well as various other stakeholders in the implementation of the Nigerian government's HIV/AIDS strategy. In addition, key issues discussed and solutions proffered were summarized and published in book format for dissemination to wider audiences.[134]

7. CHALLENGES AND OPPORTUNITIES FOR CIVIL SOCIETY: LIMITED CONNECTIVITY, RURAL ACCESSIBILITY, AND GENDER INEQUALITY

Information and communication accessibility in Africa is limited by the dearth of ICT connectivity throughout Africa, which is greatest throughout the continent in rural areas, even within relatively well-resourced countries. This limited connectivity is a major obstacle both to comprehensive dissemination of HIV/AIDS-related information and to mutual communication of pressing needs and problems to and from rural areas. Gender inequality also poses structural obstacles to access. Although overcoming these obstacles requires sustained long term developmental, social, and legal reform projects, interim measures using innovative and strategic approaches can overcome the more pressing information and communication needs. Opportunities for increasing access must also be maximized by all sectors.

7.1 INTERIM RESPONSES TO LIMITED CONNECTIVITY AND RURAL INACCESSIBILITY

Greater connectivity in Africa is clearly a critical need requiring serious and sustained efforts. However, the need for access to

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[133] Denis Gilhooly, *The Role of ICT in the Response to HIV/AIDS*, Presentation before ICT Against HIV/AIDS Coalition Working Group , slide 11 (Nov. 20, 2001), *available at* http://www.sdnp.undp.org/ictaids/UNDP_nov20_ict_hiv.ppt (last visited Dec. 4, 2004).

[134] *See* Journalists Against AIDS Nigeria, *The Nigeria-AIDS e-Forum: A Model for Public Policy Advocacy on HIV/AIDS*, slides 16-18 (2001), *available at* http://www.nigeria-aids.org/Nigeria-AIDSeForum.ppt (last visited Dec. 20, 2004).

information and communication within the epidemic cannot wait upon this progressive development. Interim measures using innovative strategies and targeted interventions should be implemented to ensure greater access to ICT and other information and communication resources and mechanisms.

As the data on African connectivity suggests, several features of ICT usage in Africa present alternative forms of access. Public ICT access holds the potential to broaden Internet access in Africa significantly, as seen in the growing numbers of telecenters which act as vital hubs of communication. Telecenters are also key sites for HIV/AIDS information and communication in the form of print media, as well as access to HIV/AIDS-related telephone help-lines, which has been shown to be a key source of HIV/AIDS-related information in South Africa.[135] This conclusion is illustrated by the SIDAREC telecenter in Kenya, which is a popular cyber café and social and educational forum. At the SIDAREC telecenter, youth can engage in discussion about health issues affecting them, including HIV/AIDS.[136]

Communal connectivity hubs in libraries, hospitals, and universities offer additional important access to online resources and services, albeit to smaller and more specialized populations.

A key challenge is reaching rural areas that have limited or no infrastructures for ICT. There are both technological and non-technological solutions to this problem. Technologies like digital and satellite broadcasting, mobile telephones, and handheld computers have enormous potential to reach rural and remote communities. Given resource constraints and infrastructural limits on the continent, ICT do not necessarily present comprehensive solutions, although there is great potential for targeted usage. In the interim, the mainstay of efforts to reach rural communities will have to rely largely on non-technological mechanisms such as print media, peer-to-peer outreach, community efforts, and training to ensure greater dissemination and penetration of relevant information and communication regarding HIV/AIDS in rural areas. As examples from the field illustrate, vans, trains, or buses can ensure that relevant information reaches outlying areas.

An example of resource sharing and capacity-building comes from the NGO sector: the practice of twinning an NGO in a developed

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[135] HSRC, *supra* note 98, at 95.

