Voices of Resilience

Stigma, Discrimination and Marginalisation of Indian Women Living with HIV/AIDS

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This book presents the results of a study that examined the multiple layers of stigma and discrimination experienced by women infected and affected by HIV/AIDS in a low socio-economic area of Mumbai, India. Using exploratory qualitative methods and underpinned by the psychosocial framework and gendered perspectives the study attempts to represent the voices of affected and infected women. The book first focuses on a global overview of HIV, presents data on the Indian context and provides a synthesis of HIV in relation to stigma, discrimination and gender. The second part of the book probes the depth of impact on women’s lives using the lenses of gender, economic status, the environment and physical health. The framework was further modified and extended to include threats revealed by and strengths indentified in infected and affected women. The analysis revealed that strategies to address stigma and discrimination need to address the social, cultural, religious and systemic barriers to changing attitudes. The book portrays the resilience of each woman’s spirit and the unique capacity of the women to cope, to find strength, to pursue life and to maintain hope when their dreams and the dreams of their children have been shattered through HIV/AIDS.
Voices of Resilience
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*Stigma, Discrimination and Marginalisation of Indian Women living with HIV/AIDS*

Pam O’Connor
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*Curtin University, Western Australia*
DEDICATION

This book is dedicated to

Indian women

in impoverished communities,

the time and labour spent on this book is dedicated
to their resilience,

their agency and their inherent ability
to navigate life’s challenges and adversities

with the hope that change may come,

for they deserve the best
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– To Shweta Desai, who acted as a cultural interpreter and translator during the field work for the study;

Finally we thank the women participants of this study who gave generously of their time, and openly shared their experiences. Without their support, the project could not have been as productive and significant. They have greatly inspired us, and we are truly grateful.

Dr Pam O’Connor & Dr Jaya Earnest
FOREWORD

Somaiya Action for HIV/AIDS Support (SAHAS) has seen a steady rise in the number of HIV infected persons in the seven years of its existence since 2003. However, what we find even more alarming is the attitude towards People Living with HIV/AIDS (PLHAs). Experiential evidence suggests that stigma and discrimination is not on the wane despite awareness programmes by Government and non-Government agencies working with PLHAs.

Dr O'Connor’s doctoral study brought her to SAHAS in 2005. A year when the flash floods devastated the eastern suburbs of Mumbai, SAHAS’s catchment area, affecting more than 250,000 people in that area alone. Vulnerable, having lost their meagre belongings, many more PLHAs, especially widows and their children, sought the supplementary nutrition provided by SAHAS each month. Yet, as the results of the study highlight, there is no hint of cynicism, but a welcoming in their hearts and to their homes and a unique resilience.

The women’s response to stigma and discrimination is heart rending. What has changed over the years? Women are comfortable to talk with SAHAS’s outreach workers but are not happy to invite them home to visit. They still fear discrimination by relatives, neighbours, the community; this stigma and discrimination has not changed with the years.

Sadly, there is not a dent in the perceptions and attitudes of people but a heightened curiosity to find out…what is wrong with my neighbour? Why are you visiting her so often? And the women request, please do not come here anymore. This is at one level.

What about the persons responsible for treating PLHAs? SAHAS has experienced the painful reality of shortcomings in the way current medical education is able to change the attitude of medical professionals. Does education (or getting a degree) really impact stigma? Presently, SAHAS is dealing with a group of post-graduate medical students who do not wish their residence to be located next to the community care centre started by SAHAS. What can then one say of the general public?

This book – ‘Voices of Resilience: Stigma, Discrimination and Marginalisation of Indian Women living with HIV/AIDS’ has been written and is being released at a time when issues related to stigma and discrimination must be highlighted and addressed. No advances in treatment can bring about the attitudinal change required to enhance care and compassion of people living with HIV/AIDS, especially infected and affected women.

SAHAS has started a Community Care Centre in March this year (2010) to precisely address these issues and to give a boost to the psychosocial well-being of PLHAs to cope with discrimination.

This book needs a Marathi & Hindi translation someday (sooner rather than later) to reach a wider audience.

Patricia Gokhale, PhD
Founder & Project Director
SAHAS
Mumbai May 2010
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<table>
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<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>AusAID</td>
<td>Australian Agency for International Development</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal Clinic</td>
</tr>
<tr>
<td>ART</td>
<td>Anti Retroviral Therapy</td>
</tr>
<tr>
<td>CHARCA</td>
<td>Co-ordinated HIV/AIDS and STD Response through Capacity Building and Awareness</td>
</tr>
<tr>
<td>CIDA</td>
<td>Canadian International Development Agency</td>
</tr>
<tr>
<td>CSW</td>
<td>Commercial Sex Worker</td>
</tr>
<tr>
<td>DOTS</td>
<td>Directly Observed Treatment, Short Course</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>GIPA</td>
<td>Greater Involvement of People Living with AIDS</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>ICHAP</td>
<td>India Canada Collaboration HIV/AIDS Project</td>
</tr>
<tr>
<td>IDU</td>
<td>Intravenous Drug User</td>
</tr>
<tr>
<td>ILO</td>
<td>International Labor Organisation</td>
</tr>
<tr>
<td>INP+</td>
<td>Indian Network for People Living with AIDS</td>
</tr>
<tr>
<td>IWLWHA</td>
<td>Indian Women Living With HIV/AIDS</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
</tr>
<tr>
<td>NACO</td>
<td>National AIDS Control Organisation</td>
</tr>
<tr>
<td>NACP</td>
<td>National AIDS Control Policy</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Government Organisation</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living With HIV/AIDS</td>
</tr>
<tr>
<td>PPTCT</td>
<td>Prevention of Parent to Child Transmission</td>
</tr>
<tr>
<td>SACS</td>
<td>State AIDS Control Society</td>
</tr>
<tr>
<td>SAHAS</td>
<td>Somaiya Action for HIV/AIDS Support</td>
</tr>
<tr>
<td>SIDA</td>
<td>Swedish International Development Cooperation</td>
</tr>
<tr>
<td>STD</td>
<td>Sexually Transmitted Disease</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Program</td>
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<tr>
<td>UNICEF</td>
<td>United Nations International Children’s Education Fund</td>
</tr>
<tr>
<td>UNIFEM</td>
<td>United Nations Fund for Women</td>
</tr>
<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
</tr>
<tr>
<td>VCCTC</td>
<td>Voluntary Confidential Counselling and Testing Centre</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>------------</td>
<td>------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Bhakti</td>
<td>Faith, surrendering to the gods</td>
</tr>
<tr>
<td>Bindi</td>
<td>Mark on forehead, often dot shaped, worn by married Hindu women</td>
</tr>
<tr>
<td>Brahmin</td>
<td>Member of the priest/scholar caste, the highest Hindu caste</td>
</tr>
<tr>
<td>Chappals</td>
<td>Sandals, thongs (Australian term)</td>
</tr>
<tr>
<td>Dalit</td>
<td>Preferred name for lowest caste, formerly “untouchables”</td>
</tr>
<tr>
<td>Dharma</td>
<td>Word used by Hindus and Buddhists to describe their moral codes</td>
</tr>
<tr>
<td>Dowry</td>
<td>Money and goods given by bride’s parents on marriage to son-in-law’s family; the practice is now outlawed, but still exists</td>
</tr>
<tr>
<td>Dravidian</td>
<td>Cultures and languages of the south</td>
</tr>
<tr>
<td>Dupatta</td>
<td>Long scarf often worn with salwar-kameez</td>
</tr>
<tr>
<td>Firangi</td>
<td>Foreigner</td>
</tr>
<tr>
<td>Ganesh</td>
<td>Hindu god of good fortune</td>
</tr>
<tr>
<td>Guru</td>
<td>Holy teacher</td>
</tr>
<tr>
<td>Haldi kum-kum</td>
<td>A celebration of women held on festival days</td>
</tr>
<tr>
<td>Gujarat</td>
<td>A state in Western India</td>
</tr>
<tr>
<td>Jain</td>
<td>Follower of religion called Jainism</td>
</tr>
<tr>
<td>Karma</td>
<td>Hindu, Buddhist and Sikh principle of retributive justice for past deeds</td>
</tr>
<tr>
<td>Kshatriya</td>
<td>Hindu warrior and ruler caste</td>
</tr>
<tr>
<td>Kum-kum</td>
<td>Red powder used to make the round mark denoting a married Hindu woman</td>
</tr>
<tr>
<td>Kurta pajama</td>
<td>Long shirt and pants worn by men</td>
</tr>
<tr>
<td>One Lakh</td>
<td>Rupees 100,000</td>
</tr>
<tr>
<td>Lathi</td>
<td>Truncheon or stick</td>
</tr>
<tr>
<td>Maidan</td>
<td>Open area, parade ground</td>
</tr>
<tr>
<td>Mangalsutra</td>
<td>Wedding necklace worn by Hindu women that carries religious significance and is regarded as sacred</td>
</tr>
<tr>
<td>Mayaka</td>
<td>Girl’s natal home</td>
</tr>
<tr>
<td>Mehndi</td>
<td>Henna, ornate designs on women’s hands and feet for festivals, marriages and occasions</td>
</tr>
<tr>
<td>Memsaib</td>
<td>Madam</td>
</tr>
<tr>
<td>Nagnika</td>
<td>Engagement</td>
</tr>
<tr>
<td>Namaz</td>
<td>Muslim prayer</td>
</tr>
<tr>
<td>Nirvana</td>
<td>Buddhist ultimate release from the cycle of existence</td>
</tr>
<tr>
<td>Panchayats</td>
<td>Village council of five people (Panch= number 5)</td>
</tr>
<tr>
<td>Parsis</td>
<td>Follower of the Zoroastrian faith</td>
</tr>
<tr>
<td>Partition</td>
<td>The division of British India into India and Pakistan in 1947</td>
</tr>
<tr>
<td>Patrivata</td>
<td>Devoted wife</td>
</tr>
<tr>
<td>Peon</td>
<td>Lowest grade clerical worker</td>
</tr>
<tr>
<td>Puja</td>
<td>Religious offering, prayers</td>
</tr>
</tbody>
</table>
GLOSSARY OF INDIAN TERMS

