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THE HIV/AIDS PANDEMIC: SHARED RIGHTS, SHARED RESPONSIBILITIES

This year the World AIDS Day will be observed on 1st December 1995, under the banner "Shared Rights, Shared Responsibilities".

"Like every other epidemic AIDS develops in the cracks and crevices of society's inequalities. We cannot face the epidemic if we try to hide the contradictions and conflicts which it exposes" - Herbert Daniel, Brazil.

The HIV/AIDS pandemic is conceptually complex. It is both a crisis and an endemic condition, at once a specific issue and a permeating one¹. Since the start of the pandemic nearly 20 million people including 1.5 million children have been infected with HIV and an estimated 4.5 million people had developed AIDS by the end of 1994². Africa has suffered the heaviest burden of the disease. There is a recent growth of the mostly heterosexual epidemic in South and South East Asia. In Thailand, HIV infection was first detected in 1985 and in India in 1986^{3,4}.

In India the first reported cases of HIV infection diagnosed were among commercial sex workers (CSWs) in Madras in May 1986⁵. By early 1987, the Indian Council of Medical Research (ICMR) began to set up a national network of HIV screening centres. The available data indicate that India is experiencing a major epidemic of HIV transmission in persons with high risk behaviour viz. commercial sex workers, sexually transmitted disease clinic patients, intravenous drug users and commercial blood donors. There is evidence of a recent spread of the epidemic

from persons with high risk behaviour to others and from urban centres to rural populations. It is estimated that 1.6 million people are currently infected with HIV in India⁶.

Certain aspects of HIV infection need to be stressed. HIV infection is primarily a family disease, rather than a disease affecting many single people. Although it may enter the family through one parent, or member, it also affects the health, social and psychological, economic and spiritual well being of the other members of the nuclear family and often those of the extended family and often those of the extended family as well. There are three social forces that are driving the spread of HIV and blocking effective prevention and care — denial, discrimination and disempowerment⁷.

Human Rights and HIV

Dr. Hiroshi Nakajima, Director General of WHO states that "The HIV/AIDS pandemic can be addressed effectively only if rights and responsibilities are shared equally across the globe".

As Justice Michael Kirby has said "Human rights matter most when they are most under threat⁸. It is therefore important to put people who are susceptible to or are affected by HIV at the centre of any analysis for incorporating special needs of human rights concerns to HIV policy.

The global burden of HIV infection will now be borne overwhelmingly by people in developing countries. Increasingly, inequalities of gender, race and wealth are emerging

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This issue commemorates the World AIDS Day (December 1, 1995)

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in the demography of HIV infection where infection rates are increasing disproportionately among women and even more so among poor women. Hence when discussing human rights in the context of the HIV epidemic and important fact that needs to be kept in mind is that the people most affected by the epidemic are those already in a socially disadvantaged position.

Everyone — men, women, children, the poor, minorities, migrants, refugees, sex workers, drug injectors, gay men — has the following rights:

- The right to be able to avoid infection
- The right to health care
- The right to be treated with dignity and without discrimination when sick with AIDS and to die with dignity.

Regardless of the HIV status, shared rights include the right to liberty, freedom of movement, to employment and to seek asylum.

It is also important to reiterate that there should be no conflict between individual rights and public health.

To uphold these rights it is necessary to create a supportive legal environment which can involve both negative and positive legal interventions. One of the primary reasons why law reform has the potential to be effective in this way is that law in any form is an important expression of social and cultural values and can therefore be used to change these values⁹.

Issues of Human Rights for People Infected/Affected by the Epidemic

When HIV first surfaced in the 1980s it was known as the Gay plague. Gays had to face discrimination and blame. In India, Section 377 of the Indian Penal Code considers homosexuality as a crime and this has acted as a barrier in intervention efforts among homosexuals, prison inmates, occupants of police barracks, *etc*¹⁰. Laws that criminalize homosexuality hinder efforts to reach homosexuals with information and education.

The next wave of the HIV epidemic was in intravenous drug users. In India, the HIV prevalence in injecting drug users in Manipur is between 60 and 70 per cent. In this connection, as drug abuse is unlawful, interventions like needle exchange or methadone maintenance programmes for drug users may be regarded as abetment or even promotion of these activities.

AIDS is a disease that affects everybody — those infected with the virus, their families, and friends. It also affects those who could be at risk of infection through blood *ie* recipients of blood transfusion/blood products and health care workers. Therefore, everyone has a right to receive safe blood and blood products. Health care workers have the right to be instructed in universal safety precautions, and to be provided with the essentials to follow these precautions.

The link between powerlessness and the risk of exposure to HIV provides the key to understanding the source of women's vulnerability to HIV infection. The HIV epidemic has taken the sexual, economic and cultural subordination of women and translated it into a death sentence¹¹.

