

PLACING PEOPLE AT THE CENTRE OF THE RESPONSE
TO THE HIV EPIDEMIC

by *Mina Mauerstein-Bail* *

The HIV epidemic and its impact on development is a complex topic, primarily because the nature and the extent of the challenges posed by the epidemic to governments and communities, and ultimately to human development are yet to be fully chartered. It is, however, already clear that the epidemic has profound implications for every aspect of national development and, if ignored or inadequately responded to, it could leave devastating consequences. The World Health Organization (WHO) estimates that by the year 2000, there will be a total of 40 million HIV infected persons. An increasing proportion of all new infections is occurring in developing countries, 65-70 per cent now; 90 per cent by the year 2000. An increasing proportion of adults becoming infected are women; at present, over one third, and at least 50 per cent, within the next 10 years. Increasing numbers of infants are being infected and children left without parents. The majority of all infected adults are in the 15 to 40 age group, the most economically and reproductively active group. At the same time, while research on the development of vaccines and chemotherapeutic treatments is moving forward, knowledgeable experts estimate that appropriate drugs and vaccines may not be available at least within the next 20 years. And even then, issues of cost and availability - especially in developing countries - will have to be addressed.

Knowledge of the social and economic costs and impact of any disease is important in formulating appropriate responses. In the case of HIV infection, this is particularly important not only because of the extent of the epidemic and the speed of its spread but also because it is anticipated that HIV-related illnesses and deaths will have a more adverse impact on families and communities than other fatal diseases. This is because of the clustering of HIV deaths in families and communities and the associated social disruption and because of the stigma and discrimination associated with the disease. In many places, human and communal survival is already threatened and children and the elderly have been left without support. The extent of the epidemic, the age groups it particularly affects and the consequences of this on communities and the economy mean that the HIV epidemic has the potential to impact on all aspects of development.

The HIV epidemic is more than a health issue. It impacts on a wide range of areas outside the health sector, including social and economic development, social welfare, education and training, employment, defence and law enforcement.

The response to the epidemic must show a sensitivity to the multitude of ways in which this epidemic has changed the lives of people all

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over the world. Only by understanding the human impact of the disease can we begin to address the very urgent and compelling needs it has created.

This means that national and international responses will need to encompass all aspects of the epidemic. In countries where the epidemic has already deepened, a spectrum of programmes is emerging, from prevention to care, support and treatment programmes, to programmes of assistance to those surviving after the death of a family member, through the programmes addressing the broader social and economic implications of the epidemic. These broader issues include, for example, the depletion of the labour force, the potential impact on the productive sectors of the economy such as agriculture, mining, industry, transport, the worsening of poverty, increasing homelessness and social and political unrest.

These consequences will not occur in isolation, but will be deeply imbedded in other obstacles to development: poverty, unemployment, indebtedness, and natural disasters, to name a few. These factors also contribute, in turn, to the expansion of the epidemic. Poverty caused by HIV-related illness and death deepens existing poverty and increases indebtedness.

The development of appropriate policies and strategies will be critical in ensuring an effective response to the epidemic. The issues upon which policies are needed are often extremely complex: moral, social, cultural, religious, psychological and legal factors must be taken into account. The epidemic forces discussion of sensitive issues about which frank public discussions may not be customary: sexuality, discrimination, and dying, for example. The very sensitivity of the issues requires a widespread consensus on appropriate responses. The diversity of options necessitates discussion. To achieve consensus, politicians, public health

officials and community leaders will need the courage to overcome discomfort and to speak openly, honestly and compassionately.

The mandate of UNDP is to assist developing countries accelerate the process of capacity building both within the government itself and within the nation as a whole, through support for human resources development, institution building, strategic planning and management and the promotion of human development. Through its network of 113 field offices around the world, UNDP has the capacity for on-going dialogue with, and the provision of flexible support to, recipient governments in over 150 countries. The greatest part of UNDP's resources are allocated to countries and people most in need.

UNDP's involvement with the epidemic dates back to 1987 when it began responding to requests from governments for support to HIV/AIDS programmes. In 1988, a formal Alliance to Combat AIDS was signed between WHO and UNDP. This Alliance provides for a complementary programme of action between the two agencies, building on their respective mandates and areas of competence. Under this Alliance, UNDP has been supporting the development and implementation of national AIDS programmes within the framework of the WHO Global Programme on AIDS. In fact, UNDP is the largest financial contributor to the WHO Global Programme on AIDS and since 1987 has provided more than 30 million dollars for country level prevention and control programmes. As the epidemic evolved, it became clearer that while there is no doubt that HIV remains a major public health problem, the nature of the epidemic, the speed of its spread and its socio-economic consequences demand a multi-sectoral, inter-disciplinary response with the fullest collaboration among the many partners involved. These include governments, international agencies, community-based

groups, NGOs, research institutions, private sector groups, and most importantly, the affected communities.