Purdah  Custom of keeping women in seclusion
Rajput  Hindu warrior caste, former rulers of north-west India
Rangoli  Elaborate flower patterns on floor made of chalk, rice-paste
Roza  Practice of fasting among Muslims
Salwar kameez  Women’s traditional dress (long tunic over pants) popular in many parts of India
Saree  Traditional woman’s attire, popular in many parts of India
Sasural  In-law’s home
Sati  The act of immolation, or a widow sacrificing herself
Scheduled caste  Dalits
Shastric  Shastras are the sacred Hindu law books
Sikh  A religion in India where the men wear turbans
Sindoor  Red powder Hindu women put in their hair parting
Tambula  A type of musical instrument
Tikka  Mark Hindus put on their foreheads
Untouchables  Now referred to as ‘dalits’
Vedas  Collection of scriptures composed in 2nd millennium BC
Veni  Braided hair or a garland of flowers
Wallah  A man, often combined with occupation as in dhudh (milk) wallah, bhaji (vegetable) wallah
Zenana  Area in an upper-class home where women are secluded
EXECUTIVE SUMMARY

This book is the result of a study conducted in Mumbai, India which explored the perceptions and experiences of women living with HIV/AIDS. Stigma and discrimination are now recognised as major factors in the spread of Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS). To date, research has focused on how to change individual responses to stigma and discrimination without exploring the social and structural dimensions. Complex community and societal dimensions, such as culture, power and difference need to be explored if progress is to be made in coping with stigma and discrimination. India now has HIV/AIDS prevalence figures to rival sub-Saharan Africa.

The disease has spread from high-risk populations such as intravenous drug users and commercial sex workers into the general population. Married, monogamous, heterosexual women are highly vulnerable. Factors such as caste, class, ethnic group, poverty and social expectations present formidable layers of stigma for these women. They have also faced discrimination since before their birth. HIV/AIDS imposes yet another layer of stigma and discrimination upon their shoulders.

The study was undertaken over three months in Mumbai, India in late 2005. The aims of the study were firstly to investigate whether stigma and discrimination existed for women living in low socio-economic conditions, by documenting and analysing literature on the individual, societal and cultural situation of Indian women living with HIV/AIDS (IWLWHAs). Secondly, the study aimed to identify, evaluate and explore the psychosocial needs and coping strategies of IWLHAs, to determine the barriers to accessing health services, and describe community perceptions as they were experienced by the participants.

The multiple layers of stigma and discrimination experienced by women infected and affected by HIV/AIDS in a low socio-economic area of Mumbai, India were examined during the research. This was achieved by interviewing women who were benefiting from a home-based service – Positive Living – *An integrated care programme for people living with HIV/AIDS* under the auspices of the KJ Somaiya Hospital in Mumbai. The programme provides nutrition and a home-based service to the nearby community slums.

The conceptual framework used for this study was a psychosocial framework underpinned by the dimensions of human capacity, social ecology and culture and values. The ability of individuals to cope with adversity is linked to social ecology - the relationship between individuals and their community. These dimensions overlap with culture and values inherent in a particular society and culture. Three other inter-locking dimensions also affect human beings – one’s economic status, the environment and living conditions, and physical health. HIV/AIDS is a tragedy that adversely affects individuals, families and communities.
EXECUTIVE SUMMARY

This framework was further modified and extended to examine threats and identify strengths that arose from the dimensions described above. An exploratory case study was considered the most suitable approach as it permitted more sensitivity and allowed for richer data to be obtained. In-depth interviews of 45 women in three different age groups, home visits and observations, a focus group discussion, key informants, narratives, vignettes and photographs were supported by documentary data collection in triangulation of the data. A reflective journal recorded daily field observations and perceptions during three months in India.

Results indicated that IWLWHAs experienced discrimination in their families, communities and health care settings. Fear of future discrimination resulted in secrecy which, in turn, prevented them accessing community services which would provide emotional and physical support. A range of reactions was demonstrated by the affected women, half of whom were also infected, and this added to their burden. Women who could not disclose their condition were extremely isolated, lacked family and community support, feared the future, and felt hopeless.

Despite their extremely difficult living conditions of poverty, overcrowding, prevalence of disease and pollution, the women displayed a sense of pride, dignity and resilience. Culturally appropriate strategies are necessary to address the lack of education and awareness as only two of the 45 women had any knowledge of HIV/AIDS before their own diagnosis which often followed their husbands’ sero-positive status. In addition, the social and cultural dimensions which affect these women have to be explored and examined in order to strengthen women who are the ‘shock absorbers’ of the family.

The community health workers and co-ordinator of the home-based service are vital in providing emotional support and health information to the women. Finally, no change is possible unless men take responsibility for their actions and are included in education and intervention processes. Policy makers and programmes need to explore strategies that would engage men in the specific context of India, so that changes in attitudes and behaviours can be initiated, and thus protect vulnerable women and children.
CHAPTER 1

INTRODUCTION

The Journey Begins

"The greatest single international failure in the response to HIV/AIDS, is the failure to intervene, dramatically, on behalf of women." (Stephen Lewis, UN Envoy on HIV/AIDS in Africa, 3rd International AIDS Society Conference, Rio de Janeiro, 2005, p. 3)

Chapter 1 commences with a brief look at HIV/AIDS statistics globally, and particularly in India. The concepts of stigma and discrimination in relation to HIV/AIDS are introduced, and the foundations for the study, which took place in 2005–6, are laid by providing the conceptual framework, the site and the community based-service (SAHAS) and the participants. Findings of the research and an overview of the following chapters concludes the chapter.

At a time when India’s dynamism and booming market economy is thrusting the country forward, through foreign investments, privatisation and globalisation, huge challenges and disparities also exist. Despite its progress, more than one third of the population of India is held back due to widespread poverty and illiteracy, reinforced by custom and tradition and entrenched caste and gender inequalities (Ali, 2006). There is an enormous economic gap between the country’s urban and rural sectors and this book is a salient reminder that not all Indians share in the rewards of globalisation and financial success. Furthermore, Pickett and Wilkinson (2007) point out that it is the association of income inequality that is more important than poverty or economic growth both in developed and undeveloped countries.