Many societies define social and cultural identity of women primarily through their role as child bearers and child rearers and now as transmitters of HIV. In their reproductive role, they are deprived of the power to determine the basis upon which their sexual relationships with men takes place. For many women, sexual intercourse is not a question of choice but rather a question of survival.

Women's access to cash economy other than through prostitution is often limited by land ownership, by their limited access to education, training, employment and through their cultural restricted mobility.

Prevention strategies will only be effective in protecting women from the effects of HIV if they recognize and actively promote the human rights of women^{9,11-13}.

Women's social and economic position needs to be improved if women are to protect themselves against HIV.

- Women have a right to knowledge about how to prevent infection. A woman's right to use vaginal microbicides will give her a choice when her partner refuses to use a condom.
- The right to health care for treatment of sexually transmitted diseases and the right that women's diseases that signify the onset of HIV related conditions and AIDS in women including cervical cancer and vaginal candidiasis; are included in the AIDS case definition, so that women could get immediate treatment.
- Women infected with HIV have the right of freedom of reproductive choice and the right to know the facts about perinatal transmission through breast feeding so that she can make an informed and responsible choice.

- Women have the right to confidentiality and freedom from discrimination when her child is found infected.

The most effective preventive strategy for women is behaviour change in men. There is a link between human rights and effective HIV/AIDS prevention for women through international law and through domestic human rights, codes and charter.

The removal of barriers to economic independence for women may be a first step towards enabling women to control the circumstances that give rise to HIV transmission risk. The law can be used to enhance the status of women within marriage or sexual relationships.

Among women, those who are commercial sex workers are especially discriminated against as reservoirs of infection. These women deserve all the human rights that would enable them to protect themselves and the right for treatment of infection of all STDs.

The Declaration on Women, Children and AIDS, issued on the 30th November 1989, reinforces the view that women issues in relation to HIV/AIDS are essentially those that also affect children¹⁴.

Most of the world's children live in developing countries where their right to protection from sexual exploitation and abuse under article 34 of the UN convention on the Rights of Child is far more vulnerable to infringement than in the case for children from affluent countries. Cultural factors that increase the risk of a child's exposure to STD have been described. A well known example is the belief reported from countries in Africa and in India that a male with urethritis can be cured by sexual contact with a virgin or prepubertal girl. Of particular concern recently are reports of an increased demand for sex with children by clients who believe that sex with children carries a lower risk of acquiring HIV. In India, sexual abuse of girls is uniquely linked to religious ritual in the *devadasi* system whereby girls from poor families are dedicated to the goddess Yellama at an early age and later channelized into prostitution¹⁵.

Hence the rights of children to education, especially sex education in schools and also for out-of-school children, is important.

With 8000 people being infected with the virus every day, every business whether it employs 10 or 10,000 will soon have to confront the HIV/AIDS epidemic. Many businesses call for movement of people *eg* transportation, seasonal jobs, *etc.* All Mobile groups of people also have the right for education because to know AIDS could be No AIDS.

All persons infected should have freedom from discrimination, freedom of liberty and freedom to work. The right to confidentiality is necessary. The law can and must be used to establish a protective and supportive framework for people affected by the epidemic and not a punitive one.

The families of persons living with HIV/AIDS (PWAs) should have the freedom from discrimination. They should also have the right for care and support. AIDS patients should also have the right to benefit from newer research and drugs which should be affordable. They should have the right to take part in trials but not be used as guinea pigs.

The association between AIDS and tuberculosis is likely to present as a major problem in Asia thereby emphasizing the need for preventive strategies for both infections. Tuberculosis is now the most common life-threatening opportunistic infection associated with HIV; 82 per cent of patients with AIDS in Myanmar, 56 per cent in India, 52 per cent in Thailand have tuberculosis¹⁶. To address this potentially serious crisis, there is an urgent need of Government commitment and enhanced collaboration between the National AIDS and Tuberculosis Programmes both in the area of prevention and care.

Shared Responsibilities

But Rights are not without Responsibilities and these are to be shared among individuals, families, Governments, communities, societies and cultures.

The Paris AIDS Summit held on 1st December 1994 had 42 heads or representatives of Governments who declared a number of the following responsibilities and obligations:

- To make the fight against HIV/AIDS a priority.
- To fight poverty, stigmatization and discrimination.
- To ensure that all persons with HIV/AIDS are able to realize the full and equal enjoyment of their fundamental rights and freedoms without distinction and under all circumstances.
- To mobilize all societies, public and private sectors, community based organisations and people living with HIV/AIDS in a spirit of true partnership.
- National policies to protect and promote the rights of individuals in particular those living with or those most vulnerable to HIV/AIDS through the legal and social environment. To ensure equal protection under the law for

persons living with HIV/AIDS with regard to access to health care, employment, education, travel, housing and social welfare.