[136] SIDAREC, *Youth Programmes*, *at* http://www.sidarec.or.ke/html/community.html (last visited Dec. 4, 2004) (SIDAREC stands for "Slums Information Development and Resource Centres").

country with one in a developing country, or twinning an urban NGO with a rural one within the same country. A 2002 survey of AIDS NGOs (thirty-four percent of which were African) confirms that many grassroots community groups do not have access to email, Internet, telephone, or fax.[137] This lack of informational and communicational access is a serious impediment to effective performance by AIDS service and advocacy NGOs, which fulfil critical needs within the epidemic.

The survey illustrates the simple and effective shortcuts to informational sharing and accessibility that can be immediately employed in this and other sectors. Thus, while connectivity cannot be assured in the immediate term for all parts of Africa, it is possible to bridge "the 'last mile' of connectivity...by providing outreach tools to those who have access to ICTs and contact with those who do not."[138] The survey found that "there are significant numbers of organizations using these tools almost everywhere and much higher numbers who want to be able to use them or find ways to access information from them."[139]

This kind of organizational support would allow respondents to share a broad range of information, skills, and experiences, including: "[b]uilding networks and coalitions[,] [a]dvocacy against stigma and for access to care and treatment[,] [p]revention in rural agricultural settings[,] [and] [p]artnering with the media."[140] Resource sharing could take the form of "collecting information during meetings, printing and distributing materials and CD-ROMs, doing simple on-line research for local organizations, or making sure localised perspectives and experience are being collected and shared through the ICT tools."[141]

Several features in the African context suggest that a community oriented approach holds great promise for bridging gaps in HIV/AIDS information and communication, especially because the primary contribution towards the response to HIV/AIDS is said to come from individuals, families, and communities confronted with HIV, rather

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[137] ICAD and CIDA, *supra* note 129, at 4, 12.

[138] *Id.* at 11.

[139] *Id.* at 12.

[140] *Id.* at 8.

[141] *Id.* at 12.

than from national and international efforts.[142] There is also a broad consensus that an effective response relies on community mobilization and active participation in all aspects of the epidemic.[143] Given resource constraints and the absolutely overwhelming needs within the epidemic, "[w]hile Government has a role to play in promoting and expanding the opportunity for access to information by its citizens, intermediary organizations such as churches, schools[,] and civil society are key community links for the flow of trusted information within the community."[144] This conclusion is especially true in Africa, where "community and oral traditions are very strong," and where "community activists and church leaders often hold positions of greater influence than health workers do."[145]

This tradition of individual responsibility for communal well-being is evident in the continent's governing human rights treaty, which, in addition to the customary human rights contained in human rights treaties, also entrenches a range of human duties, including duties towards one's family and society.[146]

A 2002 survey showed that community-level application of ICT to support informational initiatives is proving to be the most effective approach: "communication most affects the knowledge and understanding of HIV/AIDS by individuals and groups."[147] The survey found that this approach is reliant on more common broadcast technologies, such as radio, television, video, and CD-ROMs.[148]

While this paper has taken a practical approach to the question of how information and communication can assist in the fight against HIV/AIDS, theoretical approaches to behavioral change offer critical

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[142] Lieve Fransen, *HIV in Developing Countries*, *in* IMPLICATIONS OF AIDS FOR DEMOGRAPHY AND POLICY IN SOUTHERN AFRICA 4-6 (Alan Whiteside, ed.,1998).

[143] See UNAIDS, *at* http://www.unaids.org/en/in+focus/topic+areas/community+mobilization.asp (last visited Dec. 20, 2004), for a list of resources on community mobilization.

[144] D S Bateson Consulting, Inc., *supra* note 57, at 40.

[145] *Id.*

[146] *African [Banjul] Charter on Human and Peoples' Rights*, art. 27, OAU Doc. CAB/LEG/67/3 (Oct. 21, 1986), *available at* http://www1.umn.edu/humanrts/instree/z1afchar.htm (last visited Dec. 4, 2004).

[147] D S Bateson, *supra* note 57, at 40.

