

5 Involving the social sector and the judiciary

5.1 Health — Dr Raj Karim, Regional Director for Asia and the Pacific, International Planned Parenthood Federation

HIV/AIDS is a public health issue, which is of concern to all. It is a complex disease with biological, social and economic implications, and increasingly governments are finding that they are unable to deal with its impact. There is an ever-increasing burden in responding to the pandemic: prevention efforts, for example, need to be expanded and to include a special focus on young people and women. Responses are required from all sectors using coordinated and collaborative approaches. 'Risk' must be addressed including the factors that affect vulnerability and the impact of the disease. Leadership and commitment are needed at all levels, particularly to overcome stigma, denial and shame. The health sector should develop a wide range of partnerships in the fight against HIV/AIDS as it cannot successfully fight the disease without help. At the same time, however, it is the health sector that holds the key to dealing with the health aspects of the epidemic.

The health sector needs to strengthen its advocacy role within government in order to ensure that it receives the adequate budgetary allocations to carry out the work that needs to be done. The contribution of the private sector is also important, as the government is not necessarily the only or the main provider of care. Funding is also urgently required to strengthen the basic health infrastructure and it is important to ensure a balance in the provision of programmes for prevention and for treatment and care.

NGO involvement

It should be remembered when developing policies and programmes for care and treatment that frequently young people and women avoid using government health services and that it might be difficult to work in areas such as adolescent health. NGOs, on the other hand, have set up some excellent programmes in adolescent sexual and reproductive health. Efforts should be made to ensure that women's NGOs are brought into the mainstream of HIV/AIDS prevention. They have already shown that they can be particularly successful in dealing with issues around violence and their skills could be used equally well in HIV/AIDS prevention. If NGOs are going to be involved as partners, however, it is important that they are represented at all levels of the consultative process. Certain programme activities, for example, could be contracted to NGOs, eg in South Africa sexuality education has been contracted out to the Family Planning Association. The International Planned Parenthood Foundation (IPPF) provides a radio programme called Sexwise to work with commercial sex workers and migrant workers, both women and men.

In some instances NGO capacity may be limited and may need to be built up. Collaboration with the health sector may provide an enabling work environment in which they can increase their skills. One particular area in which NGOs are particularly skilful is advocacy. It is important that in undertaking advocacy activities that they involve PLWHA and also forge partnerships with a wide range of actors including the private sector.

India, Freedom Foundation, winner of the Commonwealth Award for Action on HIV/AIDS for civil society/NGOs/community-based organizations, category – Comprehensive care

A rights-based approach to meeting the complex needs of people affected by HIV/AIDS is at the heart of the work of the Freedom Foundation in Bangalore, India. Originally established in 1989 to deal with drug addiction, the Foundation expanded its remit in the mid-1990s to include working with people living with HIV/AIDS. It uses multi-pronged, developmental interventions to de-stigmatise HIV/AIDS, and integrate people affected by HIV/AIDS into the community, and provides interim, acute and palliative medical care and related services. In addition to advocating the rights of people living with HIV/AIDS, the Freedom Foundation has been campaigning for relevant legal and other structural changes. These include such things as changes to property-ownership laws that discriminate against women and the mainstreaming of HIV/AIDS in the health sector. The Foundation is represented on the National AIDS Committee, the National Technical Resource Group on the Legal and Ethical Issues of HIV/AIDS, and the Karnataka State Government Task Force on HIV/AIDS. The Freedom Foundation is considered a replicable, low-cost, community-centred model for meeting the needs of people infected with, and affected by, HIV/AIDS.

Ashok K Rau, Founding Director

Commonwealth Pharmaceutical Association Focus Group on HIV/AIDS/TB

The Commonwealth Pharmaceutical Association (CPA) is setting up a Focus Group on HIV/AIDS/TB led by Professor Stephen Denyer of the School of Pharmacy and Biomolecular Sciences at the University of Brighton. It will follow the successful template of the CPA's Malaria Project and involve a multi-sectoral approach - NGOs, government and private industry will all be included. The intention is to involve local people in sub-Saharan Africa to adopt a broad strategy in the fight against HIV/AIDS/TB to fit the local needs and to generate a niche project for pharmacists to assist in HIV/AIDS/TB treatment in local communities. Of particular importance is to demonstrate the contribution that the national pharmaceutical society can make towards promoting 'health' at the community level.

