

APC Theme Discussion Paper, 2003:

HIV/AIDS, Information and Communication in Africa

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Virus
CD-ROM	Compact Disc Read Only Memory
CIDA	Canadian International Development Agency
CSO	Civil society organization
ICAD	Inter-agency Coalition on AIDS and Development
ICT	Information and Communication Technologies
HIV	Human Immunodeficiency Virus
NGO	Non governmental organization
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
STD	Sexually Transmitted Disease
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Testing and Counselling

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 the youth.

More effective communication about the disease, and greater flows of information are central to the success of AIDS strategies, and for reducing the vulnerability that flows to and from HIV infection. Information and communication are sources of power in an epidemic characterized by its lack—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 is 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, including through the protection of human rights. Information and communication are central threads running throughout this response, providing both form and content to prevention, treatment and care, and vulnerability reduction.

While resource limitations and infrastructural gaps hamper both extensive ICT connectivity and wide-scale scaling up of a comprehensive response to HIV/AIDS, the African continent is rich in the human resources and resourcefulness necessary to enable an effective response to HIV/AIDS. This is evidenced in successes in countries like Uganda, Senegal and Zambia in lowering infection rates, and in the multitude of civil society and community initiatives and projects that are having tremendous local impact throughout the continent. These 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, and especially affected communities are critical elements of an effective response to HIV/AIDS. This participation is largely dependent on free flows of information and communication.

Nonetheless significant obstacles to effectiveness remain in the form of limited resources, stigma, discrimination and marginalisation of PLWHA; a lack of information to enable appropriate behavioural changes and to counter the dangerous social consequences of

misinformation and myths around 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; empowerment of PLWHA, women and other vulnerable groups; increased democratic participation; and greater accountability of national and international decision makers.

While not technologically dependent, information and communication are vastly enabled by technology, which in addition to offering an effective medium, are themselves sources of empowerment and human and economic development. ICT offer multidirectional flows of information, and mechanisms of communication, capable of assisting in the fight against AIDS in a variety of ways.

This research paper broadly examines the role of information and communication in the fight against the AIDS epidemic on the African continent. It is intended to increase understanding of how information and communication offer key resources in the fight against HIV/AIDS, and to suggest key actions that both AIDS and information and communication CSOs can take to assist in the fight against HIV/AIDS. The paper's structure is as follows: Part one describes the nature, scale and responses to the AIDS epidemic across the African continent. Part two briefly describes ICT, the information society and the digital divide in Africa, 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, and describes both national and international HIV/AIDS and ICT initiatives being conducted in various African countries, identifying challenges and opportunities for civil society. Finally, it identifies guiding principles and recommendations for the way forward.

Part One: The HIV/AIDS Pandemic in Africa

Almost 30 million people are infected with HIV and AIDS in Africa, with the vast majority residing in Sub-Saharan African countries.¹ Close to 22 million people have died from AIDS since the epidemic first began, and millions more are becoming ill and dying every year. Last year, 2.4 million adults and children died,² and cumulatively up to eleven million children have been orphaned.³ The projected loss of life is enormous: in response to HIV/AIDS, the UN Population Division has lowered earlier global population estimates for 2050 by 200 million people.⁴

¹ UNAIDS, *Report on The Global HIV/AIDS Epidemic* (Geneva: UNAIDS, 2002). ("UNAIDS Report" below).

² Ibid.

³ Ibid, at 133.

⁴ United Nations Population Division, "Press Release POP/850," 26 February 2003.

High prevalence countries are experiencing dramatic drops in life expectancy, the ill and dying are overwhelming already strained public health services, and millions of children are being orphaned often without adequate social safety nets. The impact of these deaths is to deepen household poverty, threaten “social cohesion, political stability, food security and life expectancy and [impose] a devastating economic burden.”⁵

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,⁶ and the New Partnership for African Development (NEPAD) to vault Africa forward into a renaissance of development and reduced poverty.⁷ 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 care for those infected, orphaned or otherwise affected by the disease. To do so demands “urgent and exceptional national, regional and international action.”⁸

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

1. The Size and Spread of HIV/AIDS in Africa

HIV in Africa is primarily transmitted through sex, which is largely heterosexual.⁹ A significant secondary cause of infections is mother to child transmission of the virus during labour or breastfeeding, with a small additional percentage caused by unsafe injection practices.¹⁰

⁵ United Nations General Assembly, “Declaration of Commitment on HIV/AIDS,” A/RES/S-26/2, 2 August 2001, at para.8. (“UNGASS” below).

⁶ 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. These commitments are captured in the Millennium Development Goals, under which all states undertook time-bound goals and targets in respect of poverty reduction and improved development. For further information on the goals, see http://www.developmentgoals.org/About_the_goals.htm (last accessed 2 May 2003).

⁷ NEPAD is a program of action for the redevelopment 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 marginalisation of Africa in the globalisation process. It provides goals and action plans in respect of eight areas: political governance, economic governance, market access, infrastructure, human development, capital flow, and environment. See the NEPAD website, at <http://www.nepad.com>

⁸ UNGASS, at para.8.

⁹ Global HIV Prevention Working Group, “Access to HIV Prevention: Closing the Gap,” May 2003, available online at <http://www.unaids.org>, last modified 15 May 2003, at 8. (“Global Prevention Working Group” below).

¹⁰ Ibid.

Regional disparities in HIV prevalence are significant. North Africa has the lowest rates of infection on the continent, with infection rates maintaining at and under 0.1 percent.¹¹ In Sub-Saharan Africa, 29.4 million people are infected, including ten million young people aged fifteen to twenty-four, and three million children under fifteen.¹² According to UNAIDS, one in every eleven adults in the region—and one in three in some countries—is living with HIV/AIDS.¹³ More troublingly, the epidemic continues to grow there: last year over seventy one percent of new infections worldwide occurred in this region.¹⁴

Epidemics in Southern and Eastern African are generalized, affecting almost every segment of society.¹⁵ In East Africa, rates are over five percent in Uganda, Ethiopia, Tanzania, Congo, Burundi and Rwanda, and at fifteen percent in Kenya. Ethiopia is displaying rapid increases in infection, with current estimates of 2.7 million infections expected to escalate to ten million by the end of the decade.¹⁶

Although epidemics in West and Central Africa are comparatively less severe, they are still extremely high, and continue to grow. Rates in Cote D'Ivoire, Sierra Leone, and Burkina Faso are over five percent, and in Cameroon and Central African Republic, rates are over ten percent.¹⁷ There is also evidence of recent rapid HIV spread in Nigeria, which is the most populous country in Africa, and has the third largest African epidemic.¹⁸ Nigeria's epidemic is projected to grow to 15 million people—more than one quarter of the adult population—by 2010.¹⁹

There have also been troubling increases in Angola among pregnant women attending antenatal clinics in Luanda.²⁰ This is a serious concern given that Luanda is a refuge for tens of thousands of people displaced by war in the region. War significantly increases vulnerability to infection by its massive displacement of people and disruption of social and governance systems.²¹ There is therefore cause to fear a similar trend in the countries

¹¹ The UNAIDS Report indicates that this is the case for Algeria, Egypt and Morocco. UNAIDS has no information on prevalence rates for Tunisia.

¹² Global Prevention Working Group.

¹³ UNAIDS Report.

¹⁴ MAP, "The Status and Trends of the HIV/AIDS Epidemic in the World," Barcelona MAP Symposium, July 2-4, 2002, XIV International AIDS Conference, at 5. See <http://www.mapnetwork.org/reports.shtml>.

¹⁵ Global Prevention Working Group, at 7. A generalized epidemic is one, which has spread far beyond the original sub-populations with high-risk behaviour, and prevalence among women attending urban antenatal clinics is five percent or more. See Tony Barnett and Alan Whiteside, *AIDS in the Twenty-First Century: Disease and Globalization* (New York: Palgrave Macmillan, 2002), at 98.

¹⁶ U.S National Intelligence Council, "The Next Wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India and China," ICA 2002-04D, September 2002. Available online at http://www.cia.gov/nic/pubs/other_products/ICA%20HIVAIDS%20unclassified%20092302POSTGERBERE.R.htm, last modified 12 May 2003. ("Next Wave" below).

¹⁷ UNAIDS Report.

¹⁸ MAP, at 6.

¹⁹ Next Wave.

²⁰ UNAIDS Report, at 27.

²¹ Ibid.

of the Great Lakes region, including Burundi, the Democratic Republic of Congo and Rwanda.²²

The countries in Southern Africa are worst affected on the continent, with prevalence rates 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.²³ Regionally, Botswana has the highest population percentage of infections (38.8 percent of the population), but South Africa has the highest numbers of infected people in absolute terms and what was until recently the fastest growing epidemic.²⁴

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 like VCT 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, it does little to explain the social and economic determinants of such behaviour. A lack of information continues to be a primary stumbling block, which together with several other factors limit the effectiveness of efforts to counter the spread and impact of the disease. These factors include stigma and discrimination; silence and denial about the disease; poverty and inequality; gender inequities; militarisation, war and conflict; and sexually transmitted diseases. High mobility is another primary risk factor for infection, as is 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 eight percent of all HIV infections, and infection rates among young women aged fifteen to twenty four are approximately twice as high as those among young men.²⁵ 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.”²⁶

The heightened risk of infection amongst women and girls is exacerbated by increased physiological vulnerability to infection, legal disenfranchisement, diminished educational opportunities, sexual violence, sexual trafficking and intergenerational sex.²⁷ Poverty is

²² Ibid.

