DIALOGUE ON AIDS

Perspectives for the Indian Context
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Perspectives for the Indian Context

Editors
Ritu Priya
Shalina Mehta

Vasudhaiva Kutumbakam Publication (P) Ltd.
New Delhi
Acknowledgement: Thanks to all who have assisted us in the editorial tasks - Sapna Desai, Swati Das, Tripti Chandra, Sutanya Mohapatra and Daya Lalvani.

Grateful acknowledgement also to the Indian Council for Social Science Research & WOTRO, Netherlands (IDPAD) as well as the Coalition for Environment & Development, Finland for funding support to organise the workshops, and to Coalition for Research and Action for Social Justice and Human Rights (CRASH) for partial support towards publication costs.

Publisher: Vasudhaiva Kutumbakam Publication (P) Ltd.
Email: vasudhaivakutumbakam@vsnl.net

ISBN 978-81-904474-4-7 (PB)
ISBN 978-81-904474-6-1 (HB)

Price: India/South Asia - Rs. 680 (PB); Rs. 950 (HB)
       Other countries  - US$ 20 (PB); US$ 30 (HB)

Designed by CAPITAL Creations, New Delhi and printed by Auxilium Printing Services, New Delhi.
Dedicated
to

Dr. D. Banerji
who has demonstrated the possibility of a
Holistic Public Health

&

Dr. Samiran Nundy
who has demonstrated the possibility of a
Socially Conscious and Humane Clinician
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*Ritu Priya & Shalina Mehta*  

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Foreword

I pen down my experience as it is both individual and collective – as a counsellor to HIV positive persons and as a member of the Indian Network for People Living With HIV/AIDS myself. Though personally not shaken by the infection, my experience as counsellor in a rural set-up forced me to confront the situation and address the issues of people living with the virus in the community.

My positivity to HIV did not stop me from hunting for a job, especially in the teaching profession, as I possessed the required qualification to become a lecturer in Zoology. It was sheer coincidence that I was, instead, offered a job in an NGO which implements the prevention programme on AIDS. My HIV status motivated me to work as office assistant as there was no vacancy in the college. Within a short span of time, I realised that there is a wealth of information for people who are infected by STIs and HIV, which is available only to a certain group of people whom the programmes are targeting. I used to wonder why this information is known only to a few people and not widely available to the public. Why only to a specific group and why not for all? I was not aware of the dynamics of the HIV infection. My understanding deepened as I started to interact and read more materials on HIV/AIDS. I felt privileged that I had access to this information. I reflected on my own attitude towards infection and realised that I too had carried myths and misinformation about HIV transmission – that healthy people will not infect or pass on the virus, that HIV kills the person immediately – and realised from my own living experience that they are not correct. The role of counselling is crucial for all, irrespective of whether they are volunteers or are referred to for diagnostic purpose, as nobody can tell or predict how a human mind reacts to the diagnosis for HIV given the prevailing stigma and discrimination practices that already exist around this infection.

For more than a year I observed the situation and happenings around me to understand the way communities react and respond. Unfortunately, most of the responses are negative at the personal and family level. Acceptance at the individual level is still an obstacle to coping with the infection. Counselling provides those hopes and
prepares the individual to seek more information with regard to his/her health; to improve the quality of life irrespective of how many years they are going to live. Community and home-based care programmes should provide that support to lead a normal life like any other individual.

I myself have observed a situation where a colleague of mine, who was a field level functionary, was treated differently as everybody knew about his HIV positive status. When he served tea, the Director of the programme took it with great reluctance and most of the time he avoided it. The fear of infection needs to be dealt through positive approach with concrete scientific back up.

While I was working as counsellor, I noticed that only men were seeking health services, whereas their spouses were not aware of their own and their husband’s status. I realised that there is a need to address this situation to make them aware that women do have equal rights to health. In the situation of HIV, the need to improve the quality of life by addressing the health and other issues related to infection is much more important in the absence of a cure.