In recognition of the wider developmental dimension of the epidemic, the Governing Body of UNDP has given specific directions to UNDP within the general context of social and economic development:

- (a) to enhance our understanding of the developmental dimensions of the epidemic;
- (b) to support community-based programmes and programmes for women; and
- (c) to strengthen national capacity to minimize the adverse effects of the epidemic.

Essential components in UNDP's strategy on HIV/AIDS and Development include support for strengthening and expanding community-based programmes and programmes for women within the framework of its support to governments for the development of multisectoral policies, strategies and programmes.

Why are these essential components of our strategy? In 1990, WHO estimated that there were between 8-10 million people worldwide infected with HIV; of these 3-4 million are women. The number of infected women rose sharply during the second half of the 1980's and, in some areas of Africa, Latin America and the Caribbean, there was more than a four-fold increase over a 2 to 4 year period. It is estimated that during the next decade prevalence rates among women will equal and, in some cases, exceed those of men.

Because of their social and sexual subordination in many societies, women are disproportionately affected by the epidemic. The dynamics of sexual, social and economic relationships

between men and women mean that many women are unable to protect themselves against sexually transmitted HIV infection, the predominant mode of infection. Globally, it is estimated that 60 per cent of all cases of infection occur through vaginal intercourse. For Sub-Saharan Africa, the estimate is 80 per cent.

As wives and sex workers, women are at risk of sexual transmission. As mothers, women must deal with the implications of HIV infection for unborn children. As mothers, aunts, sisters, grandmothers and daughters, women will have to care for the children orphaned by the epidemic. As care givers, women bear the burden of caring for sick and dying partners, children, relatives and neighbours, while attempting to hold the family unit together in the face of sickness and death. On all these counts, women are disproportionately affected.

An understanding of the factors that affect women is critical to any effective measures to contain the spread of HIV and to deal with its effects for both men and women. The vulnerability of women to HIV must be understood in the broader context of deeply embedded social and gender inequalities which lie at the heart of women's inability to deal effectively with the risks and needs created by the epidemic. Unless the interaction between HIV infection, cultural values and the rights and needs of women is recognised, the fundamental change required to stem this epidemic is unattainable.

While women require urgent consideration in the response to the epidemic, interventions must mobilize all sectors of society, including individuals, and, in particular, men, families, communities and governments. The means for reducing the risk of infection must be available, accessible and affordable. Infected people need hope and need to be able to live positively and productively. They require access to counsel-

ling, treatment, support services and hope for their children who will survive them. Survivors need support to carry on.

UNDP recognizes that there are no simple formulae for policy, strategy, and programme development for the epidemic. Approaches will vary depending on the stage of the epidemic in a country or a region, but everywhere the role of community-based organizations will be central. The impact of the epidemic is so devastating that individuals, infected and not infected, need support. Throughout the world, communities have responded to this need, a need for assistance to change behaviour and for sustenance, when infected. The unflinchingness of this response in affected communities justifies hope and the belief that the world will find ways to respond to the epidemic.

The need for psychological, emotional and financial support for people affected by HIV, for education and prevention programmes, and for the care and treatment for people with HIV can be addressed in a constructive and cost-efficient way by self-help initiatives and community-based programmes.

Community-based organizations can play multiple roles within a national strategy. They can facilitate behaviour change at the level of individuals, families, groups and communities. They can provide psychological, emotional and social support to affected families and survivors. They can provide home and community-based care, counselling and treatment. They can provide emergency support to families and communities, food and financial support. They can represent the needs and interests of the affected. They can lessen fear, stigma and discrimination. They can provide long-term assistance, including training, employment creation and income generation.

Communities around the world have started groups and programmes which respond directly to their needs and concerns. Amongst the better known of these in Africa are the AIDS Support Organization (TASO) in Uganda, the Chikankata Hospital Community-Based Care and Counselling Programme in rural Zambia, The Family Health Trust, The Umbrella Organization for community groups working with HIV in Zambia, and Wamata in Dar-es-Salaam, Tanzania. In Asia, the Duang Prateep Foundation, Klong Toey, and Empower in Thailand have initiated innovative community-based approaches to HIV/AIDS.

There must, however, also be a complementary and mutual reinforcement between the community response and the government response. In many countries, structures and mechanisms for effective interaction between these groups are not well established or lacking altogether. Collaboration and co-ordination among all participants is essential for an effective national response.

The extent to which national strategies and programmes succeed in effectively responding to the impact of the epidemic - an impact which will touch every aspect of personal, communal, social, political and economic life - will, to a great degree, be influenced by the ability of communities and governments to complement and reinforce each other.

We need to learn more about indigenous responses to the epidemic and how we, the international development community, can best support government and communities to plan, implement, monitor and evaluate effective HIV-related programmes.