²³ Ibid.

²⁴ Ibid.

²⁵ Ibid.

²⁶ Global Prevention Working Group, at 8.

²⁷ Ibid, at 12.

another risk factor for women, forcing many into sex-work, “placing them at high risk of contracting HIV and transmitting it to partners.”²⁸

The young are also at extraordinarily high risk of infection. More than forty percent of people infected in Sub-Saharan Africa are aged fifteen to twenty four, and half of all new infections—over seven thousand daily—are occurring among young people.²⁹ This vulnerability is founded in risky sexual behaviour and a lack of access to HIV information and preventive 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: half of the teenage girls in sub-Saharan Africa do not realize that a healthy-looking person can be living with HIV/AIDS.³⁰

In several countries with generalized HIV epidemics, such as Cameroon, Central African Republic, Equatorial Guinea, Lesotho and Sierra Leone, more than eighty percent of young women aged fifteen to twenty four do not have sufficient knowledge about HIV.³¹ In Botswana, where one in three sexual partners potentially have 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.³²

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 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).”³³ ‘Virgin rape’ is a particularly abhorrent offshoot of these myths and misinformation, with increasing reports of rape of young boys and girls, and even infants.

2.2 Stigma, Silence, Denial and Human Rights Violations

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

²⁸ Ibid, at 8.

²⁹ UNAIDS, “Children and Young People in a World of AIDS,” UNAIDS 01.56E, August 2001, at 2. (“Children and Young People” below).

³⁰ Ibid.

³¹ UNICEF, UNAIDS, WHO, “Young People and HIV/AIDS: Opportunity in Crisis,” July 2002, at 10. (“Young People and HIV/AIDS” below).

³² Ibid.

³³ Ibid, at 10.

ongoing discrimination against people with HIV/AIDS, particularly in health care, insurance and employment.³⁴

This stigma and discrimination has complex and multiple causes. UNAIDS reports that 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 that AIDS is incurable, social fears about sexuality, fears relating to illness and death, and fears about illicit drugs and injecting drug use.”³⁵

The stigma attached to the disease, and the direct negative consequences attached to being positive, perpetuate a persistent social and often political silence and denial around 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 voluntarily test themselves.

Silence and denial considerably limit effective communication and information availability about the disease amongst individuals and communities most at risk. This is exacerbated when national, community and religious leaders collude with social silence and denial, and deny the existence of the problem and that it requires urgent action.³⁶ 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.”³⁷ Fear of being openly HIV positive has particularly damaging consequences to efforts to normalize the consequences of infection, and significantly limits the participation of PLWHA in AIDS programmes.

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

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 are a number of regional and global declarations and commitments to taking greater and more effective action on HIV/AIDS.

³⁴ UNAIDS, “A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination,” UNAIDS 02.43E, 2002, at 4.

³⁵ Ibid.

³⁶ Ibid.

³⁷ Ibid.

At the United Nation's Millennium Summit in September 2000, heads of state and governments undertook by 2015 to halt and begun to reverse the spread of HIV/AIDS.³⁸ This commitment was elaborated on the African continent in April 2001, when heads of state and of the then Organization 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 personal responsibility and leadership in the fight against HIV/AIDS, with specific pledges including to set a target of allocating at least fifteen percent of annual budgets to the improvement of the health sector.³⁹

These commitments reached their global zenith in June 2001, when the member states of the United Nations met in a Special Session of the General Assembly on HIV/AIDS (referred to by its acronym of UNGASS). One hundred and forty two countries adopted a declaration of commitment intended to "secure a global commitment to enhancing coordination and intensification of national, regional and international efforts to combat [HIV/AIDS] in a comprehensive manner."⁴⁰

The UNGASS declaration reflects several new understandings about the epidemic. The first is that an effective response is a comprehensive one, and that effective prevention relies in fundamental ways on the availability of treatment and care. Secondly, the declaration recognizes the need for targeted interventions aimed at all high-risk groups especially young people and women. Thirdly, the declaration recognizes that the effectiveness of HIV/AIDS prevention and treatment programs also relies on addressing underlying causes of the epidemic, especially gender inequality, as well as poverty, lack of information and vulnerability from human rights violations. Fourthly, it reflects the growing recognition that community mobilization is the core strategy on which successful campaigns against HIV/AIDS have been built, with PLWHA participation a crucial component. This kind of mobilization is dependent on eliminating the stigma attached to HIV/AIDS, developing partnerships between social and government actors, and ensuring the involvement of communities and individuals infected and affected by HIV/AIDS.⁴¹

Notably, countries committed to time-bound targets and goals in all primary areas of importance in the epidemic, including leadership; prevention; care 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 resources available; and research and development.

Some of these targets include ensuring by 2005 that at least ninety percent of young people aged fifteen to twenty four have access to information, education and services

³⁸ For further information on the goals, see http://www.developmentgoals.org/About_the_goals.htm (last accessed 2 May 2003).

³⁹ Abuja Declaration On HIV/AIDS, Tuberculosis And Other Related Infectious Diseases, 27 April 2001, OAU/SPS/ABUJA/3.

⁴⁰ UNGASS, para. 1.

⁴¹ UNAIDS Report.

necessary to develop the life skills needed to reduce their vulnerability to HIV, and ninety five percent by 2010; empowering women as an essential part of reducing vulnerability to HIV; and by 2003, ensuring national strategies to strengthen health-care systems and address factors affecting the provision of HIV-related drugs, including antiretroviral drugs. Additional excerpts of relevant goals and targets are attached in Appendix A.

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 declining HIV prevalence seen since the early 1990s.⁴² More recently Zambia has seen decreases in HIV prevalence among fifteen to twenty nine year old urban women.⁴³ In addition, urban men and women are reporting less sexual activity, fewer multiple partners and more consistent use of condoms.⁴⁴

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 is hardly surprising given the limited scale of prevention, and even more so of treatment on the continent. For example, it is reported that mass media awareness programs in Africa reach only forty three percent of people at risk.⁴⁵

There are particularly troubling indications that current HIV/AIDS programs are failing amongst the highest risk groups in the epidemic. UNICEF reports that more than one-half of all young people age fifteen to twenty four in more than a dozen primarily African countries have never heard of AIDS or have serious misconceptions about how HIV is transmitted.⁴⁶ Only eight percent of out-of-school youth and a little more than one third of in-school youth have access to prevention programs.⁴⁷ The remainder of prevention priorities are being met in similarly limited fashions: fewer than one in twelve sex workers and their clients are currently targeted by behavioural programs; only fourteen percent of people in need of STD services can obtain them; and only six percent of people who want VCT have access to it.⁴⁸

Access to HIV/AIDS treatment throughout Africa is far more severely limited: under one percent of people with HIV/AIDS have access to antiretroviral medicines, and less than five percent have access to treatments for opportunistic infections.⁴⁹ Although recent years have seen dramatic price reductions, the drugs remain prohibitively expensive for

⁴² Ibid, at 24. HIV prevalence among pregnant women in Kampala fell for eight years in a row—from 29.5% in 1992 to 11.25% in 2000.

⁴³ Ibid, at 26. These declines were from 28.3 percent in 1996 to 24.1 percent in 1999.

⁴⁴ MAP, at 7.

⁴⁵ Ibid.

⁴⁶ Global Prevention Working Group.

⁴⁷ Ibid.

⁴⁸ Ibid.

⁴⁹ World Health Organization, 2003, at <http://www.who.int>, last modified 12 April 2003.

many developing countries. While a few African countries (including Botswana, Namibia and Ghana) are looking at introducing these drugs into their public health sectors, access is likely to remain negligible for some time to come.

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 test themselves, thereby bringing them into contact with preventive messages and services.

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

This lack of political will to act appropriately is also reflected in the failure of developed countries to sufficiently fund comprehensive prevention and treatment in developing countries. This international failure to respond adequately is resulting in what one prominent commentator has called “mass murder by complacency” in Africa and other developing regions.⁵⁰ If combination prevention programs are to be brought to scale in the region by 2005, additional spending of US\$ 573 million is required from all sources (including domestic governments, donor countries and affected households).⁵¹ Developed countries are also failing to contribute the resources necessary to enable treatment. The Global Fund for AIDS, Tuberculosis and Malaria, which is a critical funding mechanism for AIDS programs in the developing world, is short of US\$ 1.4 billion for 2003, with a 2004 shortfall of US\$ 3.3 billion.⁵² According to Stephen Lewis, the UN Secretary General’s Special Envoy on HIV/AIDS, after January the Fund will be in crisis due to insufficient pledges.⁵³

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

⁵⁰ Stephen Lewis, (UN Secretary General’s Special Envoy for HIV/AIDS in Africa), “Mass Murder by Complacency,” notes for press briefing at the United Nations in New York, 8 January 2003, available online at http://www.news24.com/News24/South_Africa/Aids_Focus/0.6119.2-7-659_1305165.00.html, last modified 12 February 2003. (“Steven Lewis” below).