HIV/AIDS IN THE WORLD AND INDIA

The number of people living with HIV/AIDS in the world was estimated at 33.2 million people in 2007, 15.4 million being women and 2.5 million children (UNAIDS, 2008). India’s figures have also been revised downwards in 2008, to 2.27 million people living with HIV/AIDS with an adult HIV prevalence of 0.29 percent (NACO, 2010). The reduction in numbers is attributed to better survival rates, and more accurate data collection methods (UNAIDS, 2007a). The epidemic in India is highly heterogenous and concentrated in the six states of Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka, Manipur and Mizoram. Although increases in HIV rates among ANC attendees has reduced, increases have been reported in some of moderate and low prevalence states (NACO, 2010).

Until now, the epidemic has been concentrated in high-risk populations such as men who have sex with men (MSM), injecting drug users (IDUs) and commercial sex workers (CSWs). Stigma and discrimination, the low use of condoms and safe sex,
migrant and highly mobile populations and the low status of women are additional factors in the spread of HIV/AIDS (World Bank, 2007a). These factors, which make India very vulnerable to the epidemic, are discussed in Chapter 2.

Three of the most disturbing facts about the existence of HIV/AIDS are, firstly, that an increase in the prevalence rate of merely 0.1% in a country like India would increase the number of people living with HIV/AIDS (PLWHA) by over half a million people (World Bank, 2007b). Secondly, HIV incidence amongst married monogamous women is also growing (D’Cruz, 2004). The NACO (2010) report provides epidemiological data from the Integrated Counseling and Testing Centres and Sentinel Sites across India. Data from 2009–2010 reports indicate that 87.1 percent of HIV infections in India occur through heterosexual routes of transmission.

Currently in India, parent to child transmission accounts for 5.4 percent of the HIV cases detected (NACO, 2010). Although there was an overall decline in HIV prevalence among Ante Natal Care (ANC) attendees at the all India level and in the high prevalence states, there is however, a rising trend among ANC attendees in some low and moderate prevalence states such as Gujarat, Rajasthan, Orissa, Uttar Pradesh, Bihar and West Bengal (NACO, 2010). Thirdly, it is recognised that stigma is driving the third phase of the HIV pandemic. The fear of stigma prevents people from accessing services, and there is a lack of treatment and care, both in the community and health care settings (Mawar, Sahay, Pandit, & Mahajan, 2005). Despite all the efforts to curb the epidemic, it is reported that more adult women than ever before are living with HIV/AIDS. Between 2004 and 2006, the number of infected women globally increased by one million to 17.7 million. In sub-Saharan Africa, 60% of the people infected are women, and in India a large proportion of women have acquired the disease through their husbands (UNAIDS, 2006a).

STIGMA AND DISCRIMINATION AND HIV/AIDS

Stigma and discrimination in association with HIV/AIDS are well documented. These areas have been examined from an individual, and psychological point of view, but not from a social perspective until recently. Factors such as caste, ethnic group, poverty and social expectations present formidable layers of stigma for women in India. HIV/AIDS places yet another layer of stigma onto females, and the resulting discrimination may prevent women from being diagnosed, accessing services, and receiving familial and community support. Primary prevention policies and interventions aimed at controlling the spread of AIDS in India are “totally inadequate in content, volume and orientation” according to D’Cruz (2003, p. 255). Research is now focusing on more complex community and societal factors such as culture, power and difference, in order to understand the mechanisms of stigma and discrimination.

The individual perception of stigma and discrimination is important, but only part of the jigsaw. Society’s reaction to HIV/AIDS is perceived through laws, rules, policies and procedures which further stigmatise people living with HIV/AIDS (PLWHA) as seen in the compulsory screening and testing of groups and individuals, and the prohibition of PLWHA from certain occupations or employment (Aggleton, 2000). The role of governments is crucial in the prevention, protection, treatment and care of PLWHA.
INTRODUCTION

Through denial or apathy, governments can fail to protect individuals from discrimination, or neglect to respond to those living with the infection. Legislation to ensure the right to employment, education, privacy and confidentiality are essential so that further stigmatisation does not take place (Aggleton, 2000). On the community level, stigmatisation and harassment of PLWHA has been widely reported throughout the world. Acts of violence, murder and abuse have resulted from people revealing their status (Aggleton, 2000). Children have been turned out of schools (Slater, 2004), discriminated against at play (discussed in Chapter 9), and at risk of being put out on the street, with the resulting risk of exploitation and child labour (Martin, 2005).

Women are particularly susceptible to such stigma and discrimination in countries where they are already in a disadvantaged position because of their gender. Cultural norms which prevent control of their bodies and sexual relations, combined with lack of power, decision-making processes, lack of economic independence and domestic violence, add to their vulnerability. Traditional beliefs and attitudes may give rise to erroneous assumptions of pollution by women because of their natural body functions. India is a country where women with low socio-economic status experience these inequalities of power, status and identity. In order to address this gap in the literature, we have explored the perceptions and experiences of women directly infected or affected by HIV/AIDS, living in community slum conditions in Mumbai, India. Usually, these women have little voice or have any power to make a difference in their lives.

AIMS OF THIS STUDY

This qualitative exploratory research study examined and evaluated the multiple layers of stigma and discrimination experienced by women living with HIV/AIDS in a low socio-economic area of Mumbai, India.

The overarching aim of the study was to investigate stigma and discrimination faced by Indian women living with HIV/AIDS (IWLWHAs) living in Mumbai, and to examine their perceptions and experiences. Four objectives helped address the aims. The first objective was to identify and explore the psychosocial needs and coping strategies of IWLWHAs. The second objective was to identify the barriers to accessing health services of IWLWA. The third objective of this research was to explore community perceptions as experienced by the participants. The final objective was to review and analyse literature and research on the situation of Indian women living with HIV/AIDS from the individual, societal and cultural aspects.

THE STUDY DESIGN AND METHODOLOGY

The decision to use a particular research design is guided by considerations of the nature of the aims, the amount of control of the researcher and the desired end-product (Yin, 1994). In this study, a predominantly qualitative design made use of both the data, and a methodological triangulation approach. The study used multiple data sources to examine the problem, and multiple methods to study the data from different viewpoints (Patton, 2002). Examination of the situation from multiple viewpoints strengthens a study according to Patton (2002, p. 247).
CHAPTER 1

The research used a case-study approach, combining multiple qualitative research methods. A qualitative gendered approach, considered to be more sensitive to the context, included in-depth interviews, home visits to the participants of the Positive Living Project, community mapping and observations, focus group discussions, interviews with key informants, an accumulation of documentary data, reflective diary, and narratives. The qualitative data from the interviews provide a detailed and comprehensive picture of IWLWHAs, and the findings are supported by data in the literature review and documentary data collection. The participant and key informant interviews and focus group discussion were subjected to thematic analysis, and the psychosocial framework is described fully in Chapter 5. Frame analysis was used with the documentary data to explore themes and meanings.

THE CONCEPTUAL FRAMEWORK USED FOR THE STUDY

The theoretical framework used for this study is based on the concept that the psycho-social well-being of an individual is defined with respect to three core domains: human capacity, social ecology and cultural values. Human capacity refers to the physical and mental health of a person, including his/her knowledge and skills. Social ecology includes the social connections and supports that people share, and which impact on their psycho-social wellbeing. Cultural values impart a sense of unity and identity to individuals and communities.

This framework has been drawn and modified from the Psychosocial Framework developed by The Psychosocial Working Group which comprises five academic partners (Centre for International Health Studies, Queen Margaret University College, Edinburgh; Columbia University, Program on Forced Migration & Health; Harvard Program on Refugee Trauma; Solomon Asch Centre for the Study of Ethnopolitical Conflict and University of Oxford, Refugees Studies Centre) and five humanitarian agencies (Christian Children’s Fund; International Rescue Committee, Program for Children Affected by Armed Conflict; Medecins Sans Frontieres - Holland; Mercy Corps and Save the Children Federation). The work of this group was supported by a grant from the Andrew Mellon Foundation (www.forced migration.org/psychosocial and www.qmuc.ac.uk/cihs).