The impact of HIV/AIDS on individuals varies from person to person and community to community. In my experience of work in south India, I found that the second largest group coming to the hospital is that of housewives. All are widows because their husbands died of AIDS. They are coming for treatment only after the death of their husbands. They do not go to the government hospital because they know that it does not even have the basic drugs to treat oral candidiasis or some advanced medicines like flucanazole. Positive women’s obstetrics needs are not met properly or not handled humanly on many occasions. When pregnant women come, they are shunted from one hospital to another. And no one wants to conduct the delivery. Both private and public institutions are involved in this kind of unethical practice. I knew one pregnant woman from a village, who was only nineteen years old. She was shunted from hospital to hospital. Finally, one district government hospital took her in. But even there, the mother of the pregnant woman conducted the delivery wearing gloves; all the doctors and nurses just helped by telling her how to conduct the delivery. And they bought all the equipments, gloves, etc., for Rs. 1,000/-. In all they spent Rs. 2,000/-. We know pretty well that all the gloves, etc., should be used as universal precautions with all patients, so that no one gets infected. Yet these are the grim realities.

Once I established contact with the Indian Network for People Living With HIV/AIDS and Positive Women of South India based in
Chennai, I felt inspired to initiate a self-help group of people living with HIV in my district, which later on emerged as a network for positive people with the financial assistance from Tamil Nadu State AIDS Control Society. To start with, the project created a safe space for people living with HIV/AIDS to come forward to seek more information related to their infection. Over two years, they have established their work and their identity within the district through various approaches. I was very open, utilising my HIV status just to reduce or minimise the stigma and discrimination. I used to conduct a lot of programmes. Now even the Public Health Department doctors in the district say that they want to have a programme. During discussions, the Public Health doctors admitted that they do not update their knowledge on the latest developments in the disease. Now even those people are speaking up. They have realised that now maybe PLHA networks can play a role in reducing suffering. They can send the people living with HIV to the Primary Health Centre (PHC), which will take care of their medical problems. While implementing the programmes for PLHA, we observed some issues that demand discussions and action at different levels.

We talk about confidentiality and taking consent. I think from my experience, people are not concerned about consent. If the government hospital is willing to treat people living with HIV/AIDS, if they admit them, and if they treat all the opportunistic infections, the patients are not bothered about the consent. About confidentiality, if we do not talk about it, the issue will not arise. Experience shows that good medical care with a positive attitude and social support decrease the need for it.

We know that most of the symptoms are treatable at the PHC level itself. However, the people in a village do not go to the PHC of their own village. They sometimes travel even 50 kms or more just to seek treatment for the oral candidiasis or some stomach pain or white discharge. They are spending a lot of time and money just to get treated for opportunistic infections which can be treated at the PHC level itself. But the problem is, they think that they might get identified with the disease and suffer from a social stigma. So this is a big challenge.

Anti-retroviral (ARV) really works. There is no doubt about that. But the way the pharmaceutical companies have gone to the extent of targeting the positive peoples’ networks directly is questionable. All the networks are expressing that they will reduce the price if more number of people buy their products. Therefore marketing takes place. But no monitoring mechanism exists there. Where will
they go? They cannot afford the CD4 and viral load tests. What will happen if viral resistance develops? What about side effects? Who will monitor all this? Taking realistic and practical decisions is part of the coping mechanism and in fact it should be part of our life. There are opportunities for addressing a lot of crucial issues. For instance, whose responsibility is it to ensure that the doctors update their knowledge? Certainly who can it be other than the state. I personally feel that interactions of this kind should be encouraged to ensure community participation at local level among the different actors to address the health related issues.

I have shared my experiences here since I found this effort highly commendable and appreciable to bring together the responses of various actors, which include NGOs, Government and international organisations and private sectors, in order to initiate a dialogue through sharing perspectives to create a common understanding with a broad based societal concern that is specific to our Indian context. This dialogue for societal concerns has attempted to put forth all the perspectives and insights that exist within our society in responding to an epidemic like AIDS.