- To intensify the following range of essential approaches for the prevention of HIV/AIDS.

- Promotion of and research on effective vaccines, as also access to them and effective drugs for AIDS: treatment of sexually transmitted diseases and other opportunistic infections; culturally acceptable prevention strategies and products including condoms.
- Promotion of appropriate preventive education including sex and gender education for youth in school and out of school. Educational planners will need to develop policies and programmes regarding issues related to sex education, job discrimination and human rights violations including screening and confidentiality information on HIV status. Education systems should place a stronger emphasis on ethical issues, and will require the development of better teacher guides and manuals.
- Improvement of women's status, education and living conditions.
- Specific risk reduction activities for and in collaboration with the most vulnerable population, such as groups at high risk of sexual transmission and migrant populations.
- The safety of blood and blood products
- Strengthening of primary health care systems as a basis for prevention and care and integrating HIV/AIDS prevention activities *eg* awareness programmes, into these systems, so as to ensure equitable access to comprehensive care.

Individuals have a responsibility to protect themselves and others from infection. Men, in particular, because of their dominant status in many societies have the responsibility to practice safe sex. Families and communities are responsible to educate their members in AIDS prevention and to care for those affected by HIV.

It is important to broaden responsibilities for care to a wider range of existing health and social staff, pastoral workers and PWAs, partners and family members. Broadening responsibilities will spare cost, reduce stigma and eventually make AIDS a concern for all. Integration, networking and coordination are buzz words now-a-days

and need to be carefully used as they may mean to some just shifting responsibilities continuously to others. One important aspect of care is the potential for prevention. Comprehensive care facilities help this to happen and the continuum ensures this to be sustained.

AIDS was dubbed "The first media disease" because the media played a large part both in neglecting it at first and later sensationalizing it. But journalists cannot be blamed as AIDS needs to be understood in all its aspects and journalists have the right to be given proper information to understand not just the disease but the world it affects. The responsibility of the media is in accurate and sensitive dissemination of information, which could influence certain attitudes and behaviour. The media could be a resource in mobilizing efforts against AIDS. The media should try and lead society towards meaningful behaviour changes at all levels.

It is fitting that in 1995, the United Nations International Year of Tolerance, the theme of World AIDS Day is "Shared Rights; Shared Responsibilities".

"We need to reach out to each other as one human being to another. There can be no *them* and *us* if this epidemic is to be overcome. We are engaged upon a voyage of sharing, the sharing of a sense of mystery, of a burden of sadness, of the pain of care, of the laughter of life. It will be a voyage through pain, through the dark side of the epidemic, with hope" - E Reid.

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This write-up is contributed by Dr. J.J. Rodrigues, Director-in-Charge, National AIDS Research Institute, Pune.

ICMR NEWS

The following meetings of various technical groups/committees of the Council were held:

Meetings of the Scientific Advisory Committees (SACs)/Project Review Groups (PRGs)/Task Forces (TFs) held:

SAC of the Centre for Advanced Pharmacological Research in Selected Traditional Remedies, Lucknow	November 13, 1995 (at Lucknow)
PRG of the Division of Reproductive Health and Nutrition	November 15-16, 1995 (at New Delhi)
TF on Epidemiology of Glaucoma	November 28, 1995 (at New Delhi)
TF on Male Contraception	November 30, 1995 (at New Delhi)

Participation of the ICMR Scientists in Scientific Events:

Dr. U. Sengupta, Central JALMA Institute for Leprosy, Agra, participated in a meeting on Immunology of Tuberculosis and also in a meeting regarding the project "Epitope Specificity and Function of T Cell Repertoire in Leprosy" at London (November 2 and 3, 1995, respectively).

Dr. Leela Raman, Dy. Director (Sr. Grade), National Institute of Nutrition, Hyderabad, participated in the XXVII International Congress on Pathophysiology of Pregnancy at Manila (November 5-7, 1995).

Dr. S.K. Kashyap, Director, National Institute of Occupational Health, Ahmedabad, participated in the II International Conference on Health of Miners at Pittsburgh (November 11-13, 1995).

Dr. G.V. Satyavati, Director-General, ICMR, delivered the Inaugural Address of the Annual Conference of Indian Society for Medical Statistics and Symposium on Measurement of Change in Maternal and Child Health at Madras (November 22, 1995).

Dr. Swarup Sarkar, Asstt. Director, ICMR Unit for Research on AIDS in North Eastern States of India, Calcutta, participated in the National Workshop on Drug Treatment, Rehabilitation, Community Involvement, Research Methodology and Transmission of Drug Related Diseases by IUDs at Yangon (November 27-29, 1995).