The group sought to develop a framework which would provide a structure for interventions in complex emergencies such as conflict, mass displacement or natural disasters. Because of its holistic approach, it permits detailed examination of the impact in various domains. For example, the culture and values domain explores how people perceive and understand experiences and events in their lives (The Psychosocial Working Group [The PWG], 2003). There are other influences such as the availability of economic, physical and environmental resources, which have a significant impact on psycho-social wellbeing of an individual. All these areas are interconnected, and overlap; and changes in one area will affect the other areas.

Poverty is a force on its own, and exacerbates the effect of other areas when they are combined (The PWG, 2003). In this study, the psychosocial framework was modified further to explore the negative impacts of the six dimensions, identifying these as threats; and applied the same methodology to identify strengths which affect resilience. This can be seen in the modified Figure 4 presented in Chapter 5.
By analysing in this manner, a clearer picture emerged of interventions which will strengthen the women’s resilience. The many layers of stigma and discrimination of Indian women with lower socio-economic status were examined to provide a background. HIV/AIDS attracted another layer which added to their considerable burden.

STUDY PARTICIPANTS

The participants in the study consisted of women infected, or affected by, HIV/AIDS. They lived in the community slums around K J Somaiya teaching hospital, near Sion in Mumbai, India. There were three groups of participants – the first group were aged 18–25 years, the second group 26–45 years, and the third group 46 years and more. The groups were constructed to give as wide an overview of the participants as possible. One of the inclusion criteria of the Somaiya Action for HIV/AIDS Support programme was an income below Rs 4000 (AUD 107) per month, so these women were extremely vulnerable to malnutrition, food insecurity and lacked the necessities for life, especially as floods two months previously had added to their desperate circumstances. There were young women who had been left widowed with children to raise without sustainable incomes and older women who had been called upon to provide sustenance at a time of their lives when, traditionally, they would have expected help from their own children.

Despite the poor, sparse and often unhealthy living conditions, the women portrayed individual strength and courage. The thin and gaunt HIV infected women were always well dressed in saris and their homes tidy and as clean as possible. This took enormous effort, under difficult and often impoverished circumstances, as they battled with TB or other opportunistic infections. They were always welcoming and hospitable, and talked openly about their circumstances, resulting in a diversity of opinions. The younger women showed immense resilience and strength beyond their years, and a remarkable capacity for duty of care, assuming responsibilities for the remaining members of their households.

THE RESEARCH SITE

The Somaiya Trust and the Home-based Care Programme

The Somaiya Trust and the Centre for International Health, at Curtin University in Perth, developed a collaboration in 2004, which resulted in several research students being invited to Mumbai to undertake their studies. The Somaiya Trust is an organisation founded by Padmabhushan Pujya Shri K J Somaiya, to promote social service activities in Mumbai and around India under the guiding principles of the Bhagavad Gita: “To remove the suffering of all beings afflicted by pain”. In 1992, a medical college and free hospital were built to serve the large slum communities in Mumbai of Qureshi Nagar (population 69,222), Pratiskshanagar (25,000), Chunabhatti (56,000), and Antop Hill (62,253), in all 212,425 people (Somaiya Medical Trust, 2005a).

In 2003, the Somaiya Trust realised that there was a massive need to provide health care for the growing numbers of people suffering from HIV/AIDS, in the form of holistic care that would include diagnosis, symptomatic treatment, comfort, psychological education and rehabilitation. It was also recognised that women,
young girls and children bore significantly more of the HIV/AIDS disease burden. As well as the training and sensitisation of all hospital staff, a home-based programme was set up for the holistic management of the disease and to reduce vulnerability of women and children. This programme was called Positive Living - Integrated Community and Home-based Care Program for People living with HIV/AIDS (PLWHAs), renamed Somaiya Action for HIV/AIDS support (SAHAS). It was set up with the support of Catholic Relief Services in 2004. By April 2005, the hospital had catered for more than 400 persons for pre and post-test counselling. More than 3,000 expectant mothers had been enrolled in the Prevention of Parent to Child Transmission programme, and 275 people living with HIV/AIDS had been in-patients at the hospital (Somaiya Medical Trust, 2005b).

In recognition of the poverty of most of the patients, a nutritional scheme was then set up. Because of funding, the number of participants was small, 26 persons, compared to the growing need (Somaiya Medical Trust, 2005b). During the flooding in August 2005, the programme was able to provide some clothes, mats and food. These were still being distributed in November 2005, four months after the devastating floods.

The Positive Living Program (Now Renamed SAHAS)

The home-based care program recruited and employed community health workers from the slum communities to survey the needs of the families visited, and to provide information about the Somaiya Hospital services. The team set about building rapport, and sensitisation of the communities by means of street plays. To date, more than 550 people have accessed the services. They have developed pamphlets and posters in Hindi, Marathi, Gujarati and Bengali, which have been distributed in the target communities as well as the hospital departments. A phone counselling service has been set up for people outside the target areas. Counselling was also provided by a psychologist who is the Co-ordinator of the programme. The project has developed a wide network of other agencies concerned with HIV/AIDS, in order to study best practice, referrals, advocacy and sustain project outcomes (Somaiya Medical Trust, 2005b).

In addition, an innovative course has been set up to help infected and affected women to become economically self-reliant, and manage the nutritional inputs to their families. The first course started with tailoring and embroidery, with seven sewing machines and 15 trainees in November 2005. It is planned to expand the training to book binding, envelope and file-making in the future (Somaiya Medical Trust, 2005b). Positive Living - Integrated Community and Home-based Care Program for People living with HIV/AIDS (PLWHAs) in Mumbai, India, provided Pam with the opportunity to conduct a study in the slum communities surrounding the K J Somaiya Hospital, within the auspices of the SAHAS programme.

Findings of the Research

The presence of stigma and discrimination was confirmed by the in-depth interviews with the IWLWHA. More specifically, there was an added layer of stigma and
discrimination, contributed by the disease itself. This finding was supported by evidence from research articles, documentary data collection, and key informant interviews. Stigma and discrimination occurred in families, communities and healthcare. Fear was a dominant feature, and this led to secrecy, and, in turn, to restriction of access to healthcare and other services for IWLWHA.

The study also confirmed that men are a pivotal reason for vulnerable women contracting HIV/AIDS due to ignorance, fear, promiscuity, irresponsibility and high mobility. Cultural factors such as religion, gender disparities and traditional mores, are still strong in these communities, and affect women significantly. Research literature, interviews with IWLWHA and key informants were in agreement with this finding. IWLWHA were shown to be resilient despite their difficult circumstances, and positive interventions can be made, which will strengthen their human capacity. The interviews were a major source of this data.

This study examined stigma and discrimination faced by Indian women with HIV/AIDS, and provides urgently needed data on their perceptions and experience. The epidemic has existed in India for more than 20 years, and it is important to examine what progress has been made, particularly for women. Research by Pradhan, Sundar, and Singh (2006) has shown that Indian women with lower socio-economic status are neglected in regard to prevention, treatment and healthcare. The study highlights those areas which still exist and increases knowledge of interventions for women living with HIV and AIDS especially in a heavily populated developing country context. The views and perceptions of the participants are vital in planning interventions which are responsive to their needs, by sustaining and strengthening their capacity. The role of stigma and discrimination in forming barriers to health care and treatment has been explored. It is hoped that recommendations arising from the study will impact on policy-makers and strengthen those existing programmes which are providing good service.

OUTLINE OF THE BOOK

The design, methodology, development of this research study, and its findings, are presented in twelve chapters.

Chapter 1 has provided the background for the study, the prevalence of HIV/AIDS globally, and in India, and the setting for the field research. The aims and objectives of the study, its theoretical and conceptual framework, and the findings of the research are included in the chapter.