The scope of the project will be limited in the first instance in order to achieve the proposed outcomes with confidence. The African Pharmacy Students Association are particularly keen to be involved. The CPA is particularly pleased to be working with them, as well as the other organisations, to produce something practical and useful that can be used at ground level.

Tony Moffat, Secretary/Treasurer

5.2 Education: the role the higher education sector can play — Adeeba bte Kamarulzaman, FRACP, Head, Infectious Diseases Unit, University Malaya Medical Centre, Malaysia

2001 marks the twentieth year of the recognition of a new disease that has since become known as the Acquired Immunodeficiency Syndrome or AIDS. Over these last two decades the response to the devastation caused by this pandemic has traditionally been associated with governments

and non-governmental organizations. But most important and often most effectively it has come from the community itself. As the prevalence, mortality and adverse economic, developmental and social consequences of the pandemic continue to worsen, more ways have to be found to fight it and to overcome the problems it has created. This calls for the involvement of every sector of society.

Universities as creators and disseminators of knowledge, and as providers of tomorrow's leaders of society and employers of large numbers of staff must play a major role in responding to the pandemic. Sadly their response has, in most instances, been piecemeal, lacking well-developed action plans, and heavily reliant on the initiative of a few interested and committed members of staff and students. Often the involvement of universities has gone no further than the addition of HIV/AIDS to the medical curriculum and research activities.

By and large universities continue to view HIV/AIDS exclusively as a public health or medical problem. In a mapping survey recently carried out by the Association of Commonwealth Universities (ACU) to gauge institutional perceptions and levels of policy development in the universities of its member countries, two thirds of the respondents felt that universities should not assume any major responsibility in the context of HIV/AIDS, which, they felt, was a problem for governments and NGOs.

However universities and the higher education sector in general do have an ethical and intellectual responsibility because they have the capacity to introduce strategies that will contain the spread of the disease, and to set and to advocate standards of good practice within society as a whole in terms of prevention, care, and support for those infected by the disease. Furthermore, as described by Kelly and Chetty in their reports, universities are high-risk institutions for the transmission of

HIV because their populations include a large proportion of sexually active persons, many of whom may be engaging in multiple sexual partnerships, unprotected sex and sexual experimentation. Whether universities choose to recognize it or not, the fact remains that high-risk sexual behaviour is an accepted feature of the life and culture of students on university campuses.

How can the higher education sector play a much needed and greater role in responding to this HIV/AIDS pandemic? In fulfilling their traditional function of teaching, universities, particularly those in areas of high HIV/AIDS prevalence, need to be aware that the needs of students, graduates and societies are being fundamentally changed by the pandemic. Education and training of students about the disease has to go beyond courses on virology and the care and treatment of infected patients. It needs to be integrated into the curriculum of all teaching programmes and courses, underlining their relevance to subsequent professional life and practice. As envisaged by Kelly, “the goal of universities should be to develop AIDS-educated and AIDS-competent graduates who will be adequately qualified to carry AIDS concerns into their subsequent life, to address AIDS issues in their professions and to bring AIDS into the open within their societies”. Universities have traditionally taken a leading role in carrying out research into the scientific, medical, social and communications aspects of HIV/AIDS. However, such research is often hampered by lack of funding and of skilled personnel, particularly in less developed countries. During the next and third decade of the pandemic research by universities and other tertiary institutions must move beyond the health issues and carry out multi-sectoral and multidimensional studies into the factors that characterise HIV/AIDS. Whilst clinical studies on care and treatment, prevention, epidemiology and vaccine development should remain high on research agendas, with particular focus

on the specific needs of individuals and countries, impact studies over a different range of disciplines such as education, economics and development need to be intensified.

Likewise behavioural studies and research into the ethical issues surrounding HIV and AIDS need to be further explored. An important aspect of this research must be the participation of, and consultation with, the communities involved, especially those living with HIV/AIDS. The findings of such research activities should be communicated within and between universities, the community and the public at large. The objective should be the translation of relevant research findings into action.