⁵¹ Global Prevention Working Group.

⁵² The Global Fund Against AIDS, Tuberculosis and Malaria, Questions and Answers, available online at <http://www.globalfundatm.org/qa.html>, last modified 22 April 2003. The website indicates that in two rounds, the Global Fund has approved grants to 92 countries—US \$1.5 billion has been committed to 153 programs: Sixty percent of this total is for Africa; sixty percent is for AIDS. Half of the money will be used by governments; half by NGOs. Half is for the purchase of drugs and commodities, and half is for infrastructure and training. Over five years, an estimated 500,000 people will begin receiving antiretroviral treatment, representing a tripling of current coverage in poor countries (including a six-fold increase in Africa). An expected 500,000 children orphaned by AIDS will receive support. Between 2002 and 2004, contributions to the Fund total US\$ 2.3 billion, with an additional US\$ 1.1 billion pledged for the four year period 2005 to 2008. While significant, pledges through 2004 (US\$ 2.3 billion) are not enough to finance Rounds 3, 4 and 5, which are scheduled to occur between October 2003 and October 2004.

⁵³ Stephen Lewis.

workers like 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 amongst 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, people living with HIV/AIDS and all civil society to ensure that governments and other relevant sectors act accountably and responsibly in the AIDS epidemic.

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 globalised 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 development holds the potential to play an important role in the fight against HIV and AIDS.

The following section elaborates 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 on the role of information and communication and ICT in the fight against HIV/AIDS in Africa that follows.

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 generated by the merger of computers and telecommunications,”⁵⁴ it also encompasses traditional broadcasting media like 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.”⁵⁵

⁵⁴ Alexander G. Flor, “ICT and Poverty: The Indisputable Link,” Paper for Third Asia Development Forum on Regional Economic Cooperation in Asia and the Pacific, organized by Asian Development Bank, 11-14 June 2001, Bangkok, available online at

<http://www.worldbank.org/html/extdr/offrep/eap/eapprem/infoalexan.pdf>, last modified 10 February 2003.

⁵⁵ DS Bateson Consulting Inc, “Health, HIV/AIDS and Information and Communication Technologies: A Needs Assessment,” May 21, 2002, conducted for the Digital Task Force of the G8 countries, at 7. Available online at http://www.dotforce.org/teams/health_hiv-aids_ict_report.doc, last modified 10 February 2003. (“DOT Force Needs Assessment” below).

Major ICT include telephone and faxing; broadcast technologies like radio and television, multimedia like video and CD-ROM, computer and Internet connections, email, distance learning technologies, telecentres, videoconferencing, telemedicine, and electronic networks. All save for radio, television, video and CD-ROM 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, centred around information technologies as “reshaping at accelerated pace the material basis of society.”⁵⁶ This reshaping is transition from an industrial to an information-based society.⁵⁷ 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, capital and communication.

The result of these developments has been to transform economic and social structures and relations,⁵⁸ as well as the socio-cultural strata of nations around the world.⁵⁹ While it has been long 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. The promise of the information society is therefore of a “knowledge-based society, yielding untold dividends for education, health, development, democracy and much more.”⁶⁰

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 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.

4. The Status of ICT in Africa

⁵⁶ Manuel Castells, *The Information Age: Economy, Society and Culture: Volume 1: The Rise of the Network Society* (Oxford: Blackwell Publishers, 1996), at 1.

⁵⁷ World Summit on the Information Society, Geneva 2003, “Basic Information,” available online at <http://www.itu.int/wsis/basic/faqs.asp>, last modified 12 February 2003.

⁵⁸ World Summit on the Information Society website, *ibid.*

⁵⁹ Audrey N. Selian, “ICT in Support of Human Rights, Democracy and Good Governance,” ITU, August 2002, at 5. (“Selian” below).

⁶⁰ CRIS, “The Communications Rights in the Information Society (CRIS) Campaign,” at <http://www.crisinfo.org>, last modified 1 April 2003.

The reasons for the African digital divide are diverse. The NEPAD initiative sums them up as follows: “poor 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.”⁶¹

Of the approximately 816 million people in Africa, it is estimated that only:

- 1 in 4 have a radio: 205 million.
- 1 in 13 have a television: 62 million
- 1 in 130 have a computer: 5.9 million
- 1 in 160 use the Internet: 5 million.⁶²

Radio is by far the dominant mass medium in Africa, with twenty five percent of Africans owning radio sets. Current estimates are of over 205 million radio sets, compared with only sixty two million televisions. Existing radio transmitter networks are estimated to cover over sixty percent of the African sub-continent. Community broadcasting is also slowly taking off in the region, with notable numbers of new community radio licenses seen in Ghana, Mali, Niger, Uganda and South Africa.

Television coverage is far more limited at 7.59 percent: national television coverage is largely confined to major towns, and some countries do not yet have their own national television broadcaster. Even relatively well-developed Botswana only launched a national television broadcaster in 2002. There are increasing numbers of commercial broadcasters, however their news and information output is often either a rebroadcast of national state controlled broadcaster news, or of international broadcasters or news agencies. Local news and current affairs, especially those focusing on events outside of the capital is rarely broadcast.

There is extremely limited individual ownership of personal computers and Internet connections: 0.7 percent of people have computers, and 0.6 percent have Internet connections. This figure is not representative of all end users though—Jensen indicates that there are up to three users per dialup Internet account.

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 North Africa and South Africa, with a smattering of subscribers in the remaining forty nine Sub-Saharan African countries.⁶³ Although higher Internet use tends to be associated with more developed economies and infrastructures as in North and South Africa, countries like Senegal and Cape Verde have a higher level of connectivity than their gross domestic product per capita would suggest.

⁶¹ NEPAD, “Bridging the Infrastructure Gap: Bridging the Digital Divide: Investing in Information and Communication Technologies,” available online at <http://www.nepad.com>, last modified 12 April 2003.

⁶² Mike Jensen, “The African Internet – A Status Report, July 2002,” available on the APC website, at <http://www3.sn.apc.org/africa/> last modified 12 February 2003. The figures and information in this section are drawn extensively from this source, and are not individually referenced.

⁶³ Jensen indicates that by mid-2002 there were 1.7 million dialup Internet subscribers in Africa, with 1.2 million in North and South Africa, and the remaining 500 000 in forty nine other countries.

The overall fixed line teledensity is extremely limited, with only one in one hundred people in Africa, or one percent, having telephones.⁶⁴ Infrastructure is focused in capital cities—in 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. There is however a high degree of variability between countries and regions, even within the Sub-Sahara. The countries of the Sahel and Central Africa have the least phone lines: Mali, Congo, Niger and Chad have one phone line for every 200-500 people. North Africa and South Africa have a teledensity of around one in thirteen, and West and East African coastal countries have densities varying from one in fifty to one in one hundred. Countries with teledensity above one in fifty are Botswana, Cape Verde, Gabon, Mauritius, Namibia, Sao Tome, Senegal and Swaziland.

There has also been very rapid growth in mobile cellular telephony in Africa—there are currently over one hundred networks in forty-eight countries. Estimates are of over thirty four million users in Africa (with fourteen million in South Africa).⁶⁵ 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 is skewed towards urban areas, with ICT users in cities and towns vastly outnumbering rural users. While these figures illustrate limited ICT access, none of these figures represent all end 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 newspapers often above 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 telecentres, kiosks, cyber cafés and other forms of public Internet access, such as computers added to community phone-shops, schools, police stations and clinics. One of the best known examples is in Senegal, which has over ten thousand commercially run public phone bureaus, with a growing number in remote locations and increasing access to Internet and other more advanced ICT services.

While most public access centres are in urban areas, a growing number are being established in rural and remote locations, with some centres also serving needs for providing Internet access and other more advanced ICT services to the public.

Part Three: Information And Communication In The Fight Against HIV/AIDS

⁶⁴ NEPAD.

⁶⁵ Cellular Online, “Stats Snapshot for Africa: February 2003,” available online at <http://www.cellular.co.za>, last modified 12 April 2003.

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 around the epidemic. 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. 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.