Chapter 2 examines the global prevalence of HIV/AIDS and interventions undertaken such as increased condom use, treatment of sexually transmitted infections, reducing the number of sexual partners, harm minimisation with injecting drug users, education of commercial sex workers, and prevention of mother-to-child transmission. Interventions in various countries are described. The history of HIV/AIDS in India is outlined, with its particular vulnerabilities and responses, both nationally and internationally. Finally, the situation regarding HIV/AIDS in the state of Maharashtra, and particularly Mumbai, is described.
CHAPTER 1

In Chapter 3, stigma and discrimination and prejudice are examined. The historical and cultural antecedents, characteristics and functions of these areas are important for interventions to be effective. Theoretical approaches such as Goffman’s work, (Goffman, 1963) and mental illness are outlined, as well as the psychological effects. Lastly, interventions, both international and Indian, are described. HIV/AIDS brings with it another layer of stigma and discrimination. The discussion of gender issues is initiated and continues in Chapter 5.

In Chapter 4, Indian history is briefly explored, particularly regarding women, and the contribution of Manu. His influence on the status and identity of women has been considerable. The effect of British colonisation and the role of women in the Independence movement are examined, as are the interactions between women and society. The impacts of culture through class, caste and religion, community and family are interlinked and affect each other. The structural obstacles facing women are also outlined.

Chapter 5 and 6 are concerned with the aims and objectives of the research study. Firstly, the rationale, aims and conceptual framework are discussed. The site of the field research is explained, as well as the sample and recruitment methods. The methodology described includes focus group discussion, in-depth interviews, observation and community mapping, and the use of cultural interpreters, key informant interviews, reflective journaling, narratives and vignettes. The data analysis section includes ethical considerations, the dilemmas encountered, and determination of rigour in the study.

Chapter 7 continues the contextualising of Indian women with regard to HIV/AIDS and stigma and discrimination. The factors which make Indian women particularly vulnerable are discussed. These include general factors such as female biology and sexual violence and other factors such as poverty and deficiencies in nutrition, education and decision-making. Lifelong stigma and discrimination and gender inequality are major factors that make women vulnerable and increase their burden when they contract HIV/AIDS. Children are also especially vulnerable, and mothers worry about their future when their own is compromised. The position for widows is serious and difficult.

In Chapter 8, the data analysis commences and environmental factors which impinge on women’s wellbeing such as overcrowding, poor sanitation and disease, are discussed. Economic threats such as poverty and finances, and the increases in workload, brought about through HIV/AIDS, are examined. The threats and strengths arising from culture and values are evaluated from the data collected from the participants of the study.

Chapter 9 continues analysis of the data collected from the in-depth interviews. The dimension of Social Ecology is explored. The data is analysed through the threats and strengths perceived by the participants, in areas such as awareness of the community, disruption of family structures, and changing roles and responsibilities, as HIV/AIDS affects families.

The Human Capacity dimension is analysed in Chapter 10. The threats which have been discussed in the previous chapters are understandably overwhelming, and
yet the women participants showed resilience and flexibility in adjusting to the rigours of HIV/AIDS, both for themselves and their families.

Chapter 11 explores the human dimension of the study through the power of narratives, photos and the researcher’s perceptions.

In the final and concluding Chapter 12, the significance of the study is discussed from the perspective of IWLWAs, service providers, policy-makers and recommendations are proposed that include education and awareness, changing attitudes and beliefs, community and employment initiatives and promoting rights based approaches. A final statement concludes the book.
CHAPTER 2

OVERVIEW OF HIV/AIDS GLOBALLY
AND IN INDIA

"Mumbai is a major partner in global development. It has all the various features that have made the city a breeding ground for drug peddlers, traders of flesh and people indulging in high risk behaviour, bearing serious consequences for the spread of the HIV epidemic.” (Shalini Bharat, as cited in D’Cruz 2002, p. 2)

Chapter 2 examines the global prevalence of HIV/AIDS and interventions undertaken such as: increased condom use, treatment of sexually transmitted infections, reducing the number of sexual partners, harm minimisation with injecting drug users, education of commercial sex workers, and prevention of mother-to-child transmission. Interventions in various countries are described. Then the focus changes to India and its particular vulnerabilities where HIV/AIDS is concerned. Factors such as poverty, socio-economic conditions and lack of awareness are common difficulties in managing the spread of HIV/AIDS. Gender inequality, failures in the judiciary system, corruption and crime further compound the difficulties. The history of HIV/AIDS in India and interventions which the government and international aid have implemented are outlined. Finally, the situation regarding HIV/AIDS in the state of Maharashtra, and particularly Mumbai, is described.

THE INTERNATIONAL CONTEXT AND OVERVIEW

A Global Overview

The UNAIDS & WHO (2009) & UNAIDS (2008) report detail that on a global scale, the HIV epidemic has stabilised, although there continue to be unacceptably high levels of new HIV infections and AIDS deaths. The following epidemiological statistics provides a brief global snapshot:

– The number of people living with HIV worldwide continued to grow in 2008, reaching an estimated 33.4 million;
– The latest epidemiological data indicate that globally the spread of HIV appears to have peaked in 1996, when 3.5 million new HIV infections occurred. The annual number of new HIV infections declined from 3.0 million in 2001 to 2.7 million in 2007. Overall, 2.0 million people died due to AIDS in 2007, compared with an estimated 1.7 million in 2001;
– While the percentage of people living with HIV has stabilised since 2000, the overall number of people living with HIV has steadily increased as new infections occur each year, HIV treatments extend life, and new infections still outnumber AIDS deaths;
Southern Africa continues to bear a disproportionate share of the global burden of HIV. 35% of HIV infections and 38% of AIDS deaths in 2007 occurred in that subregion. Altogether, Southern and Sub-Saharan Africa is home to 67% of all people living with HIV (UNAIDS & WHO, 2009, pp. 8–9; UNAIDS, 2008, p. 32).

**Women, Youth and Children Globally**

Women account for more than half of all people living with HIV worldwide, and nearly 60% of HIV infections in sub-Saharan Africa. Although, over the last 10 years, the proportion of women living with HIV has remained stable, it has increased in many regions like the Caribbean, Eastern Europe and Central Asia with slight increases in Latin America and Sub-saharan Africa. Young people aged 15–24 years account for an estimated 45% of new HIV infections globally. An estimated 370,000 children younger than 15 years were infected with HIV in 2007. Globally, the number of children younger than 15 years living with HIV increased from 1.6 million in 2001 to 2.0 million in 2007 and 90% of these children live in sub-Saharan Africa (UNAIDS, 2008, pp. 33 & 36).

**The Epidemic in Asia**

In Asia, an estimated 5.0 million people were living with HIV in 2007, including 2.3 million in India and 380,000 people in Asia were newly infected with HIV that year. National HIV infection levels are highest in South-East Asia, and this region has disparate epidemic trends explained below. Approximately 380,000 died from AIDS-related illnesses. The epidemics in Cambodia, Myanmar and Thailand all show declines in HIV prevalence. However, epidemics in Indonesia (especially in its Papua province), Pakistan, and Viet Nam are growing rapidly (UNAIDS & WHO, 2008).

**The World’s most Diverse Epidemic - the Multiple Modes of HIV Transmission in Asia and its Impact on Women**

The multiple modes of HIV transmission make Asia’s epidemic the world’s most diverse. *Injecting drug use* is a major risk factor in the epidemics of several Asian countries. According to Chandrasekaran et al. (2006) & the Ministry of Health in Pakistan (2006), the overlap of *injecting drug use and sex work* is a known risky phenomenon in India and Pakistan. The most recent HIV outbreak since 2005 has been in Afghanistan, due to a significant increase in the injecting of narcotics (opium traditionally was either inhaled or ingested orally as documented in the Afghanistan Opium Survey (UNODC, 2005)). *Unprotected sex* (commercial and between married partners) is the most important risk factor for the spread of HIV in Asia. Since 2004, low risk married women, and spouses account for a growing percentage of new infections. These low risk groups are infected by their regular partner who in turn has been infected through commercial sex (National Centre for HIV/ AIDS, Dermatology and STIs, 2004).
HIV is increasingly affecting people traditionally considered to be at lower risk of infection especially married women. About 43% of new infections in 2005 were among women, who were infected by husbands or partners who had unprotected paid sex with commercial sex workers or had used contaminated injecting equipment. In India, a significant proportion of women with HIV are infected by their husbands who paid for commercial sex (Lancet, 2006). Since 2002, more funding has been made available for anti-retroviral therapy medication (ART); however the number of people newly infected continues to increase; and the number of people in developing countries receiving ART remains a small proportion of those who could benefit from the treatment (UNAIDS, 2004a; 2004b, p. 2).