Appointments:

Dr. U. Sengupta has taken over as Director of the Central JALMA Institute for Leprosy, Agra, w.e.f. November 13, 1995.

85th Anniversary Celebrations of ICMR:

The Indian Council of Medical Research has entered 85 years of its existence in November 1995. To mark the occasion the Council and its Permanent Institutes/Centres located in different parts of India have planned various

scientific programmes spread over a year (till November 1996) with the aim of disseminating to scientists and the common man, the various contributions of ICMR. In this connection the Council's National Institute of nutrition highlighted the Nutrition theme on November 28, 1995.

ICMR AIDED SYMPOSIA/SEMINARS/WORKSHOPS/COURSES/CONFERENCES

Symposium/Seminar/Workshop/ Course/Conference	Date & Place	Contact Address
XXVI Annual Conference of the Endocrine Society of India.	December 1-3, 1995; (at Ahmedabad)	Dr. J.M. Bhatavdekar, Organising Secretary, ESICON-1995, Division of Molecular Endocrinology, The Gujarat Cancer Society, Ahmedabad.
International Symposium on Prospects of Zona Pellucida Glycoproteins for Immunocontraception and VII Annual Meeting of Indian Society for the Study of Reproduction and Fertility.	December 2, 1995; (at New Delhi)	Dr. S.K. Basu, Director, National Institute of Immunology, New Delhi.
International Symposium on Trends in Microbiology.	December 5-8, 1995; (at Calcutta)	Prof. T.B. Samanta, Organising Secretary of the Symposium, Bose Institute, Calcutta.
International Symposium on Radiomodifiers in Human Health.	December 28-31, 1995; (at Manipal)	Prof. P. Uma Devi, Convenor, ISRHH, Department of Radiobiology, Kasturba Medical College, Manipal.
Symposium on Casava in Nutrition and Health.	February 10-11, 1996; (at Thiruvananthapuram)	Dr. K.T. Shenoy, Organising Secretary of the Symposium, Department of Gastroenterology, Medical College, Thiruvananthapuram.
V National Conference of Biomechanics	February 22-24, 1996 (at Madras)	Dr. S. Radhakrishna, Organising Secretary of 5NCB, Department of Applied Mechanics, Indian Institute of Technology, Madras.
International Conference on Current Status and Challenges in Medical and Veterinary Microbiological Research, Particularly in Third World Countries.	February 26-28; 1996 (at Jabalpur)	Prof. S.M. Singh, Organising Secretary of the Conference, Department of Biological Sciences, R.D. University, Jabalpur.

COUNCIL'S TRAINING PROGRAMMES

Reproductive Biology

At the Institute for Research in Reproduction, Bombay:

- Training Course on Techniques in Neuroendocrine Research (February 6-10, 1996).

Nutrition

At the National Institute of Nutrition, Hyderabad:

- Annual Training Course in Nutrition (December 1, 1995 - February 28, 1996).

Occupational Health

At the National Institute of Occupational Health, Ahmedabad:

- Training Course on Air Pollution Monitoring and Risk Assessment (December 13-19, 1995).

ICMR PUBLICATIONS

	Price (Rs.)
Nutritive Value of Indian Foods (1985), by C. Gopalan, B.V. Ramasastri and S.C. Balasubramaniam, Revised and Updated (1989), by B.S. Narasinga Rao, K.C. Pant and Y.G. Deosthale (Reprinted 1995)	23.00
Growth & Physical Development of Indian Infants and Children (1972, Reprinted 1989)	10.00
Studies on Weaning & Supplementary Foods (1974, Reprinted 1986)	6.00
Studies on Pre-School Children (1974, Reprinted 1984)	6.00
A Manual of Nutrition (Second Edition 1974, Reprinted 1992)	4.50
Low Cost Nutritious Supplements (Second Edition 1975, Reprinted 1994)	4.00
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Menus for Low Cost Balanced Diets and School Lunch Programmes Suitable for North India (Second Edition 1977, Reprinted 1994)	4.50
Some Common Indian Recipes and their Nutritive Value (Fourth Edition 1977, Reprinted 1991) by Swaran Pasricha & L.M. Rebello	10.00
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Diet and Heart Disease (1994) by Ghafoorunissa and Kamala Krishnaswamy	26.00
*Depressive Disease (1986) by A. Venkoba Rao	58.00
**Medicinal Plants of India Vol.2 (1987)	136.00
**The Anophelines of India (Revised Edition 1984) by T. Ramachandra Rao	150.00

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Grant-in-aid for organising Seminars/Symposia/Workshops

The Council provides partial financial assistance for organising Seminars/Symposia/Workshops. Applications for grant of financial assistance (complete in all respects in the prescribed proforma), will be considered only if furnished at least four months before the date of commencement of the Seminar/Symposium/Workshop, etc..

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