Several issues that struck me as important were:

The impact of a fragmented and compartmentalising approach to address the HIV/AIDS issue has been expressed and articulated very well by the authors of the papers and the discussant.

I agree with Dr. Ritu Priya’s statement on macro concept “an environment of social responsibility together with pluralism” as crucial for AIDS prevention, care and support. People/institutions involved in HIV/AIDS work should take up the responsibility to translate this through their programmes.

As raised by Professor Arun Kumar in his paper on “Globalization of the India Economy: Some Current Issues Pertaining to the Health Sector” - the issue of impact on the lives of individuals tempts me to raise the following questions - Is Globalization for the People or are People meant for Globalization?

It is unfortunate that HIV/AIDS disease too is caught in the market approach when millions of people are dying without access to medication. India, too, needs to revise its stand on WTO to promote access to drugs.

Has HIV/AIDS given the opportunity to raise many issues related to health which never got the chance to get addressed/discussed widely before? The answer is ‘Yes’. There is a lot of evidence from various sources of information, meetings and conferences that reiterates the fact that HIV/AIDS has opened up a gamut of issues in
respect to health, with a focus on public health, in responding to any epidemic in several countries - India is also one among these.

That HIV/AIDS is a developmental problem is a well-established fact from the experience of sub-Saharan countries. Individual studies conducted by researchers in India also acknowledge and reaffirm the fact that if HIV/AIDS is not dealt with utmost sensitivity and appropriate responses, there is every possibility that this health issue will emerge as a development issue. To my mind, as a layperson who does not even understand what is a development issue and what it means, I ask when does a health issue become a development issue and what facilitates this? According to my understanding, HIV/AIDS is primarily a health issue; if not handled with appropriate sensitivity at all levels due to prejudice and stigma and poor health infrastructure, it will naturally evolve into a socio-economic issue when the households of communities are denied the opportunity to cope with the disease burden.

When it comes to public versus private health systems, my thinking is on similar lines with those who strongly believe and emphasise the issue that public service should play a major role in addressing the health needs and must ensure good quality of care. Any compromise on this aspect should not be encouraged.

The importance of community action for support and care to HIV positive persons cannot be emphasized enough. Several papers suggest relevant approaches to develop this, in spite of all the difficulties of the existing social situation.

The papers devoted to raise and address the issues around sexuality and gender have brought new insights into these issues. They open a Pandora’s box of issues that need to be addressed while dealing with HIV/AIDS issue as a development issue. Every perspective presented by the authors of the papers enables us to understand the dynamics of the issue and reminds us of the challenges involved in handling the issues in a comprehensive way.

The overall process of discussion and the way the issues have been articulated in the book would stimulate a lot of thinking in the minds of readers who are concerned about these issues. It was a great opportunity for me to be a part of this exercise, and I am grateful to the editors.

Anandi Yuvaraj
Preface

"Medicine is a Social Science
And
Politics Nothing but Medicine on a Grand Scale"

- Virchow, 1848

We are witnessing an unprecedented period of human history. Among the many upheavals causing human misery and suffering across the world at the end of the 20th century and beginning of the 21st, HIV/AIDS is surely a cause for perception of disaster. In the history of humankind, misfortunes such as large-scale epidemics have shaped societies through their contribution to development of the understanding about natural phenomena and social relationships in determining health, disease and death, as well as through generating the organised responses to ill-health. At present, the AIDS pandemic has opened up a Pandora’s box. At least in some of the most affected regions (such as some countries of sub-Saharan Africa) an almost overall restructuring of societies is anticipated. HIV/AIDS has caused, and will continue to cause, immense suffering. Yet it also provides an opportunity for us to re-examine and re-work several social institutions and notions that are of significant consequence to the well-being of the affected groups and the societies in general. Several issues call for such restructuring exercises for control of HIV/AIDS (for instance - gender relationships, the conditions of women in prostitution, determinants of sexual behaviour patterns, the media’s role in the commodification of sexuality, the problem of frustrations and drug abuse among our youth, the issues relating to access to basic needs and human rights, the quality of health care services and their relationship with the community, community support for women and orphans in destitution, and so on). These issues are of significance irrespective of the threat of AIDS. The need for addressing most of them had been recognised and expressed well before AIDS appeared on the scene, but not much action had been taken. It may be worthwhile to do so now, making use of the opportunity offered by the pandemic.
While the need to give serious thought to these issues at a societal level is uncontested, the perspective with which they are to be approached remains controversial.