FACTORS AFFECTING THE SPREAD OF HIV

There are now proven successful strategies to combat HIV/AIDS such as: increasing condom use; treating STIs; reducing the number of sexual partners; safe injecting behaviour; drugs to prevent mother-to-child transmission; and providing PLHIV with access to ART medication (Ainsworth and Teokul 2000; World Bank 2007).

STIs and their Treatment

Sexually transmitted infections (STIs) are a source of major concern, especially in poorer countries, because they are a recognised co-factor in HIV transmission, increasing the acquisition tenfold (AVERT, 2005). Furthermore, a person who is HIV positive, and has an untreated STI, has the potential to progress to AIDS quicker. It is therefore important to treat STIs, however no single organisation reports STD statistics globally, and the last estimates of global STIs were completed by the World Health Organisation in 2001. A major reason for this lack of reportage is stigma.

Reducing Number of Sexual Partners

Many young people globally continue to engage in high-risk behaviour with respect to acquiring STIs and HIV/AIDS. The spread of HIV/AIDS is also influenced by men having sex with men, and those who have sex with both men and women, particularly in mobile populations such as truck drivers or commercial sex workers. In Andhra Pradesh in India, 42% of men having sex with men were married, 50% were having extramarital sex with women, and just under half of those men did not use condoms (UNAIDS/WHO/UNICEF, 2007).

Safe Injecting Behaviour

HIV spreads quickly in intravenous drug user communities, however there is only 5% coverage of ART medication for this population across the world. The use of contaminated equipment accounts for 80% of all HIV infections in this population. There is a growing epidemic of intravenous drug use in sub-Saharan Africa, South East Asia and Asia (Indonesia, Malaysia, & Vietnam) where traditionally heroin was smoked but is now increasingly being injected. In the Russian Federation, the
provision of safe needle exchanges and drug substitution therapy is known to be effective, and yet funding has been cut in recent years. Harm-reduction strategies have been endorsed by UNAIDS, and have proved efficient in Australia, Sweden, China, Hong Kong, Thailand and the United States; yet some countries such as the Russian Federation prohibit the use of methadone or buprenorphine. In most Asian countries IDU is criminalised with harsh punitive measures leading to amplification of HIV in the prisons. India has no harm-minimisation policy, which leads to a lack of co-ordination in designing and implementing interventions (UNAIDS, 2006b).

Commercial Sex Workers

Commercial sex workers (CSWs) and injecting drug users (IDU) are linked, and thus further associated with increases in HIV spread. Manipur in India has a well-established HIV epidemic where nearly 20% of the sex workers were found to be injecting drugs and HIV positive. The rate was much lower for those CSWs not on drugs (8%) (UNAIDS, 2006b).

Drugs to Prevent Mother-to-Child Transmission

Mother-to-child transmission (MTCT) is also known as vertical transmission or perinatal transmission, as it mainly occurs around the time of delivery. In sub-Saharan Africa, it has been shown that if there are no medical interventions for the mother, then due to breastfeeding, the HIV rate increases by 25–40%. Several antiretroviral (ART) courses have shown to be effective. These include zidovudine alone, zidovudine and lamivudine, and nevirapine. They have been shown to be effective long term up to 24 months, protecting the infant even while the mother is breastfeeding (UNDP/UNFA/WHO/World Bank Special Program of Research & Development and Research Training in Human Reproduction, 2003). The limiting factors of success are therefore not the efficacy of the medication, but cost and availability to women.

The United Nations agencies recommend a four-pronged approach to prevent MTCT of HIV. This includes

– the prevention of HIV infection in the parents;
– the prevention of unwanted pregnancies in HIV-infected women;
– the prevention of HIV transmission from mother to child; and

Education

In Zambia, studies have shown that educated young people have less likelihood of having casual partners, and use condoms more readily. Despite the overwhelming facts that education helps, 40% countries still have not introduced HIV/AIDS education into schools. Uganda is a success story in reaching 10 million children via the
classroom, and reducing the figures of sexual activity from 60% in 1994 to 5% in 2001 (UNAIDS/UNFPA/UNIFEM, 2004).

**Medical Interventions**

Throughout the world, 64 million female condoms have been distributed in the last decade. The uptake rates differ – in Brazil, the acceptance rate is 41–95% (Royce, Sena, Cates, & Cohen, 1997; UNAIDS, 2006b). There have been promising microbicide trials in India, Brazil and Zimbabwe, but the costs are prohibitive, and therefore limiting. Several microbicide trials were stopped due to adverse reactions of patients (Royce, Sena, Cates, & Cohen, 1997). Female condoms can kill, neutralize or block HIV and other STDs and theoretically; this gives women more decision-making power, and less reliance on partners and partner use of the male condom. In India, the Council of Medical Research has a task force on microbicides; however research is progressing very slowly because of underfunding and political marginalisation as it is seen as a female issue (Krishnakumar, 2005).

The World Health Organisation and UNAIDS implemented the 3 x 5 initiative to provide 3 million people with antiretroviral treatment (ART) by the end of 2005 in 50 developing countries. These medications not only extend survival rates, but also increase quality of life for people living with HIV/AIDS (PLWHA). The Global Coalition on Women and AIDS asked for half that allocation to be made to women. The programme concentrated on five areas: simplified, standardised tools to deliver ART, new services to ensure effective reliable supply of medicines, rapid identification, dissemination and application of research and successful strategies, urgent and sustained support for countries, and a global leadership, strong partnership and advocacy (UNAIDS, 2006b).

Antiretroviral therapy coverage rose from 7% in 2003 to 42% in 2008, with especially high coverage achieved in eastern and southern Africa (48%) (UNAIDS/WHO, 2009). While the rapid expansion of access to antiretroviral therapy is helping to lower AIDS-related death rates in multiple countries and regions, it is also contributing to increases in HIV prevalence. As PLWA feel better with ART, they indulge in risk-taking behaviour and in some instances reveal the desire to have children (UNAIDS/WHO, 2009).

By 2006, 700,000 people or 28% of 7.1 million people were receiving ART in low-middle income countries. The coverage in sub-Saharan Africa had increased from 2% to 28%, and in East, South-east and South Asia, the figures had increased fourfold to 19%. There was increased survival on ART, but data was from small research studies. In June 2006, 81% of patients started in 2004 were still on first line regimens, whilst 8% had died and 9% were lost to the research. Thailand not only had the distinction of success in condom use but increased survival of 90% after four years, and the largest percentage of people on ART. There were similar increased survival rates in Botswana, Cameroon, Ethiopia, Peru, Trinidad and Tobago, and Uganda. In addition, increased quality of life was reported in Kenya and Thailand (UNAIDS, 2006b).

Ninety countries had provided target data at least. Ninety per cent had a national AIDS policy and 85% had a national body to co-ordinate strategy. Financial resources
globally had increased with an annual average increase of US$1.7 billion. Some countries had increased coverage for prevention services, but the goal of 25% reduction in HIV prevalence in young people remained elusive. Only five countries met that target. HIV/AIDS continues to affect women and young people, with half of new infections being in the 15–24 year old range. Stigma and discrimination was reported in 30 countries and remain key barriers in implementing successful prevention programmes. Governments continue to fail to care for the 15 million children orphaned by AIDS (UNAIDS 2006b). The goal posts then moved to the aim of universal access of ART drugs by 2010. In order for that to happen, the same problems of inequality of access, IDUs, children, financial resources, and drug-resistant tuberculosis need to be addressed (WHO/UNAIDS/UNICEF, 2007).