As institutions with a large number of those 'at risk' universities have a responsibility to protect them against infection and to provide care and support for those that have become infected. A major starting point would be for universities to recognize HIV explicitly as an institutional problem and develop HIV/AIDS policies to deal with it. Key elements of such policies should include raising the level of understanding of HIV/AIDS among students and staff by providing on-going education and training, access to voluntary counselling and testing, and care and support for those who have been infected, all of which have important human rights and legal implications.

In some cases many aspects and components of such policies already exist in various parts of certain universities. But what is required is integration and coordination into one HIV/AIDS policy that is both cohesive and comprehensive. It is, of course, essential that university administrations should not start developing these policies without ensuring that they have the resources and commitment to fulfil them.

As disseminators of knowledge, universities should be taking a lead role in raising awareness in the community through

outreach programmes. Students can be very powerful channels for the best kind of HIV/AIDS education to young people particularly if they themselves have been involved in programme design and delivery, taking into account their own youth culture and language. It is however important to ensure that such programmes are sustained beyond the dynamism of a few individuals. Universities have to be at the forefront of providing avenues for open discussions about HIV/AIDS and should challenge the discrimination and prejudice that currently surrounds it.

What is clearly needed is a comprehensive response that encompasses and utilizes the traditional functions of a university, as creator and disseminator of knowledge; influencing opinions in the community and providing future leaders of society. Such a comprehensive response will require leadership and commitment from the highest levels of the university hierarchy in order to secure the necessary human and financial resources. It will also required a strategic approach, as outlined by Kelly, involving a situational and response analysis; formulation of broad guiding principles; identification of priority areas; and determination of the institutional framework and structures needed for implementation. Finally the response should include clear targets in line with national and international strategic plans and actions such as those outlined in the UNGASS Declaration of Commitment. The fight against HIV/AIDS requires partnerships and collaboration. Universities can show the way through partnerships between students and staff; between the campus, the government and the community; and between universities at local, national and international levels.

References

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Namibia, Ministry of Basic Education, Sport and Culture, winner of the Commonwealth Awards for Action on HIV/AIDS: category – Prevention

Namibia has one of the highest rates of HIV infection in the world, and a high prevalence of STDs among adolescents. It is no surprise then that important elements of that country's HIV/AIDS strategy are programmes for adolescents. My Future is My Choice is a behavioural change programme that has reached approximately eighty thousand aged 15 to 18 throughout the country. It is implemented by Catholic AIDS Action and the University of Namibia under the auspices of the Ministry of Basic Education, Sport and Culture. The programme provides an enabling environment to empower adolescents through information, motivation, and social skills development. This multi-faceted, extra curricular programme also includes a national media campaign and the establishment of health clubs in selected regions of the country. It complements in-school programmes and the national natural science and health educational curricula. My Future is My Choice is recognised as an example of good practice for peer education programming.

Loini Katoma, Permanent Secretary

5.3 Judiciary — Anand Grover, Project Director, Lawyers Collective HIV/AIDS Unit, New Delhi, India

India has a common law system and a written constitution. There is also separation of powers ie the legislature, the executive/bureaucracy and the judiciary. Under a common law system judges have the power to be constructive in their interpretation of the law. The High Courts have the power to strike down a law if it is unconstitutional and the judiciary is very active in this area.

With respect to HIV/AIDS, India has tended towards an isolationist policy, as can be seen in the decision of the Mumbai High Court where a worker was denied work as he was HIV positive. The Indian system allows for someone to be sued without the use of a pseudonym. One of the most prominent recent cases in India has been the case of the 'Lucknow four' in which four employees of the Naz Foundation were distributing materials on HIV/AIDS (pamphlets etc) which led them to being charged under the law in question.

Members of the judiciary in India are becoming much more conversant with issues on HIV/AIDS such as declarations of HIV status before marriage, through workshops which involve as resource people, judges from other Commonwealth countries. The holding of such workshops for judges could be an important means of increasing their understanding of judicial issues around HIV/AIDS in other Commonwealth countries. The success of the Indian experience can be seen in the fact that it is no longer necessary to have to convince judges that they must not disclose the identity of PLWHA.

6 Recommendations

The following recommendations are based on the presentations made at the conference and decisions made by the working groups:

6.1 Overall recommendation for *Para55* Group:

Members of the *Para55* Group are urged to work to obtain the commitment of Heads of Government to adopt a multi-sectoral response to HIV/AIDS and implement the necessary actions both nationally and internationally to minimize the impact of the disease.