The threat of the virus has galvanized some sections of society, prompting them to launch an aggressive campaign against the epidemic. First the WHO’s Global Programme on AIDS, and then UNAIDS, have spearheaded ‘the global war against AIDS’. In a special session in June 2001, the UN General Assembly vowed to create a special fund amounting to US $7-10 billion to meet the challenge of the epidemic. Individual activists and philanthropists are putting their might by setting up foundations to confront the onslaught of the HIV/AIDS menace. Members of civil society, the media, academics and social activists have organised prevention and care efforts on large and small scales. The scientific community has, with unprecedented speed in relation to any other disease in the past, discovered the causative agent and the conditions creating vulnerability to it. Modes of transmission are known. National governments have instituted AIDS control programmes. Yet the epidemic remains perplexing not only to practitioners of ‘western medicine’ and to practitioners of medicine in any system, but it is equally challenging to students of human behaviour and society. Science, medicine and society need to connect and interface intimately to meet this public health challenge.

India has had organised action against HIV/AIDS since 1985, and as such there is by now concrete empirical basis to examine the epidemiology of the epidemic and the efforts made to control it, so as to strengthen the responses for the future. This volume was conceived to contribute to the processes of self-evaluation and drawing upon sharing of lessons learnt from the experience of others. With a range of experience and information from international and local contexts, persistent efforts have been made to put forth ideas and bring people from diverse fields onto a common platform. This volume has drawn upon selected papers from two such workshops organised by the two editors, as well as additional papers written subsequently specifically for it. The workshops, organised in June 2001 and January 2002, were conceived independent of each other, but the themes had a logical continuity.

The June 2001 Amsterdam workshop, organised by the IDPAD (a collaborative programme of the Indian Council for Social Science Research [ICSSR] and WOTRO), started the day the historic UN General Assembly was signing the 103 Point Declaration to meet the AIDS pandemic in different parts of the world. The workshop titled
‘Prevention and Care for People Affected by HIV/AIDS in India: A Transnational Perspective’, had participants from Africa, Thailand, the Netherlands and the USA, along with a large delegation comprising of academics, activists, administrators and researchers from India. The workshop organised at Jawaharlal Nehru University (JNU), New Delhi, in January 2002, was a collaborative project of the Centre of Social Medicine & Community Health (CSMCH - JNU) and the Centre for the Study of Developing Societies (CSDS), New Delhi, India, supported by the Coalition for Environment and Development (CED, Helsinki, Finland). Titled ‘Societal Concerns and Strategies for AIDS Control in India’, the workshop was organised with the perspective that no amount of funds, whether from a ‘Global Fund’ or otherwise, can lead to an effective response to the problem if significant rethinking is not done. Conceptual issues related to the programme need to be addressed, not merely the issues of implementation. It brought together physicians, public health analysts, AIDS programme administrators, office bearers of sex workers’ organisations, women’s groups and activists, sociologists and psychologists, academics working on gender issues, communication analysts and media persons, to dwell upon the varied dimensions of the response to the epidemic.