THE CONTEXT OF HIV/AIDS IN INDIA

India is particularly vulnerable to HIV/AIDS because of socio-economic conditions, poverty, difficulties in providing information and awareness, gender inequality and disparities, corruption, and the judiciary process. Interventions are necessary in community and health care, workplace and legal structures. These interventions are implemented by the national government and also international programmes. The state of Maharashtra and its capital, Mumbai, are considered high-risk areas for HIV/AIDS because of the huge migrant population, socio-economic conditions, and the number of commercial sex workers in the largest brothel-based industry in India. The dominant mode of transmission in India is heterosexual sex, except in the north-eastern states where injecting drug use is the principal mode of transmission (WHO/UNAIDS/UNICEF, 2007). Another factor which hastened the spread of HIV/AIDS was the rapid expansion of economic growth which led to more slums, more migrant populations, more casual workers, child labourers and poverty. Poor people could not afford condoms. Prostitution and the lack of treatment of STIs led to easier transmission of HIV/AIDS.

At first the population of PLWA was seen as deviant, and not “our” problem, and seems still to be tainted with that stigma. Changing patterns in India led to more nuclear families, women working outside the home, and poorer children. Virginity in women is still valued in the community, but promiscuity in men, which involves risky behaviour, is widely tolerated (Gaitonde, 2001; Mohan, 2007). India had the second highest incidence of HIV/AIDS in the world after South Africa, according to some authors (Chatterjee 2004; Lal 2003; NACO, 2004b). Solomon, Chakraborty, and Yepthomi (2004) noted the significant underreporting of data because of stigma and discrimination problems. The spread of HIV/AIDS in India has been accentuated, because people do not present at hospitals until they have recurrent opportunistic infections such as tuberculosis (Mehta & Gupta, 2007). Indian women, in particular, do not seek medical assistance until late stages of the infection for reasons that are later discussed. In turn, the infections of HIV/AIDS and tuberculosis are amongst the health related ‘shocks’ which can drive people into poverty (Mehta & Gupta, 2007).

The population of India is estimated at over 1.2 billion (Census of India, 2001), and although the prevalence in India is considered low, 0.29%, in comparison to
less than 0.2% in Australia and 0.4% to 1.00% in the United States, it is a serious epidemic as even a small increase in the percentage translates to increases in the number of PLWHA in millions (Mehta & Gupta, 2007) in a number of areas (UNAIDS, 2009). According to Chatterjee (2004), the low prevalence is itself a problem, as it makes it harder to raise sensitivity. There is considerable regional difference in prevalence. For example, the states of Andhra Pradesh, Karnataka, Maharashtra, Manipur and Nagaland have generalised epidemics, whereas other states have low level epidemics. In high prevalence states such as Maharashtra, the epidemic is spreading from urban to rural areas and from high-risk groups to the general population (Chatterjee, 2004). High mobility of the population and lack of information are two reasons why it is difficult to track (Chatterjee, 2004). Social reactions to the disease are overwhelmingly negative, as shown in 36% of respondents in one study who felt it would be better if infected individuals killed themselves (Ambati, Ambati, & Rao, 1997).

India’s Vulnerability to HIV/AIDS

India has particular vulnerability to HIV/AIDS because of poverty, and because it is a vast country with great socio-economic disparities, and very low levels of literacy in certain regions. There are huge migrant populations, untreated STIs, and women are particularly vulnerable due to their low levels of awareness and education, low status and limited access to resources (Chatterjee, 2004). The high-risk groups are injecting drug users, men who have sex with men (MSM), who may infect their wives, and women who are unable to negotiate safe sex. MSM are particularly a high risk as the culture and legal issues surrounding homosexuality in India drive it underground. Therefore many MSM are married in order to conform with cultural expectations – thus putting their wives at risk (World Bank, 2007a).

Economy

In the early 1990s, India faced a severe financial crisis; the gross fiscal deficits reached 10% of GDP; and the annual inflation rate was nearly 17%. Therefore, India put emergency measures into place and embarked on a Structural Adjustment Programme (SAP) which included liberalising foreign investment and exchange, reducing tariffs and trade barriers and reforming and modernising the financial sector. These measures had beneficial effects on the economy, although progress has been uneven, and foreign investment remains lower than in other developing countries. There were corruption scandals in 2001 related to defence procurement, stock market manipulation and mismanagement of the largest state-owned mutual fund. Richer states appear to be increasing incomes faster, and therefore poverty has been increasingly concentrated in the slower growing states (Ekstrand, Garbus, & Marseille, 2003). The government’s structural adjustments aimed at shifting spending on health to the private sector. Consequently the private sector in India now provides 81.6% of all health spending. The government has the responsibility to spread literacy and access to primary health care, and to undertake public health campaigns.
in the areas of HIV/AIDS and major infectious diseases, but these have been com-
promised by lack of budgeting (Ekstrand et al., 2003).

Poverty

There has been a decline in poverty in India in the 1990s, but the actual decrease
remains debatable. Some states have been more successful in reducing the poverty rate.
There are more than 200 million people with malnutrition, or chronic food shortage,
even though India has one of the largest targeted food assistance programmes in the
world (Ekstrand et al., 2003). The anti-poverty programmes provide employment,
productive assets such as land or animals, training, credit and food security to the
poor. However, these programmes are criticised for being inefficiently managed,
badly targeted, and fragmented (Ekstrand et al., 2003). The World Health Organisa-
tion states that poverty is the main reason babies are not vaccinated, clean water
and sanitation are not provided, drugs and treatment are not available, and mothers
die in childbirth in India (Mehta & Gupta, 2007). The large numbers of people
living below the poverty line in India - over 320 million (UNAIDS, 2008) - pose
enormous challenges in the detection and treatment of HIV/AIDS. Poor sanitation,
overcrowding and sub-standard living conditions, leads to lowered resistance to co-
morbid conditions such as tuberculosis, and contribute to the spread of disease.
HIV/AIDS is only one of many health conditions that people in slum communities
face every day.

Socio-economic Factors

The diversity in levels of society and employment make it difficult to implement
programmes across the board. People in slum communities are not able to afford
proper health and medical care, and this is particularly applicable to women. HIV/
AIDS places even more financial burdens on those least likely to afford them. The
effects of living in a slum community in Mumbai have been documented by Parkar,
Fernandes, and Weiss (2003). They found that the overcrowding, pollution and
limited social supports, because of the breakdown of families, disrupted social
networks affecting individuals and communities.

Education and Awareness of HIV/AIDS

Chatterjee (2006), and Population Foundation of India (2005), both estimate the
number of illiterate women in India to be nearly 245 million (over 50%). Education
provides a conduit for accurate information, whilst a lack of education means more
dependency on unreliable sources. There is a lack of empowerment to make decisions,
and to act independently without health information. This is a major problem for
women in poor circumstances in India. Figures for literacy vary greatly from state
to state in India. For example, the literacy rate is highest in Mizoram i.e. 90%,
and lowest in Uttar Pradesh i.e. 30% (YOUANDAIDS, 2005). Whatever the literacy
levels, education about HIV/AIDS and sexual matters in general is still limited,
particularly amongst women, because of sexual taboos. In Maharashtra, 82% of
people had heard of HIV/AIDS, but only 6.5% married women had heard about the disease from a health worker. Their information was mostly from media sources, family or friends, which indicates the information may be incorrect or incomplete (Population Foundation of India, 2005).

Lack of Awareness about HIV/AIDS and STIs

India has a very high rate of STIs. Unlike HIV, STIs can be treated and cured relatively easily if treated properly and early (AVERT, 2007). The current estimates are that approximately 6–9% of the population in India suffer from STIs, with more than 40 million new infections reported per year. Those on low incomes cannot always afford to buy condoms, or access treatment (Solomon et al., 2004). Women with STIs are considered to be two to four times more at risk of contracting HIV than women without such infections (Royce et al., 1997). Researchers in Mumbai found that men attending public STI clinics had a high prevalence of HIV, associated with HSV-2 infection, and visiting female sex workers (CSWs). Of the married men, 46% had visited a CSW in the past three months (YOUANDAIDS, 2005).