[148] *Id.*

insight into how individuals respond to information and communication.[149] Moreover, when it comes to information dissemination, there are approaches to methods of messaging which may significantly increase effectiveness.[150]

7.2 GENDER INEQUALITY

While the poor lack access to ICT, this lack of access is greater for women because of: lower levels of education among females than males in many countries; the tendency for males to receive technical education more often than females; and the disproportionate representation of males in technology-intensive workplaces.[151] This trend suggests that ICT programs should ensure that gender inequalities are not unwittingly reinforced through policies that fail to account for women's and girls' more limited access to ICT. ICT policies and initiatives on HIV/AIDS should therefore be gender-sensitive, and take specific and targeted steps to ensure that women and girls enjoy the equal benefits of such programs.

This gender-sensitivity is a critical aspect of the use of ICT in relation to HIV/AIDS in Africa, given the dramatic impact that gender inequality has on increasing women's and girls' disproportionate susceptibility to HIV infection. Thus, both ICT and AIDS civil society organizations should prioritize the targeting of women and girls for education and training in both AIDS information and ICT usage as one strategy towards increasing their empowerment.

That gender inequality replicates in ICT access is borne out by a gender assessment study, which shows that in many places, girls do not enjoy equitable access to school-based computer labs. The reasons for this denial included: high student-to-computer ratios and first-come-first-serve policies in circumstances where girls were typically

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[149] *See, e.g.* EVERRET M. ROGERS, DIFFUSION OF INNOVATIONS (4th ed. 1995) (discussing theoretical frameworks addressing behavioral change such as diffusion of innovations theory); *see, e.g.*, EVERRET M. ROGERS & D.LAWRENCE KINCAID, COMMUNICATION NETWORKS: TOWARD A NEW PARADIGM FOR RESEARCH (1981) (discussing social influence theories).

[150] *See, e.g.*, M. KREUTER, D. FARRELL, L. OLEVITCH AND L. BRENNAN, TAILORING HEALTH MESSAGES: CUSTOMIZING COMMUNICATION WITH COMPUTER TECHNOLOGY (2000) (health message tailoring is an innovative approach to public health which combines information and behavior change strategies intended to reach one specific person based on characteristics unique to individuals related to the outcome of interest and derived from an individual assessment).

[151] *Id.*

outnumbered by boys at the secondary level; that girls typically had earlier curfew times and domestic responsibilities which limited their access time; and that local patriarchal beliefs tended to allow boys to dominate the computer laboratory environment.[152]

The study reported that seventy percent of girls in Mauritania emphasized that the Internet provided freedom to them as women, because they no longer needed to limit themselves to the controlled information given by their society and families.[153] Girls also reported increased self-esteem and autonomy from the education, information, and online access gained through the World Links program.[154]

Since ICT can be effective tools of empowerment for women (and men) by enabling their participation in economic and civic life, and by helping to move them out of poverty, the use of ICT in HIV/AIDS programs offers compound benefits for all users.

7.3 Regional and International Opportunities for Funding

There are a diverse range of international, national, and regional initiatives to increase connectivity and access to ICT in Africa, which could provide funding for national and local initiatives or AIDS NGOs. Some of these include ACACIA,[155] the G8 Dot Force,[156] NEPAD, international initiatives such as SatelLife that are focused on health professionals, and regional ones such as Kabissa that are focused on the African non-profit sector. These organizations increasingly recognize the important role of ICT in the African AIDS epidemic, and serve as alternative funding sources to enable ICT and HIV/AIDS initiatives and programs across the continent.

Conclusion and Recommendations

In general terms, information and communication, technological or otherwise, are inextricable and key components of the fight against

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[152] Gadio, *supra* note 83, at 8.

[153] *Id.* at 10.

[154] *Id.* at 13.

[155] See ACACIA, *at* http://web.idrc.ca/en/ev-5895-201-1-DO_TOPIC.html (last visited Jan. 24, 2005).