This volume is the outcome of these collaborative efforts. The issues of 2001-2002 are just as relevant, and data has been updated wherever possible. Some data-sets are not available for later years in the same way and so have been retained without updating. While organising the material by themes, the flavour of the different perspectives and writing styles has, consciously, not been ironed out. It is being offered to readers across various fields with the hope that it will contribute to a more extensive and contextualised debate that will result in increasing effectiveness of responses to the epidemic.

The Editors
List of Contributors

Alpana Sagar
(Medical doctor and public health analyst)
Assistant Professor
Centre of Social Medicine & Community Health
Jawaharlal Nehru University
New Delhi - 110067

Amar Nath Sinha
(Social scientist and administrator)
Alumnus Research Scholar
Centre of Social Medicine & Community Health
Jawaharlal Nehru University
New Delhi - 110067

Amita Dhanda
(Legal and social policy studies)
Professor of Law
National Academy of Legal Studies and Research (NALSAR)
University of Law
Hyderabad

Anandi Yuvaraj
(AIDS activist, Biological scientist, ex-office-bearer South India Network of Positive Women)
Programme Officer
HIV/AIDS Alliance
New Delhi

Arun Kumar
(Economist)
Professor
Centre of Economic Studies and Planning
Jawaharlal Nehru University
New Delhi - 110067

Atul Kotwal (Lt. Col.)
(Classified Specialist Preventive & Social Medicine & Epidemiologist)
Joint Director (Medical & Health)
Management Information Systems Organization
Integrated HQ Ministry of Defence (Army)
West Block – III, R.K. Puram
New Delhi - 110066
and
Ph.D. Scholar
Centre of Social Medicine & Community Health
Jawaharlal Nehru University
New Delhi - 110067

Chris M. Kurian
Research Scholar
Centre of Social Medicine & Community Health
Jawaharlal Nehru University
New Delhi - 110067

Deepti Priya Mehrotra
(Political scientist specialising in gender issues and activist in the women’s movement)
Visiting Faculty
Lady Shri Ram College
University of Delhi
and
Sampurna Trust
B-26, Soaminagar
New Delhi - 110016

Dick Schapink
(Social scientist)
Technical Advisor Intervention Development
The Tanzania Netherlands Support programme on AIDS Control in Mwanza
The Royal Tropical Institute (KIT)
Amsterdam, The Netherlands

Flavia Agnes
(Women’s rights lawyer)
Secretary
‘Majlis’ (a legal and cultural resource centre)
Mumbai

Françoise Jenniskens
(Medical doctor, Masters in Community Health in Developing Countries & Epidemiology)
HIV/AIDS and Reproductive Health Group
The Royal Tropical Institute (KIT)
Amsterdam, The Netherlands
Ietje Reerink  
Reproductive Health Technical Advisor  
The Royal Tropical Institute (KIT)  
Amsterdam, The Netherlands

Imrana Qadeer  
(Medical doctor and public health analyst)  
Professor  
Centre of Social Medicine & Community Health  
Jawaharlal Nehru University  
New Delhi – 110067

Josef Decosas  
Southern African AIDS Training (SAT) Programme  
Harare, Zimbabwe

Jyotsna Bapat  
(Sociologist)  
Senior Consultant  
Feedback Ventures (P) Ltd.  
New Delhi

Krishna Soman  
(Nutrition scientist and Women’s health researcher)  
Associate Professor  
Centre for Economic and Development Studies  
Kolkata

Lalitha  
(Civil society leader and Gay Rights activist)  
‘Prakriti Sahodaran’  
Chennai

Madeleen Wegelin-Schuringa  
(Social scientist)  
Senior AIDS Advisor  
The Royal Tropical Institute (KIT)  
Amsterdam, The Netherlands

Manimala  
(Biological scientist, reputed journalist, Women’s movement and JP Movement activist)  
Editor  
Books for Change (Hindi)  
New Delhi
Manisha Joshi  
(Social scientist)  
Alumnus Research Scholar  
Centre of Social Medicine & Community Health  
Jawaharlal Nehru University  
New Delhi - 110067