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 as critically on overcoming obstacles posed by misinformation and myths about the disease; silence, denial, stigma and discrimination; and limited knowledge about HIV/AIDS prevention services including VCT and 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 more effective flows of information and communication about HIV/AIDS extends to all facets of the disease and appropriate responses to it, enabling treatment care and support; epidemiological and health research and reduction of vulnerability to and from 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.⁶⁶

Information and communication are also powerful tools for AIDS service organizations, human rights advocates, and PLWHA organizations, to enable advocacy, mobilization, networking and capacity building. They 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 increased democratic participation. They 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 for informational accessibility and free communication in a society. 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 rooms offer users free expression and communication on topics otherwise taboo, and for people otherwise silenced. This is borne out by an independent gender assessment study

⁶⁶ See Committee on Economic, Social and Cultural Rights, "General Comment 14: The Right to the Highest Attainable Standard of Health," E/C.12/2000/4, para. 11.

conducted in schools in Senegal, Mauritania, Uganda and Ghana which found that school girls primarily used the Internet to research for 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.”⁶⁷ 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: “ICT means government cannot monopolise information on governance ... there is more oppression of journalists in my country. But the authorities cannot shut down every Internet user.”⁶⁸

The broadcasting technologies of radio and television are the most prevalent forms of ICT in Africa, and are the primary vehicles for transmitting information about both prevention and treatment services to large sectors of the population, and in 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 of 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 and repositories of knowledge, with particular benefits for health care workers, AIDS advocates and national decision makers. PLWHA, communities and ASO 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 not only confers knowledge. Effective use of connectivity is now itself a form of political power, with the capacity to leverage social change. In the new information society, “because information and communication circulate primarily through the media system, politics becomes increasingly played out in the space of media.” and this media includes computer mediated communication networks.”⁶⁹

There are considerable examples from across the African continent of the innovative use of information and communication and their technologies in various aspects of the fight against HIV/AIDS. The following section elaborates how information and communication, and ICT are being used in various aspects of the HIV/AIDS epidemic including prevention; health care; population research and epidemiology; advocacy and mobilization, and particularly treatment access; networking and empowerment of AIDS NGOs and PLWHA; and increased governance and accountability.

⁶⁷ Dr Coumba Mar Gadio, “Exploring the Gender Impact of the World Links Program In Some Selected Participation African Countries: A Qualitative Approach,” World Links, December 2001. Available online at <http://www.world-links.org/english/html/genderstudy.html>, last modified 3 March 2003.

⁶⁸ UN Integrated Regional Information Networks, “Still Waiting for the Information Revolution,” 15 May 2003, available online at <http://allafrica.com/stories/printable/200305150744.html>, last modified May 20, 2003.

⁶⁹ Castells, at 476.

1. Prevention

Given the predominance of HIV amongst young people, and in particular the startling figures showing knowledge gaps on HIV/AIDS, AIDS prevention strategies should include interventions targeted at this group. This means that general prevention strategies must focus specifically on high-risk groups, including women, youth, 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 information and communication, and ICT.

1.1 School Based Education

Education and life-skills training in schools is a fundamental part of effecting appropriate behavioural changes among youth. UNAIDS global best practices indicate that national AIDS programmes should aim to provide one hundred per cent of schoolchildren with AIDS education addressing effective prevention, care and support for people with HIV/AIDS, and non-discrimination.⁷⁰ This has been shown to help young people to delay sex, and when they become sexually active, to avoid risk behaviour.⁷¹

While this may seem fairly obvious, children and young people are often denied AIDS education in schools, due to religious or social sensitivities over sexuality and around HIV/AIDS. Moreover the availability of information does not guarantee its application—in some places, schools may teach information on AIDS but not the behavioural skills needed for prevention and support.⁷²

UNAIDS indicates that maximum effectiveness requires partnerships between policy-makers, religious and community leaders, parents, and teachers in formulating sound policies on AIDS education; using curricula adapted to local culture and circumstances, focused on life skills rather than biomedical information; teaching primary and secondary students to analyse and respond to social norms, including understanding which ones are potentially harmful and which ones protect their health and well-being; and training of teachers and peer educators.⁷³ UNAIDS also recommends that HIV prevention and health promotion programmes 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.⁷⁴

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 itself offering individual empowerment with social and

⁷⁰ UNAIDS, “Best Practices: School Based Interventions and Services,” available online at <http://www.unaids.org>, last modified 15 April 2003.

⁷¹ Ibid.

⁷² Ibid.

⁷³ Ibid.

⁷⁴ Ibid.

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 or knowledge is low, and access to technology is highly limited.

This is evidenced in a World Bank initiative called World Links that is establishing Internet learning centres in schools and community learning centres 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.⁷⁵ The project specifically aims at reaching rural youth, by basing three quarters of its Internet Learning Centres outside of capital cities, and using mobile van telecentres and satellite technology.⁷⁶

1.2 Mass Media Campaigns

Mass media and social marketing, using popular culture, and especially popular youth culture are able to convey important information about how to protect against HIV/AIDS, as well as 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 key technologies 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 is a highly effective means of disseminating HIV/AIDS information.⁷⁷

A South African project called loveLife is scaling up a comprehensive package of proven prevention approaches, with the goal of reducing by one-third the number of young people engaging in high-risk sex, and to encourage many young people to delay the initiation of sexual activity.⁷⁸

The key components of loveLife's approach are nationwide media campaigns, including youth-focused television and radio programming, weekly youth newssheets, billboards and taxis that promote sexual responsibility and link young people to counselling and clinical services. It runs service and support programmes, including a network of youth centres that provide HIV prevention services, and accessible adolescent health services in

⁷⁵ Anthony Bloome, "Fighting the Insidious Killer: African Teenagers Battle HIV/AIDS Through ICT," Development Outreach Magazine, Spring 2002. Available online at <http://www1.worldbank.org/devoutreach/article.asp?id=160>, last modified 20 April 2003.

⁷⁶ Ibid.

⁷⁷ Nancy Coulson, "Developments in the Use of Mass Media At the National Level for HIV/AIDS Prevention in South Africa," at 1. Available online at <http://www.comminit.com/stcoulson/sld-5496.html>, last modified 18 April 2003. Coulson indicates ninety nine percent of people have access to radio and seventy five percent have access to television.

⁷⁸ loveLife is a partnership between the South African government, over a hundred community-based organizations, US foundations, and the corporate sector.

public clinics nationwide. LoveLife also works with over one hundred community-based organisations known as loveLife franchise-holders. Rural areas are accessed with loveTrains that visit rural towns and villages across South Africa's rail network, and loveTOURS run through a travelling radio broadcasting unit.

A primary feature is its combination of well-established public health approaches with innovative marketing techniques, reaching young people by “speaking in language that young people relate to and understand; using a tone of optimism, rather than relying on scare tactics – which have little credibility with youth; and harnessing the power and influence of South Africa's youth culture, including television, music, and sports to promote healthy living.”⁷⁹

A survey of South African youth between the ages of twelve and seventeen found that sixty two percent of young South Africans say they have heard of loveLife, and sixty five percent report making behavioural changes as a result, including delaying or abstaining from sex.⁸⁰ Among sexually-experienced young people who are aware of loveLife—sixty nine percent say loveLife has caused them to abstain from sex or reduce their number of sexual partners, seventy eight percent say loveLife has caused them to use condoms.⁸¹

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.⁸² This implies that 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 by especially poor and rural communities, and especially for 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 their ability to “conduct effective epidemiological work and other basic research contributing to evidence-based decision making.”⁸³ ICT offer “access to information, applications to analyse data and tools to communicate,” which can help overcome some of these limitations.⁸⁴

⁷⁹ Ibid.

⁸⁰ loveLife website, at <http://www.lovelife.org.za/corporate/index.html>. The study was conducted by Africa Strategic Research Corporation and the Henry J. Kaiser Family Foundation.

⁸¹ Ibid.

⁸² Human Sciences Research Council, *Nelson Mandela/HSRC Study of HIV/AIDS South African National HIV Prevalence, Behavioural Risks and Mass Media Household Survey 2002*, (Cape Town: Human Sciences Research Council Publishers, 2002). Available online at <http://www.hsrcpublishers.co.za/index.html?hiv.html~content>, last modified 23 April 2003.

⁸³ DOT Force Needs Assessment, at 41.

⁸⁴ Ibid.

PASEi is a CIDA funded project aimed at improving integrated epidemiological surveillance in West Africa. The project is integrated into the Nationwide Health Information Systems of six West African countries: Benin, Burkina Faso, Côte d'Ivoire, Guinea, Mali and Niger. It is aimed at improving popular health conditions through sustainable and efficient reinforcement of West African epidemic control mechanisms, and strengthening their institutional capability in regard to epidemiological surveillance. Its aims include skill and ability improvement of professionals on all levels of the epidemiological plan, and “reinforcing acquired knowledge and experience through continued use of new information technology solutions and the creation of a Website allowing data exchange.”⁸⁵

Epidemiological information using ICT is also being gathered from the private sector. AngloGold, a massive South African mining corporation, is rolling out a comprehensive AIDS reporting tool, using a health care information system to analyse the impact of AIDS on health care costs, giving information on disease profiles and medical and facilities usage, and thereby enabling the mining group to estimate the cost impacts of AIDS and allowing it to project future cost impacts.⁸⁶

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, 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, as well as access to information with relevant local content and language.⁸⁷ Websites and CD-ROMS also enable access to information from conferences, major projects and collections of documents in clearing-houses.⁸⁸ There is a tremendous amount of online information for HIV/AIDS related health care. General as well as medical information is available on AIDS specific websites like 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. It provides summaries of clinical presentations by leading researchers and clinicians, as well as featured reports on major

⁸⁵ Centre for International Cooperation, Health and Development, “Integrated Epidemiological Surveillance Support Project, Phase 2 (2003-2008),” Available online at <http://132.203.52.55/ang/index3b.html>, last modified 23 April 2003.