[156] See ICT Development Agenda, *DOT Force – Review*, *at* http://www.ictdevagenda.org/frame.php?dir=07&sd=10&sid=1&id=49 (last visited Feb. 7, 2005).

HIV/AIDS. ICT offer considerable instrumental value to this fight, facilitating various key aspects of an effective response to HIV/AIDS, including prevention, treatment and care, and vulnerability reduction, as well as advocacy, mobilization, and networking. ICT also have direct and indirect intrinsic value in their capacity to empower users by building skills, and ultimately by increasing connectivity rates, which will encourage economic development and growth. The human and non-technological enablers of communication and information are equally critical and, in contrast to ICT, are abundant resources in the fight against the epidemic. The participation of PLWHA and communities is critical to the success of AIDS strategies in Africa.

The findings of this research paper suggest some guiding principles for initiatives on ICT and HIV/AIDS:

- First, the choice and location of ICT and HIV/AIDS initiatives should be informed by the key elements of an effective response to HIV/AIDS (prevention, care and treatment, and vulnerability reduction measures including human rights protections), and especially by the gaps and deficiencies in national and international strategies.

- Second, initiatives should favor approaches targeted at:
  - High risk populations like women, youth, sex workers, men who have sex with men, refugees, and truck drivers;
  - The social and economic determinants of vulnerability, including poverty, gender inequality, stigma, and discrimination; and
  - The key workers of the epidemic, including health care workers, AIDS NGOs, educators, and people living with HIV/AIDS.

- Third, local content must play a central role in project formulations, accounting for varying social and cultural practices, as well as varying languages.

- Fourth, capacity-building of both intermediaries and end users of initiatives should be a key focus of any such initiatives.

- Fifth, community participation should be a key focus and outcome of initiatives, because it powerfully enhances the effectiveness of HIV/AIDS strategies. Rural and rural-proximate communities in particular appear to hold much promise in overcoming some of the challenges to the comprehensiveness of HIV/AIDS prevention and treatment campaigns, as well as the challenges of limited connectivity in

> reaching outlying areas. They are the human connections in places where technology is absent or limited.

This paper suggests a number of key actions that civil society organizations can take with regard to information and communications ownership and technologies to assist in the fight against HIV/AIDS. Recommendations arising from this paper are as follows:

1. TARGETED INTERVENTIONS:

A) PREVENTION

The glaring inadequacies and gaps in prevention messages and services suggest the need for more effective programs, strategies, and initiatives. General information indicates severe gaps, especially in youth focused programs, both in prevention services like VCT and PMTCT, and in mass media campaigns. This general information should be supplemented nationally, and civil society organizations could play a key role in identifying deficiencies in national prevention strategies and recommending how to bridge them. Possible strategies include independent audits of national prevention programs. Similar audits could also be done of NGO initiatives with a view to finding solutions to problems identified in the coverage, content, and methodologies of programs.

The statistics suggest targeted interventions for other high prevalence groups – such as women, sex workers, pregnant women, and truck drivers – using ICT, print media, and education. Possible interventions using ICT include: safer sex messages transmitted to C.B. radios used by truck drivers along commercial routes, or transmitted as S.M.S. messages to cell phones; print media in antenatal clinics; sex worker education; and increased condom availability.

B) TREATMENT

CSOs can play vital roles in advocacy for increasing treatment access, including to PMTCT and to post-exposure prophylaxis for rape survivors. Community participation is a critical part of ensuring access and adherence, and AIDS NGOs should act as intermediaries and participants within communities and in national programs.

c) Stigma, Discrimination, and Enabling Legal Environments

CSO initiatives should target AIDS-related stigma and discrimination wherever possible. This targeting should be done by correcting myths about the disease, by presenting positive information about the capacity for productive and happy lives once infected, and by promoting knowledge of legal protections against discrimination. Similarly, to the extent that legal protections for PLWHA remain inadequate, AIDS NGOs and PLWHA should engage in advocacy for greater legal protections, including against discrimination in employment, insurance, and health care.