Pradeep Krishnatray  
(Communications analyst)  
Director  
Centre for Research and Education (CREED)  
B-3, Meera Apartments  
Hyderabad - 500029  
and  
Editor  
Journal of Creative Communications  
Mudra Institute of Communications  
Ahmedabad

Putul  
(Social activist JP Movement, Social researcher on informal sector workers’ & women’s rights)  
Yuva Bharat  
Lucknow

Rajeev Sadanandan  
(Economics graduate and public health analyst, member of the Administrative service)  
Consultant  
National AIDS Control Organisation  
Ministry of Health & Family Welfare  
Government of India  
New Delhi - 110001

Rama V. Baru  
(Social scientist and public health analyst)  
Associate Professor  
Centre of Social Medicine & Community Health  
Jawaharlal Nehru University  
New Delhi - 110067

Ritu Priya  
(Medical doctor and public health analyst)  
Associate Professor  
Centre of Social Medicine & Community Health  
Jawaharlal Nehru University  
New Delhi - 110067
and
Advisor
Technical Resource Group on HIV Prevention in the Workplace, NACO

Ros Beatson
Southern African AIDS Training (SAT) Programme
Harare, Zimbabwe

Shaleen
(AIDS and Gay Rights activist)
Naz India Foundation
D-45, Gulmohar Park
New Delhi

Shalina Mehta
(Anthropologist, Policy analyst)
Professor
Department of Anthropology
Punjab University
Chandigarh - 160014

Shalini Bharat
(Researcher in Social Work and Family studies)
Professor
Unit for Family Studies
Tata Institute of Social Sciences
Deonar, Mumbai – 400088

Shanti George
(Social scientist, development researcher)
The Hague, The Netherlands

Stacy Leigh Pigg
(Development Anthropologist)
Associate Professor of Anthropology
Department of Sociology and Anthropology
Simon Fraser University, Burnaby, BC V5A 1S6 Canada
and
Editor
Medical Anthropology: Cross-Cultural Studies in Health and Illness

Usha V.T.
(Researcher in Language and Women’s studies)
Reader and Coordinator
Centre for Women’s Studies
University of Pondicherry
Pondicherry
Vijay Rai
(Medical doctor and health administrator)
Chief Medical Officer
Department of Health
Government of Delhi (NCT)