⁸⁶ ITWeb, “South Africa: AngloGold rolls out IT against AIDS,” 29 April 2003, AfricaPulse, available online at <http://www.africapulse.org>, last modified 30 April 2003.

⁸⁷ DOT Force Needs Assessment, at 41.

⁸⁸ Development Gateway, “The Expanding Role of ICT in HIV/AIDS Program Design and Implementation: Interview with Dr Malcolm Bryant,” October 29, 2002. Available online at <http://www.developmentgateway.org/node/130640/sdm/docview?docid=366014>, last modified 10 April 2003.

clinical and scientific meetings in the USA and, when possible, internationally. *The PRN Notebook* is distributed free of charge to interested healthcare providers and researchers worldwide.⁸⁹

While Internet and distance learning technologies may be costly or require infrastructure where there are 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.”⁹⁰ 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.⁹¹

Similarly, handheld computers are proving to be a useful and viable technology in rural health settings, for data collection, information dissemination, and access to medical reference materials. An appraisal of a Satellife PDA project in Ghana, Kenya and Uganda illustrates that handheld computers offer enormous potential for improving service delivery, and offer specific utility in rural healthcare settings.⁹²

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 is targeted to 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.⁹³

Another resource targeting health care workers is 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.⁹⁴

⁸⁹ Physicians Research Network, at http://www.prn.org/prn_cntnt/about.htm

⁹⁰ Ibid.

⁹¹ The TALC website is at <http://www.talcuk.org/>.

⁹² Bridges.Org, “Evaluation of Satellife PDA Project 2002: Testing the use of handheld computers in Ghana, Uganda and Kenya,” available online at <http://www.bridges.org/satellife>, last modified 5 July 2003.

⁹³ Holly Ladd, “Satellife: HIV/AIDS Related IT Programming,” Presentation at ICT Against HIV/AIDS Coalition Meeting (undated). Available online at <http://www.sdn.undp.org/ictaids/meetings.html>, last modified 20 April 2003.

⁹⁴ Procaare website, <http://www.procaare.org/about.php>, last modified 17 May 2003. Procaare is established between SATELLIFE, the Harvard AIDS Institute, Harvard School of Public Health, and Health and Development Networks.

ProCAARE ensures that health professionals in the developing world can communicate and exchange information on HIV/AIDS with colleagues around the world. A special focus is to stimulate and support communication within the region among colleagues who share similar challenges and concerns. The group is moderated, and moderators support the network by supplying summaries of current and relevant research findings and other material of interest.⁹⁵

Other email discussion groups like AFRO-NETS and AF-AIDS are important avenues for government officials, health care workers, researchers and advocates to connect with each other and to access up to date research and best practices. The IP-Health list of the US Consumer Project on Technology is an excellent resource on 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.⁹⁶ As one example of a multitude of initiatives, the US based John Hopkin's University 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."⁹⁷

There are several examples of initiatives aimed at supplementing existing health care programs with various ICT. For example, 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.⁹⁸

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 of key legal and political battles.

⁹⁵ Ibid.

⁹⁶ Dr Malcolm Bryant, Ibid.

⁹⁷ See <http://www.jhpiego.org/pubs/index.asp>, last modified 18 May 2003.

⁹⁸ Enhancing Care Website, http://www.eci.harvard.edu/about_eci/index.html. The initiative is coordinated by the Harvard AIDS Institute in collaboration with the Program on International Health and Human Rights of the François-Xavier Bagnoud Center for Health and Human Rights and the Department of Population and International Health.

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.”⁹⁹

Mass media in particular has played an important role through the negative publicity which actions obstructing developing country access to medicines has garnered. Media coverage backed by broad civil society protests has decisively altered the outcomes of several of these disputes. This was evidenced when the US government placed South Africa on its trade watch list (a step preceding sanctions) for its amendment of its Medicines Act in 1997 and AIDS activists staged public protests against then Vice President Gore during his campaigns for the US presidency. The adverse media attention, and its feared impact on Gore’s political future, led to the withdrawal of South Africa from the list, as well as an official change in US policy regarding Sub-Saharan African country efforts to access HIV/AIDS drugs.¹⁰⁰

Similarly, when thirty-nine pharmaceutical companies sued the South African government to prevent the promulgation of the same Medicines Act, intensive international media attention was focused on the case, and the extensive public protests conducted around the world. With negative publicity mounting, and their public profile plummeting, the pharmaceutical companies withdrew their case.¹⁰¹

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

ICT also offer to reduce informational asymmetries that hamper appropriate and effective action by governments and civil society from accessing lower priced medicines and diagnostics around the world. Informational availability is facilitated by international organizations like UNAIDS, WHO and UNICEF, and the international NGO Medicines sans Frontieres, who publish up to date information on the sources and prices of

⁹⁹ Selian, at 33.

¹⁰⁰ This was affected through the issuing of an executive order directing the US 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.

¹⁰¹ *Pharmaceutical Manufacturers Association and others v Government of South Africa*, Unreported case no: 4183/98, High Court of South Africa (Transvaal Provincial Division), March 2001. (“The Pharmaceutical Manufacturer’s Case,” below).

antiretroviral drugs and diagnostics, and also provide a list of HIV medicines, test kits and suppliers of AIDS-related products for procurement agencies and countries.¹⁰² 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 recognises that the absence of price information is one of the barriers to access to drugs in countries with limited resources.¹⁰³ Thus

even where affordable alternatives exist, many decision-makers do not have the information they need to identify those manufacturers that can supply these drugs ... Without this information, there is a risk that low-income countries may be paying more than needed to obtain essential drugs.¹⁰⁴

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 broadly disseminate their message, 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.¹⁰⁵ It 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. It 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.

It extensively promotes treatment awareness and literacy among South Africans, and targets "pharmaceutical companies to lower the costs of all HIV/AIDS medications and maintains pressure on the government to fulfil its HIV/AIDS obligations."¹⁰⁶ A key objective is to build a mass membership, currently standing at 10 000 people in seventy branches across the country.¹⁰⁷ Its 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. It has been actively involved in litigation, including the Pharmaceutical Manufacturer's case referred to above, a case to force the government to provide comprehensive PMTCT, and most

¹⁰² UNICEF, UNAIDS, WHO and Médecins Sans Frontières (MSF), "Sources and Prices of Selected Drugs and Diagnostics for People Living with HIV/AIDS," 26 June 2002. Available online at <http://www.supply.unicef.dk/health/hiv aids.htm>, last modified 23 December 2002.

¹⁰³ Ibid, at 1.

¹⁰⁴ Ibid.

¹⁰⁵ The TAC website is at <http://www.tac.org.za>.

¹⁰⁶ TAC Website, "Objectives," <http://www.tac.org.za>, last modified 23 February 2003.

¹⁰⁷ Ofeibe Quist-Arcton, "Mbeki Still in Denial Says HIV Treatment Activist," allAfrica.com, May 29, 2003, available online at <http://allafrica.com/stories/200305290027.html>, last modified May 30, 2003.

recently a claim at the competitions commission against two pharmaceutical companies alleging excessive pricing of antiretroviral medicines.¹⁰⁸

5. Networking and Capacity Building for AIDS Groups

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

ICT are also excellent means of building 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, “to enhance skills in human rights fact finding and documentation, share practical prevention materials and innovative prevention strategies, ... [and] learn more about publicity and media work, campaigning, mobilizing legal support and reporting for domestic and international audiences.”¹⁰⁹

6. Governance and Accountability on AIDS

Free flows of information and communication offer greater transparency in national policy and decision-making on AIDS, as well as more effective governance. This association is described as follows: “good 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.”¹¹⁰ ICT are enabling even remote NGOs and communities to widely publicise human rights violations, and national or local policy and program failures, increasing accountability.

ICT also offer “empowerment of stakeholders through consultation and bottom up inputs into policy formulation.”¹¹¹ For example, the Nigeria AIDS e-forum is holding a six month long open electronic conference on key HIV issues in Nigeria, intended to mobilize stakeholders’ input into the national response to the HIV/AIDS epidemic in

¹⁰⁸ *Minister of Health and others v Treatment Action Campaign and others* [2002] 5 S.Afr.L.R. 721(S.Afr.Const.Ct), at para.20. Further details regarding the claim at the competitions commission are contained on the TAC website.

¹⁰⁹ Inter-agency Coalition on AIDS and Development (ICAD) and The Communication Initiative of 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 Organizations Responding to the HIV/AIDS Crisis,” October 2002, at 12. Available online at <http://www.comminet.com/icad/>, last modified 2 April 2003. (“ICAD and CIDA” below).