CSOs in both HIV/AIDS and ICT should also advocate for enabling legal and policy environments to facilitate free communication and information access generally, as well as through ICT. Strategies to promote and protect privacy rights and freedom of expression should be incorporated into advocacy by ICT and AIDS NGOs alike.

2. Targeting Increased Access to ICT: AIDS NGOs, Health Care Workers, and Educators

National and international bodies should target increased use of and access to ICT for the workers of the epidemic, given their valuable utility as tools for advocacy, education, and improved health care service provision. This suggests, at a minimum, targeting access for AIDS NGOs and PLWHA organizations, healthcare workers, and educators.

3. Investigating Regional, National, and International Bodies and Initiatives for Funding

CSOs should consider conducting audits of available funding and sponsorship from international, regional, and national initiatives, particularly funding of civil society organizations like AIDS NGOs to help access sponsored connectivity and ICT facilities wherever possible. International initiatives include the G8 Dot Force, ACACIA, the International Development Research Centre, United Nations bodies (including the International Telecommunications Union and the United Nations Development Program), the World Bank World Links Program, the Organization for Economic Cooperation and Development, the African Information Society Initiative, and regional initiatives under NEPAD that aim to promote and accelerate existing projects to connect schools and youth centers. Other regional

initiatives under the Southern African Development Community, the Economic Community of West African States, and the African Union should be audited for their potential to sponsor and facilitate information and communication initiatives on HIV/AIDS. Sponsored access and facilities should also be sought from the private sector, including national and regional internet service providers, computer manufacturers, and telephone service providers.

4. EDUCATION AND RESOURCE SHARING

African NGOs with resources and ICT facilities should consider "twinning" themselves to PLWHA and AIDS NGOs in their own or other African countries in order to educate on ICT use, share informational resources, document human rights violations in outlying areas, and conduct training in advocacy, mobilization, and use of media campaigns.

Wherever possible, PLWHA organizations should empower their own members through training and use of ICT. These initiatives should aim at enabling AIDS NGOs to document their experiences and make these available electronically for researchers, policy makers, and PLWHA elsewhere in Africa or in other nations.

5. GENDER INEQUALITY

AIDS NGOs as well as gender and ICT NGOs should place high priority on initiatives aimed at empowering women and girls through education, ICT use, or any other available means. In particular, such initiatives should ensure that social and economic barriers to access experienced by women and girls do not pose obstacles to their access to ICT or HIV/AIDS educational measures. Gender and ICT NGOs should link with AIDS NGOs to strategize on more effective use of ICT for women and girls in increased education and empowerment. Gender should also be mainstreamed into all initiatives on AIDS and ICT.

6. EFFECTIVE USE OF EXISTING ICT CSOS FOR AN HIV/AIDS RESPONSE

Civil society should promote the "mainstreaming" of AIDS into ICT policy and initiatives in high-prevalence countries. Effective use of HIV/AIDS communication and information should be made by existing information and communication CSOs such as telecenters, schoolnets, libraries, and Internet companies. Print media and posters

in telecenters could alert Internet users to relevant Internet resources, and direct telephone users to AIDS and health information hotlines. Similar AIDS contact information or prevention messages could be carried on Internet banners by Internet service provider sites.

7. MONITORING ACCOUNTABILITY

To the extent possible, civil society groups should consider how to use ICT to monitor the compliance of governments with political commitments under Abuja and UNGASS, using ICT to gather and publicize "shadow" reports on government compliance. Similarly, state compliance with national and international legal obligations on HIV/AIDS should be monitored and widely publicized.

8. COMMUNITY FOCUS

ICT and HIV/AIDS initiatives should aim at incorporating community-based activities into programs, and at involving various elements of communities, including community leaders, neighborhood health communities, community health care workers, traditional birth attendants, and community condom distributors. Community radio should be targeted as a valuable mechanism for disseminating important information on HIV/AIDS and for empowering communities.