Vijay Thakur
(Psychiatrist)
Coordinator, Network of HIV Related Community Based Interventions
and
Member, Technical Resource Group on Counseling, NACO
and
Visiting Faculty, Maharashtra Institute of Mental Health, Pune
8/8-2 Priyanka Niwas
3rd Lane (Canal), Karvenagar, Pune - 411052
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immuno-Deficiency Syndrome</td>
</tr>
<tr>
<td>AmFAR</td>
<td>American Foundation for AIDS Research</td>
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<tr>
<td>ANC</td>
<td>Antenatal Clinic (Attendees)</td>
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<tr>
<td>ANM</td>
<td>Auxiliary Nurse Midwife</td>
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<tr>
<td>APAC</td>
<td>AIDS Prevention and Care (a project in Tamil Nadu)</td>
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<tr>
<td>ARCON</td>
<td>AIDS Research &amp; Control Centre (an autonomous institution of the Government of Maharashtra)</td>
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<tr>
<td>ART</td>
<td>Anti-retroviral Therapy</td>
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<tr>
<td>ARV</td>
<td>Anti-retroviral</td>
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<tr>
<td>AZT</td>
<td>Azidothymidine (also called ZDV) is an anti-retroviral drug, the first approved for treatment of HIV</td>
</tr>
<tr>
<td>BCC</td>
<td>Behaviour Change Communication</td>
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<td>BSS</td>
<td>Behavioural Sentinel Surveillance</td>
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<td>CAAC</td>
<td>Community AIDS Action Committee</td>
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<td>CAW</td>
<td>Crimes Against Women</td>
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<td>CBO</td>
<td>Community-based Organizations</td>
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<td>CDC</td>
<td>Centers for Disease Control, Government of USA</td>
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<tr>
<td>CIDA</td>
<td>Canadian International Development Agency</td>
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<tr>
<td>CMH</td>
<td>Commission on Macroeconomics and Health</td>
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<tr>
<td>CPHA</td>
<td>Canadian Public Health Association</td>
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<tr>
<td>CPHC</td>
<td>Comprehensive Primary Health Care</td>
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<tr>
<td>CSW</td>
<td>Commercial Sex Workers</td>
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<tr>
<td>CWDS</td>
<td>Center for Women Development Studies, New Delhi</td>
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<tr>
<td>DALY</td>
<td>Disability Life Adjusted Years</td>
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<tr>
<td>DANIDA</td>
<td>Danish International Development Agency</td>
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<tr>
<td>DOTS</td>
<td>Directly Observed Therapy, Short course</td>
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<tr>
<td>ELISA</td>
<td>Enzyme-Linked ImmunoSorbent Assay</td>
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<tr>
<td>FBO</td>
<td>Faith-based Organizations</td>
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<tr>
<td>FHAC</td>
<td>Family Health Awareness Campaign</td>
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<tr>
<td>GAVI</td>
<td>Global Alliance for Vaccines and Immunization</td>
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GFATM - Global Fund to Fight AIDS, Tuberculosis and Malaria
GHRF - Global Health Research Fund
GPPPs - Global Public-Private Partnerships
HAART - Highly Active Anti-retroviral Therapy
HIV - Human Immunodeficiency Virus
HSR - Health Sector Reforms
IBBA - Integrated Behavioural-Biological-Assessment
ICMR - Indian Council of Medical Research
IDPAD - Indo-Dutch Programme on Alternatives in Development
IDUs - Injecting Drug Users
IEC - Information, Education and Communication
IPC - Indian Penal Code
IVDUs - Intravenous Drug Users
IVR - Initiative for Vaccine Research
KAB - Knowledge, Attitude, Behaviour
KABBMP - Knowledge, Attitude, Belief, Behaviour and Practice
KAP - Knowledge, Attitude, Practice
KIT - Royal Tropical Institute (Amsterdam)
LC - Law Commission
LGBT - Lesbian Women, Gay Men, Bisexuals and Transgender Groups
MCH - Maternal and Child Health
MISA - Maintenance of Internal Security Act
MNP+ - Manipur Network of Positive Persons
MSM - Men Who Have Sex With Men
NAC - National AIDS Committee
NACB - National AIDS Control Board
NACO - National AIDS Control Organization
NACP - National AIDS Control Programme
NARI - National AIDS Research Institute
NCRB - National Crime Records Bureau
NCW - National Commission for Women
OR - Operations Research
PBD - Professional Blood Donors
PHC - Primary Health Centre
PITA - Immoral Traffic (Prevention) Act
PLWA - Person/People Living with AIDS
PLWHA - Person/People Living with HIV and AIDS
PMTCT - Prevention of Mother-to-Child Transmission
PSI - Population Service International
RCH - Reproductive and Child Health
RTIs - Reproductive Tract Infections
SADC - Southern African Development Community
SAP - Structural Adjustment Policies/Programmes
SAT - Southern African AIDS Training
SC - Sub-Centre
SIGN - Safe Injections Global Network
SL - Special Laws
SPHC - Selective Primary Health Care
STD - Sexually Transmitted Disease
STI - Sexually Transmitted Infection
SWA - Sector-wide Approach
SWW - School Without Walls
TANESA - Tanzania Netherlands Support Program to Control AIDS
TI - Targeted Intervention
TRGs - Technical Resource Groups
UNFPA - United Nations Population Fund
VAW - Violence Against Women
VCT - Voluntary Counselling and Testing
WHO - World Health Organization
WIP - Women In Prostitution