¹¹⁰ UN Integrated Regional Information Networks, “Still Waiting for the Information Revolution,” May 15, 2003, available online at <http://allafrica.com/stories/printable/200305150744.html>, last modified May 20, 2003. The quote is by the UN Economic Commission for Africa Executive Secretary K.Y. Amoako.

¹¹¹ Denis Gilhooly, “The Role of ICT in the Response to HIV/AIDS,” ICT against HIV/AIDS Coalition Working Group, UN ICT Task Force Launch, November 20, 2001, available online at http://www.sdn.unep.org/ictaids/UNDP_nov20_ict_hiv.ppt, last modified 3 February 2003.

Nigeria. The discussions are 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 Emergency Action Plan. In addition, key issues discussed and solutions proffered will be summarized and published in book format for dissemination to wider audiences.¹¹²

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 in rural areas within even relatively well-resourced countries throughout the continent. This is a major obstacle to comprehensive dissemination of HIV/AIDS related information, and mutual communication to and from rural areas of pressing needs and problems. Structural obstacles to access are also posed by gender inequality. While overcoming these obstacles requires sustained long term developmental, social and law reform projects, interim measures using innovative and strategic approaches can overcome the more pressing informational and communicational needs. Opportunities for increasing access must also be maximised 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 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 significantly broaden Internet access in Africa, seen in the growing numbers of telecentres that act as vital hubs of communication. Telecentres are also key sites for HIV/AIDS information and communication in the form of print media, or access to HIV/AIDS related telephone help-lines, and the latter has been shown to be a key source of HIV/AIDS related information in South Africa.¹¹³ This is illustrated by the SIDAREC telecentre in Kenya, which is a popular cyber café and social and educational forum for youth, to engage in discussion about health issues affecting them, including HIV/AIDS.¹¹⁴

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

¹¹² See Nigeria AIDS E-Forum website, at <http://www.nigeria-aids.org/eForum.cfm>, last modified 12 April 2003.

¹¹³ Mandela/HSRC Report.

¹¹⁴ SIDAREC website is at <http://www.sidarc.or.ke>. SIDAREC stands for "Slums Information Development and Resource Centres."

A key challenge is in 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 hard to reach communities. However given resource constraints and infrastructural limits on the continent, such ICT do not necessarily present comprehensive solutions. Their utility however remains high for targeted usage. In the interim, the mainstay of efforts to reach rural communities will have to largely rely on non-technological mechanisms like print media, peer-to-peer outreach, community efforts and training to ensure greater dissemination and penetration of relevant information and communication around HIV/AIDS in rural areas. As examples from the field illustrate, vans, trains or buses can ensure that relevant information reach outlying areas.

An example of resource sharing and capacity building comes from the NGO sector, and the practice of twinning NGOS in developed countries with those in developing countries, or within countries twinning urban NGOS with rural. A survey of AIDS NGOs (thirty four percent of which were African) confirms that many grassroots community groups do not have access to, and cannot be accessed directly through email, Internet, telephone or fax.¹¹⁵ This lack of informational and communicational access is a serious impediment to effective performance by AIDS service and advocacy NGOs, who fulfil critical needs within the epidemic.

The survey illustrates 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 to those who have access to ICT and contact with those who do not.”¹¹⁶ 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.¹¹⁷

This kind of organizational sharing and support would enable respondents to share a broad range of information, skills and experiences, including building networks and coalitions, would allow advocacy against stigma and for access to care and treatment, as well as prevention in rural agricultural settings, and partnering with the media.¹¹⁸ Resource sharing could take the form of “collecting information during meetings, printing and distributing materials and CD-ROMS, doing simple online research for local organizations, or making sure localized perspectives and experience were being collected and shared through the ICT tools.”¹¹⁹

Several features in the African context suggest that a community oriented approach holds great promise for bridging gaps in HIV/AIDS information and communication. This is

¹¹⁵ ICAD and CIDA, at 12.

¹¹⁶ Ibid.

¹¹⁷ Ibid

¹¹⁸ Ibid, at 8.

¹¹⁹ Ibid.

especially so since the primary and largest contribution towards the response to HIV/AIDS is said to come from individuals, families and communities confronted with HIV, rather than from national and international efforts.¹²⁰ There is also broad consensus that an effective response relies on community mobilization and active participation in all aspects of the epidemic.¹²¹ Given resource constraints and the absolutely overwhelming needs within the epidemic, “while 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.”¹²² This is especially so in Africa, where “community and oral traditions are very strong,” and where community activists and church leaders often have greater influence than health care workers.¹²³

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 towards one’s family and society.¹²⁴

A study illustrates that community-level application of ICT to support informational initiatives are proving the most effective approach, and where “communication most affects the knowledge and understanding of HIV/AIDS by individuals and groups.”¹²⁵ The survey found that this approach is reliant on more common broadcast technologies, such as radio, television and video, and CD-ROMs and printed material.¹²⁶

7.3 Gender Inequality

While many in Africa lack access to ICT, this lack of access is greatest for women, because of lower levels of education among females than men 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.¹²⁷ This indicates that ICT programs should ensure that gender inequalities are not unwittingly reinforced through policies that fail to account for women and girls’ more limited access to ICT. ICT policies and initiative 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 programs.

¹²⁰ Lieve Fransen, “HIV in Developing Countries,” in Alan Whiteside (ed.), *Implications of AIDS for Demography and Policy in Southern Africa* (Pietermaritzburg: University of Natal Press, 1998), at 4.

¹²¹ See UNAIDS website at

<http://www.unaids.org/publications/documents/responses/index.html#community> for a list of resources on community mobilization.

¹²² DOT Force Needs Assessment, at 40.

¹²³ Ibid.

¹²⁴ African [Banjul] Charter on Human and Peoples' Rights, adopted June 27, 1981, OAU Doc. CAB/LEG/67/3, (1982), entered into force Oct. 21, 1986, article 27. Available online at <http://www1.umn.edu/humanrts/instreet/z1afchar.htm>, last modified 23 February 2003.

¹²⁵ DOT Force Needs Assessment, at 3 and 40.

¹²⁶ Ibid.

¹²⁷ Ibid.

This seems 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 girl's disproportionate susceptibility to HIV infection. This suggests that both ICT and AIDS civil society organizations should prioritise 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 included high student to computer ratios and first come first serve policies in circumstances where girls were typically outnumbered by boys at the secondary level; girls typically had earlier curfew times and domestic responsibilities which limited their access time; and local patriarchal beliefs tended to allow boys to dominate the computer laboratory environment.¹²⁸

The study reported that seventy percent of girls in Mauritania emphasized that the Internet provided freedom to them as women since they no longer needed to limit themselves to the controlled information given by their society and families.¹²⁹ Girls also reported increased self-esteem and autonomy from the education, information and online access gained through the World Links program.¹³⁰

Since ICT can be effective tools of empowerment for women (and men) by enabling their participation in economic and civic life, and helping to move them out of poverty,¹³¹ their use in HIV/AIDS programs offers compound benefits for all users.

7.4 Regional and International Opportunities for Funding

There are a diverse range of international, regional and national initiatives to increase connectivity and access to ICT in Africa, which could provide funding for national and local initiatives or to AIDS NGOs. Some of these include ACACIA, the G8 Dot Force, NEPAD, international initiatives like Satelife focused on health professionals, and regional ones like Kabissa, focused on the African non-profit sector (further information is contained in the Appendix). These organizations increasingly recognize the important role of information and communication ownership and technologies in the African AIDS epidemic. These are alternative funding sources to enable ICT and HIV/AIDS initiatives and programs across the continent, and are important facilitators in this realm.

¹²⁸ Dr Coumba Mar Gadio.

¹²⁹ Ibid.

¹³⁰ Ibid.

¹³¹ World Bank, "Engendering ICT Study Program: Gender and ICT." Available online at <http://www.worldbank.org/gender/ict/>, last modified 31 March 2003.

Conclusion and Recommendations

In general terms, information and communication, technological or not, are inextricable and key components of the fight against 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 through skills building, and to ultimately increase connectivity and therefore economic development and growth. The human and non-technological enablers of communication and information are equally critical, and by contrast, abundant resources in the fight against the epidemic. The participation of PLWHA and of communities is critical to the success of AIDS strategies in Africa.

The findings of this research paper suggests 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 (viz. 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 favour targeted approaches:
 - ◆ To high risk populations like women, youth, sex workers, men who have sex with men, refugees and truck drivers.
 - ◆ To the social and economic determinants of vulnerability, including poverty, gender inequality, stigma and discrimination.
 - ◆ To 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, and 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, holding as it does such powerful effectiveness for 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, and more effective programs, strategies and initiatives. General information

indicates severe gaps especially in youth focused programs, in programs for sex workers and their clients, 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 assessed.