6.2 Business and labour

Business and labour should:

(Policy and programming)

- collaborate with the negotiated development of HIV/AIDS policies that are non-discriminatory and enforceable;
- collect and exchange examples of best practices with the assistance of organizations such as the Commonwealth Trade Union Council, the Commonwealth Business Council, the *Para55* Group and other concerned NGOs;
- develop joint programmes and projects;
- agree initiatives for responding to the epidemic;
- cooperate with government in providing legal protection eg by introducing empowerment for women and equity act codes where they do not exist.

(Care & Support)

- encourage the development of support groups and counselling for those infected and affected by the disease;
- promote the development of impact studies, such as those currently being carried out in South Africa;
- support the development of health monitoring of workplaces by country and by sector;

6.3 Women, children and orphans

Advocacy and capacity building are required at the highest level of Government to reduce the impact of HIV/AIDS on women, children and orphans in order to ensure that:

- poverty issues which impact most heavily on women, children and orphans are addressed;
- adolescents (including those who are not yet infected), and particularly girls, have access to education across disciplines;
- children who head households receive advice and support;
- street children are provided with support so that they do not have to live in destitution; resort to prostitution ; or suffer sexual abuse;
- resources for foster care resources are provided;
- psychological development of children affected by HIV/AIDS is addressed;
- nutritional needs of women and children, whether or not infected by HIV, are addressed, including the provision of information on nutrition and the necessary research;
- women providing care for those infected by the disease are provided with the necessary support;

- mother-to-child transmission is reduced by making anti-retroviral therapy available for both mother and child and further research is carried out into transmission through breast-feeding;
- empowerment of women is promoted to prevent infection and support is provided for those infected or otherwise affected by HIV, particularly high risk groups such as young girls; illiterate women; and female sex workers;
- measures are introduced, as appropriate, and implemented to eliminate domestic violence, including sexual violence, against women;
- the rejection from family care and support of widows who are infected with HIV/AIDS is strongly discouraged.

6.4 Education and youth

Half of all new cases of HIV/AIDS and a rapidly increasing number of STIs are now occurring in adolescents and young people. Heads of Government are therefore urged to:

- promote, support and monitor youth-friendly, appropriate, and confidential sexual and reproductive health information and services, including HIV/AIDS and to involve young people actively at all levels in planning and services.
- provide safe spaces where young people can meet;
- provide compulsory schooling for young people
- promote informal programmes for adolescents and young people, particularly out-of-school youth;
- set up sexual and reproductive health education programmes for young people including the girl child and adolescent girls who are at high risk of infection;

- include boys in these programmes to increase their awareness and understanding and help them to develop a sense of responsibility for the opposite sex;
- ensure that adolescent-friendly safe spaces are available for the discussion of personal issues;
- make a commitment to integrate sex education into the school curriculum and ensure that adolescents, in particular, receive information on sexuality and sexual behaviour.

6.5 People living with HIV/AIDS (PLWHA) and high-risk groups

Heads of Government are urged to ensure that:

- People living with HIV/AIDS (PLWHA) are included in all programmes and activities addressing HIV/AIDS prevention, treatment care and support as they can provide expertise and understanding of the needs of those infected or otherwise affected by HIV. Efforts should be made to ensure that they are fully represented and not merely included as 'tokens' for political correctness, and that capacity building is instituted to ensure their effective representation;
- A public health approach should be adopted to address the effects of the pandemic, as recommended in the *Ottawa Charter of Health Promotion*;
- Partnerships should be forged between mainstream service delivery systems and the communities which they serve and their respective roles and responsibilities should be clarified including those relating to financial commitments;

- Accessible and affordable health care and treatment should be made available to those infected by the disease on an ongoing basis;
- Existing legislation should be examined and amended as necessary to ensure that discriminatory practices and stigmatisation are neither promoted nor enforced and are preferably eliminated; Greater awareness should be promoted about the interrelationship between drug taking and drug abuse and risk of HIV/AIDS infection;
- Commonwealth regional activities on HIV/AIDS should be considered.