The statistics suggest targeted interventions for other high prevalence groups like women, sex workers, pregnant women and truck drivers using ICT, print media, and education. Possible interventions using ICT include safer sex messages transmitted to CB radios used by truck drivers along commercial routes, or transmitted as SMS messages to cell phones, print media in antenatal clinics, and sex worker education and condom availability.

b) Treatment

CSO can play vital roles in advocacy for increasing treatment access, publicizing government action or inaction, as well as pharmaceutical company actions. Community participation is a critical part of ensuring access, as well as of ensuring drug 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 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 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 National, Regional and International Bodies and Initiatives for Funding

CSOs should consider conducting audits of available funding and sponsorship from international, regional and national initiatives in particular to fund civil society organizations like AIDS NGOs to access sponsored connectivity and facilities wherever possible. International initiatives and interested bodies 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 centres. 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 outer lying areas, and conduct training in advocacy, mobilization, and use of media campaigns.

Where 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 internationally.

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 be mainstreamed into all initiatives on both 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 for HIV/AIDS communication and information should be made of existing information and communication CSOs such as telecentres, schoolnets, libraries and Internet companies. Print media and posters in telecentres 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, neighbourhood 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 empowering communities.

Appendix A: Excerpts of Relevant Commitments from the UNGASS Declaration of Commitment

- By 2005, ensure: that a wide range of prevention programmes which take account of local circumstances, ethics and cultural values, is available in all countries, including information, education and communication, in languages most understood by communities and respectful of cultures; expanded access to essential commodities, including condoms; expanded access to voluntary and confidential counselling and testing; and early and effective treatment of sexually transmittable infections.
- By 2005, ensure that at least 90 per cent, and by 2010 at least ninety five percent of young men and women aged fifteen to twenty four have access to the information, education, including peer education and youth-specific HIV education, and services necessary to develop the life skills required to reduce their vulnerability to HIV infection.
- By 2005, reduce the proportion of infants infected with HIV by twenty percent, and by fifty percent by 2010, by ensuring that 80 per cent of pregnant women accessing antenatal care have information, counseling and other HIV-prevention services available to them.
- By 2003, ensure national strategies to strengthen health-care systems and address factors affecting the provision of HIV-related drugs, including anti-retroviral drugs.
- By 2003, enact, strengthen or enforce legislation, regulations and other measures to eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and develop strategies to combat stigma and social exclusion connected with the epidemic.
- By 2003, in order to complement prevention programmes that address activities which place individuals at risk of HIV infection, such as risky and unsafe sexual behaviour and injecting drug use, have in place in all countries strategies, policies and programmes that identify and begin to address those factors that make individuals particularly vulnerable to HIV infection, including underdevelopment, economic insecurity, poverty, lack of empowerment of women, lack of education, social exclusion, illiteracy, discrimination, lack of information and/or commodities for self-protection, and all types of sexual exploitation of women, girls and boys, including for commercial reasons. Such strategies, policies and programmes should address the gender dimension of the epidemic, specify the action that will be taken to address vulnerability and set targets for achievement.

Appendix B: Resources, Organization and Background Papers

1. Email Discussion Groups

AFRO-NETS

<http://www.afronets.org/>

The electronic conference for the 'African Networks for Health Research & Development' (AFRO-NETS) was established in 1997 to facilitate exchange of information among different networks active in Health Research for Development in Anglophone Africa, and to facilitate collaboration in the fields of capacity building, planning, and research.

Topics for discussion include: Advocacy for health research & development; priority setting; capacity building; resource mobilisation; evaluation; dissemination of results; utilisation of research findings; networking; use of information technology for the health sector; announcement of meetings, training courses and other events of interest to our subscribers; HIV-AIDS issues.

AF-AIDS

<http://archives.healthdev.net/af-aids/>

AF-AIDS is an email discussion forum on HIV/AIDS in Africa. It has over 2300 e-mail members, over 500 web-based browsers and at least another 500 secondary readers. AF-AIDS membership represents over thirty countries in Africa and internationally, and has operated since 1998. Individual members use AF-AIDS to communicate ideas, request information, discuss current issues, and announce events.

E-Drug

<http://www.essentialdrugs.org/edrug/about.php>

E-DRUG is used by health care professionals, researchers and policy makers to obtain and discuss current information on essential drugs, policy, program activities, education and training. Members also use E-DRUG to announce and learn of upcoming conferences or courses in their field.

HealthDEV

<http://www.hdnet.org/mainlinks/projects/moderation.htm>

Health & Development Networks (HDN) is a non-profit organisation, which manages and moderates electronic discussion forums and provides communication support to conferences. Its mission is to mobilize a more effective response to HIV/AIDS and other health-and-development-related issues by improving information, communication and the quality of debate. It comprises both regional and topic-specific forums, including: AF-AIDS (regional forum for HIV/AIDS in Africa); Gender-AIDS (links between PWHA groups, women's organizations and other AIDS NGOs); Int-AIDS (international forum on HIV/AIDS for discussion and advocacy); PWHA-Net (enable knowledge about PWHA networks and to enable networking, strategizing and action); Sex-Work

(concerned with organizational issues facing sex work projects and increasing knowledge and understanding about sex work, sexual health and HIV); Treatment Access, brings together varied groups and organizations making practical, advocacy and policy-related efforts to document and improve the availability of medications and other treatments for HIV/AIDS-related conditions including other STDs and TB, and other care services, such as referral mechanisms and provision of voluntary counselling and testing in developing countries; Break the Silence (arena for all, including government representatives and UN officials); Stigma (discussion forum on stigma in Africa with structured debates); Procaare (a forum for clinical and public health physicians, nurses, researchers, policy-makers, program managers, and other interested health practitioners, with discussion centred on the continuum of biomedical and care issues); STOP-TB - email discussion forum providing electronic networking support to the STOP TB Initiatives' communication strategy.

IP-Health

<http://www.cptech.org/ip/health/>

A discussion forum hosted by the US based Consumer Project on Technology, on intellectual property and health care. Posts address the latest national and international developments in this area, focused particularly on HIV/AIDS, as well as notifying of conferences, new research and initiatives.

Nigeria AIDS e-forum:

<http://www.nigeria-aids.org/eForum.cfm>

An open electronic conference, which inputs to Nigeria's national response to HIV/AIDS.

Pro-NUT: HIV Nutrition and HIV/AIDS

<http://www.pronutrition.org>

ProNut-HIV, a new electronic forum, aims to share up-to-date information, knowledge and experiences on nutrition and HIV/AIDS.

2. Selected Online resources on HIV/AIDS

UNAIDS

<http://www.unaids.org>

Key United Nations body addressing HIV/AIDS, with extensive publications, resources and links.

International AIDS Economic Network:

<http://www.iaen.org>

Information, tools, analysis and research support on the economics of HIV/AIDS treatment and prevention, as well as online conferences, an online library, monthly email newsletter/AIDS.

The Africa HIV/AIDS Research Database (Africa HARD)

<http://www.wangonet.org/Hard>

The Africa HIV/AIDS Research Database (Africa HARD) is a WANGONeT (West African NGO Network) initiative to complement the ongoing continent-wide response to the HIV/AIDS epidemic. It attempts to integrate continent-wide data, views, opinions, debates and facts about HIV/AIDS “with the more traditional and pervasive Western views on the matter.”

The Africa HARD site will situate and contextualise research on HIV/AIDS in Africa; consolidate current and historic data on the subject matter; encourage on-line conference and research on the subject and catalyse debate, advocacy and action on behalf of Africa; facilitate the networking of national, continental and international stakeholders in a coordinated and informed offensive against the epidemic.

The Body

<http://www.thebody.com/>

This is one of the largest HIV/AIDS resources sites, with many useful resources, such as "ask-the-expert" advice on transmission, prevention and treatment.

Monitoring the AIDS Pandemic (MAP) Network

<http://www.mapnetwork.org/reports.shtml>.

MAP is a network of internationally recognized technical experts seeking to assess the status and trends of the global HIV/AIDS pandemic. MAP was created in 1996, through the collaboration of the AIDS Control and Prevention (AIDSCAP) Project of Family Health International, the Francois-Xavier Bagnoud Centre for Health and Human Rights of the Harvard School of Public Health, and Joint United Nations Programme on HIV/AIDS (UNAIDS).

Physicians Research Network

http://www.prn.org/prn_cntnt/about.htm

Latest information on research, diagnosis and management of HIV.

3. Non-governmental organizations and initiatives

African Women's Media Center

<http://www.awmc.com>

The African Women's Media Center, a project of the International Women's Media Foundation, was founded in 1997. Located in Dakar, Senegal, and directed by an advisory committee of African women in the media, the center is the only continent-wide organization working with and on behalf of African women in the media. Since the center's founding, more than 900 women journalists have taken part in 21 programs and workshops conducted by the AWMC.

The AWMC has created a wide range of programs for women journalists throughout Africa with the goal of bringing the voices of African women more prominently into the media -- as reporters, producers, managers, executives, CEOs and media experts. The AWMC offers a wide range of programs for women journalists throughout Africa and

provides women journalists with the opportunity to network throughout the continent. It conducts online training on HIV/AIDS for journalists in Senegal.