6.6 Vaccine development

Vaccine development is crucial to the prevention of HIV/AIDS infection. Heads of Government are therefore urged to give strong support to the introduction, and implementation of programmes and activities that:

- raise awareness about vaccine trials in Commonwealth countries;
- advocate support for vulnerable groups participating in trials;
- provide education and information at the local level on the impact of vaccine trials;
- address ethical issues, including the development and implementation of protocols for trials;
- ensure the availability and distribution of vaccines when they become available;
- ensure the involvement of high-risk groups such as men who have sex with men, lesbians, and transsexuals and bisexuals.

South Africa, Positive Art, winner of the Commonwealth Award for Action on HIV/AIDS for civil society/NGOs/community-based organizations, category – Policy and Advocacy

Art can be an effective medium for transmitting messages about HIV/AIDS. Positive Art of Pretoria, South Africa has combined the use of art as a vehicle for raising awareness and combating the stigma attached to HIV/AIDS with sound business practices. In so doing, it has provided a source of income for artists from communities around Johannesburg and Pretoria, some of whom are HIV positive. The group has successfully used a relationship marketing approach to secure a stable customer base for a range of functional and decorative handmade items that prominently feature the red AIDS awareness ribbon. It counts among its clients South African Government departments, private sector companies, foreign diplomatic missions and international NGOs, who use these items in their own HIV/AIDS awareness campaigns. Positive Art is fully self-financing, with 50 percent of its profits going to a charity that provides services for people with HIV/AIDS. Positive Arts combines the therapeutic value of art and craft with an economically sustainable endeavour that generates income and provides tangible support for HIV/AIDS care.

Barbara Rijks

Malawi, Story Workshop, winner of the Commonwealth Awards for Action on HIV/AIDS for the media, category – Prevention

The soap opera is a popular radio and TV format the world over. In Malawi, the weekly half-hour radio drama, Zimachitika, which in English means ‘these things happen’ is the vehicle through which a range of social, cultural and economic issues in rural and urban townships is explored. Story Workshop, the creative and production team behind this popular programme, engages in extensive community research to develop story lines that document realities and uncover the social, economic and cultural barriers to behavioural change. Through the story of Zione, a chief’s granddaughter who marries a truck driver and contracts HIV/AIDS, listeners follow the dramatisation of the realities that confront many women in Malawi in the face of HIV/AIDS and the gender issues that contribute to the spread of the epidemic. In a context of mass denial of certain family behavioural norms, encouraged by cultural attitudes towards gender roles, the non-confrontational opportunities for discourse that the programme provides are important. The work of Story Workshop is helping create acceptable ways to break the silence and face up to social truths.

Marvin Hanke, Managing Director

7 Concluding comments based on the closing remarks by the Hon Dr Neal Blewett, former Federal Minister of Health and former Australian High Commissioner to the United Kingdom

Since CHOGM was held in Durban in 1999, Heads of Government have begun to confront the HIV/AIDS epidemic. Nevertheless the international response has been deflected by the events that took place in New York in September 2001. While ensuring that terrorism is not allowed to continue, Heads of Government should not neglect the other major scourges that are also having a devastating impact on the lives of so many people, particularly in the developing world. When they meet in the spring of 2002, Heads of Government should ensure that the priority, commitment and leadership that they gave to the fight against HIV/AIDS in 1999 are not jeopardised.

HIV/AIDS is very much a Commonwealth priority, as all the statistics show. Yet the application of programmes and activities at the community level are fraught with controversy. What is unquestionable is that the most successful interventions are multi-sectoral and recognise that HIV/AIDS is not just a health problem, it is also a social welfare problem, a development problem, an economic problem and a security problem. Multi-sectoralism must be introduced at all levels – from the highest level of government right down to the community level. The talents and imaginations of all those who can contribute to fighting the epidemic in their own sphere of influence must not be ignored, neglected and dissipated. The inter-relatedness of the problems faced by different sectors must be recognised – this will logically lead to a truly multi-sectoral approach.

Political will is imperative for an effective multi-sectoral response to the HIV/AIDS epidemic. The only person capable of bringing together the various sectors of Government is the Executive Head. Therefore engendering political will is crucial. Politicians, moreover, must recognise that NGOs can make an effective contribution to combating HIV/AIDS and that they should be involved wherever possible.