Enhancing Care Initiative

<http://www.eci.harvard.edu>

This provides AIDS care teams in Senegal, South Africa, Brazil, Puerto Rico and Thailand, with intranet support including email, group discussions, shared document editing, a documents database, provides team members with a virtual research community for archiving and sharing the latest knowledge about HIV and AIDS care.

Journalists against AIDS

<http://www.nigeria-aids.org/>

Nigerian media NGO that aims to enhance reporting of HIV/AIDS and reproductive health issues through training of journalists and making available information resources, aims to fulfil HIV/AIDS information needs of the media and public, to promote the rights of people infected or affected by AIDS, and to promote and ensure a culture of transparency, accountability and inclusiveness in the national response to HIV/AIDS, ensuring the involvement of all stakeholders in the policy formulation and implementation process

Kabissa

<http://www.kabissa.org/>

Provides Internet tools for the African non-profit sector, including standard email mailboxes, FTP accounts, web space, mailing lists and low cost Internet domain hosting. It also enables organizations to integrate ICT into their advocacy work through capacity building programs, and fosters interaction within the non-profit sector through information sharing and networking tools. There are currently over 320 Kabissa members from thirty two African countries, the Kabissa site receives over 100,000 hits per month (not including member websites), and there are over forty mailing lists dedicated to social change in Africa which members are hosting on the Kabissa server.

Satellite

<http://www.healthnet.org>

Satellite is a US based NGO which seeks to increase connectivity and access to information for health professionals in Africa using satellite, telephone, email and Internet. It enables the exchange of information for decision-making through discussion groups on urgent health topics that support daily communication with colleagues, publications featuring current, reliable public health and clinical content, and GetWeb, a tool that enables users to obtain useful web page content via email. SATELLIFE's global communication network is called HealthNet, and links healthcare workers around the world via e-mail. HealthNet has come to encompass SATELLIFE's information resources, as well as e-mail technology, with over 10,000 members worldwide. HealthNet currently has partners in Eritrea, Ethiopia, Uganda and Zimbabwe.

Soul City

<http://www.soulcity.org.za/03.01.asp>

Soul City is a multimedia 'edutainment' project, with HIV/AIDS occupying sixty percent of its health promotion content. It runs television and radio series, and school life-skills programs, complemented by print media and adult education. It has recently added children focused programming in Soul Buddyz, which is a multimedia intervention aimed at children eight to twelve and their parents. Soul City has a regional program that aims to adapt its TV, radio and print media in eight Sub-Saharan African countries (Lesotho, Swaziland, Namibia, Botswana, Zambia, Malawi, Zimbabwe and Mozambique), and to provide systematic training in the development of a multi-media health initiative.

Auntie Stella: Teenagers talk about sex, life and relationships

<http://www.auntiestella.org>

Auntie Stella was originally produced as an activity pack for young Zimbabweans aged thirteen to seventeen years, and later developed as a website. It aims to encourage young people to discuss key teenage issues, and also gives information that teenagers find hard to get elsewhere. Both the print and website versions use the question and reply format of problem page letters written to agony aunts in magazines, a popular source of information for young people. There are over 30 "questions" covering physical and emotional changes in adolescence, relationships with parents, peers and the opposite sex, gender roles, forced sex, HIV/AIDS and STDs. It is underwritten by AIDSWEB in collaboration with a Zimbabwean NGO, Training and Research Support Centre (TARSC).

Teaching-AIDS at Low Cost (TALC)

<http://www.talcuk.org/>

TALC is a registered charity based in the United Kingdom. The majority of its work is focused on the production and supply of low cost books, which includes many essential texts on tropical medicine, nursing, surgery, HIV/AIDS, child-to-child teaching books and infectious diseases. TALC also provides other teaching aids including 35mm slides sets, PictureCard training packs, rehydration spoons, child growth monitoring equipment. TALC has also recently taken over the Strategies for Hope series, which includes the well-known publication called Stepping Stones.

TALC has also started to develop health information on CD-ROM under a project heading called e-TALC, which seeks to provide urgently needed free health information to developing countries using CD-ROMS.

Wangonet

<http://www.wangonet.org/>

The West African NGO Network is an electronic community of civil society organisations across the region. It is intended to harness the global reach of the steadily evolving Information and Communications Technology sectors for the benefit of Non Governmental Organizations, media, cultural and educational institutions, providing high bandwidth Internet connectivity, while hosting, organizing, managing and providing content online for non-profit organizations, cultural and educational institutions in Nigeria, Ghana and ultimately the West African sub-region

4. Selected Regional and International ICT organizations

The Acacia Initiative

<http://network.idrc.ca>

The Acacia initiative is an international program to empower sub-Saharan communities with the ability to apply ICT to their own social and economic development. This initiative is designed as an integrated program of research and development and demonstration projects to address issues of applications, technology, infrastructure, policy and governance.

Conceived and led by the International Development Research Centre (IDRC), Acacia supports Canada's contribution to the African Information Society Initiative (AISI) that was endorsed by African governments as an action framework to build Africa's information and communication infrastructure.

African Information Society Initiative

<http://www.uneca.org/aisi/>

The African Information Society Initiative (AISI) is an action framework that has been the basis for information and communication activities in Africa for the last six to seven years. Its website says that AISI is "not about technology, [but] about giving Africans the means to improve the quality of their lives and fight against poverty."

Its aims are building the capacities of African telecommunications policy makers and regulators; building global, regional, sub-regional and national networks on ICT for development; harnessing the potential contribution of the diaspora in improving ICT and knowledge in Africa; and analysing and evaluating ICT and content trends in Africa.

ICT against HIV/AIDS Coalition

<http://www.sndp.undp.org/ictaids/browse.html>

Initial founding partners include the Italian presidency of the G8 group of developed countries, developing country governments in South Africa, India, and Brazil; private sector companies (including Accenture, Alcatel, Ghana Computer Systems, Grameen Telephone, Hewlett Packard); non profit and academic organizations (including Markle Foundation, MIT Media Lab, Soros Foundation); UN organizations (including UNDP, UNICEF, UNAIDS, WHO, UNFPA). Intended to affect a broader understanding of how ICT can assist with enhancing prevention and treatment, and social support for communities affected by HIV/AIDS, and provide support to importing policy formulation, coordination and programme implementation.

G8 Digital Opportunity Task Force (DOT Force)

<http://www.dotforce.org/about/>

The DOT Force original membership includes stakeholders from G8 and developing country governments, private and not-for-profit sectors, and international organizations. The DOT Force Implementation Teams have created a wide range of projects in areas such as national e-strategies, access and connectivity, human capacity building, entrepreneurship, and local content. Various projects have been or are in the process of

being implemented. Reports from Implementation Teams have helped lay the groundwork for future work and have identified additional partners for key initiatives.

UN Economic and Social Council Information and Technologies Taskforce

<http://www.unicttaskforce.org/about/planofaction.asp>

In March 2001, the Economic and Social Council requested the Secretary-General to establish an Information and Communication Technologies (ICT) Task Force. This initiative is intended to lend a truly global dimension to the multitude of efforts to bridge the global digital divide, foster digital opportunity and thus firmly put ICT at the service of development for all. The Task Force is supported by the Heads of State and Government of all UN Member States who endorsed the ECOSOC Ministerial Declaration at the Millennium Summit in September 2000.

The objective of the Task Force is to “provide overall leadership to the United Nations role in helping to formulate strategies for the development of information and communication technologies and putting those technologies at the service of development and, on the basis of consultations with all stakeholders and Member States, forging a strategic partnership between the United Nations system, private industry and financing trusts and foundations, donors, programme countries and other relevant stakeholders in accordance with relevant United Nations resolutions.

4. Forthcoming Conferences

Hellina 2003: Information and Communication Technology in the Fight against HIV/AIDS in Africa, 12-15 October 2003, South Africa.

<http://www.helina2003.org/helina2003/default.asp>

The International Medical Informatics Association (IMIA) will convene the fourth Health Informatics in Africa conference in South Africa from 12 to 15 October 2003, focused on ICT in the fight against HIV/AIDS in Africa. The conference aims to bring expert clinicians and researchers in HIV/AIDS together with regional and international experts in health informatics in a unique forum. The goal of this meeting is to introduce all participants to the broad range of issues of mutual concern facing those who develop and manage HIV/AIDS interventions, and the potential for information and communication technologies to further these aims.

UN World Summit on the Information Society, Geneva 2003 and Tunis 2005

<http://www.itu.int/wsis/>

The purpose of the WSIS is to develop a 'common vision and understanding of the information society and the adoption of a Declaration of Principles and Plan of Action for implementation by Governments, international institutions and all sectors of civil society', as it is officially stated. The Summit will be held in two phases: in Geneva in 2003 and in Tunis in 2005. The second phase will provide an ideal opportunity to assess the effectiveness of this action plan, and to make further refinements as required.

5. Selected background papers

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