Widespread and Entrenched Gender Inequality

Sen (2008) states that there are several kinds of gender inequality in many parts of the developing world, with South Asia including India bearing a significant burden of gender inequality.

Firstly, mortality inequality is unusually high for women in India; it takes the brutal form of high mortality rates of women and as a consequence a higher proportion of men in the total population. In India, the figures show a 0.93 male female ratio i.e. 930 female babies born for every 1000 male babies and results in a missing female population of 36 million. Sen called this population: “the missing women who should have been born”. Secondly, there is natality inequality – the preference for boys, leading to sex-selective abortion and female foeticide and infanticide especially in the rich Northern states of Punjab and Haryana.

Thirdly, Sen describes basic facility inequality where girls do not receive equal education and are also not encouraged to develop natural talents. Lack of opportunities for higher learning and professional training creates special opportunity inequality. Professional inequality exists in India in terms of employment as well as promotion in work and occupation where women often face greater disadvantage than men.

Females are not equally represented in property ownership leading to ownership inequality in most parts of India. The last inequality is household inequality, which refers to the lack of decision-making by women in families and households (Sen, 2008).

Although the status of women in India is changing, particularly in the upper and middle classes, there are still large numbers of women who have little say in many facets of their lives, from childhood, education, marriage, economic decisions to negotiating safe sex. Cultural and religious beliefs relegate women to a lower level than men, with resulting disempowerment and difficulties, despite the fact that
Indian women work hard, and shoulder the caregiver burden for the family. Female children receive less education and less nourishment, and are discriminated against from birth onwards. These factors are major contributors to stigma and discrimination, and are further discussed in Chapter 4.

Corruption and Crime

Corruption pervades all areas of economic and political life in India. The corporate sector contributes to both public and private sector problems. The high levels of corruption lead to leakage of funds from those allocated to HIV/AIDS programmes, as well as the common practice of paying bribes to expedite action on projects. With decentralisation, the states are being made responsible for corruption; however they may lack the will or the resources to tackle it (Ekstrand et al., 2003). There is significant organised and random violence. The dislocation of population from ethnic violence and human trafficking has particular significance for women, and makes targeting programmes more difficult (Ekstrand et al., 2003).

Judiciary

The Indian judicial system is another area affected by corruption at the state level. Added to this is the enormous backlog of cases (estimated to be 28 million), extremely slow processing (5–10 years), low levels of knowledge about new legislation, and weak enforcement of decisions (Ekstrand et al., 2003). These factors have implications for the human rights of PLWHA, as well as police harassment of certain groups such as sex workers, men who have sex with men, and even the workers in HIV/AIDS programmes. In addition, there is no national legislation in India to protect PLWHA (Ekstrand et al., 2003).

INTERVENTIONS IN HIV/AIDS IN INDIA

Responses to HIV/AIDS in India

A review of interventions in HIV/AIDS in 2003 revealed that interventions have targeted high-risk groups such as sex workers, intravenous drug users, men having sex with men, truckers, migrant labourers and street children (Chatterjee, 2004). The United Nations Office of Drugs and Crime (UNODC) worked at the national level with the Ministry of Social Justice and Empowerment, as well as the Ministry of Health and Family Welfare, to include HIV/AIDS in ongoing programmes. Peer networks were started in the North Eastern states and metropolitan cities, mainly in the area of drug users, and detoxification camps were held (Chatterjee, 2004).

The United Kingdom Department of International Development (DFID) has been working in partnership with the NACO, and with centres in Gujarat, Orissa, Andhra Pradesh, West Bengal and Kerala, to reduce the spread of HIV, targeting commercial sex workers (CSWs), injecting drug users (IDUs) and men having sex with men (MSMs). In West Bengal, 100,000 people have been reached through non-government organizations (NGOs). State AIDS Control Societies (SACS) have
designed targeted programmes according to prior needs assessments. The United States Agency for International Development (USAID) have ongoing focused intervention programmes in Tamil Nadu and Maharashtra, helping NGOs to design strategies to high-risk groups especially in the sex industry (Chatterjee, 2004).

The NACO report details Phase-III (2007–2012) of the National AIDS Council Plan where the overall goal is to reduce and reverse the epidemic in India over the five-year period. Highest priority has been placed on preventive efforts integrating prevention with care, support and treatment through a four-pronged strategy:

- Preventing new infections among high risk groups and general population through:
  - saturation of coverage of high risk groups with targeted interventions;
  - scaled up interventions in the general population
  - Providing greater care, support and treatment to larger number of PLHA.
  - Strengthening the infrastructure, systems and human resources in prevention, care, support and treatment programmes at the district, state and national levels.
  - Strengthening the nationwide Strategic Information Management System.
  - Prevention of HIV transmission in the general population (NACO, 2010, p.7)

It has been acknowledged that monogamous married women are a high-risk group. Collaboration of the United Nations Development Fund for Women (UNIFEM), the United Nations Development Program (UNDP), the Indian Railways and NGOs has resulted in the use of peer counsellors working towards a gender-sensitive approach on HIV/AIDS care and prevention. To date, peer counsellors have reached 70,000 people in the five entry points of the railway community and a Railway Women’s Empowerment and AIDS Prevention Society (REAPS) has been set up. Gender and HIV education has been introduced into all the Indian Railway Schools, from the ninth grade, encouraging young people to question gender stereotypes, and for women to negotiate safer sex and promote male sexual responsibility (Chatterjee, 2004).

**Interventions Focusing on Children and Young People**

Chatterjee (2004), reports that with UNICEF funding, 291 Prevention of Parent-to-Child Transmission (PPTCT) teams are providing services across high and low prevalence states in India. The overall intervention uptake rate is 87.6% of HIV positive women and their newborn babies receiving Nevirapine. The United Nations Children’s Fund (UNICEF) and the National AIDS Control Organisation (NACO) are developing a plan to reach young people who have finished school; and have also implemented a programme of prevention and education in four high-prevalence states including Maharashtra (Chatterjee, 2004). In addition, the World Bank, the Ministry of Health and the Ministry of Home Affairs are providing education in schools and universities and colleges. The United Nations Development Program (UNDP) and National Indian IT Programme (NIIT), a premier IT education institute,
have collaborated to raise HIV/AIDS awareness in young people by using peer educators (Chatterjee, 2004; WHO, 2004).

**Community-based Care Models**

The India-Canada Collaborative HIV/AIDS Project (ICHAP) has developed a community-based care model for HIV prevention and care for rural migrant men and their families, in 133 villages in Rajasthan. In Karnataka, ICHAP works with the state AIDS Prevention Society to help establish sustainable systems (ICHAP, 2004a, b). In 2003, VCTCs were increased from 6 to 31. Model voluntary counselling and testing centres have been set up in Chennai, Mumbai and Imphal, with the help of the World Health Organisation (WHO, 2004).

**Community Interventions**

D’Cruz (2002; 2004) claims that primary prevention activities, aimed at controlling the spread of HIV/AIDS in India, are totally inadequate in content, volume and orientation, and leave much to be desired in terms of the effectiveness of programmes and policies. The development of secondary and tertiary health interventions has burdened populations with the responsibility of providing home-based care for ill members. Community care has become the watchword for secondary and tertiary care. In India, community care is a euphemism for family care. These community care models were supposed to be an ideal model, however, families have to provide the community care services. HIV/AIDS families deserve special attention because the family members are also stigmatised and isolated, and infection in one member points to another member being infected. The enormous upheaval and change in the family structure has not been the subject of research. D’Cruz (2004) reports that the women were angry, resentful and bitter, but still provided care to their husbands, and said there was no change in their respect for their husbands. Changes in family life affected children, although they had limited understanding of the problems.

**Workplace Interventions**

The Central Board of Workers Education (CBWE), an institution of the Ministry of Labour in India, in collaboration with the International Labor Organization (ILO) is imparting HIV/AIDS education to workers in the organised, unorganised, informal and rural sector throughout India, as well as encouraging trade union leaders, labour inspectors to be more aware of difficulties for their labour force. A national workshop was organised to highlight stigma and discrimination issues in the workplace (ILO, 2009). The United Nations Country Team has initiated a project to ensure that all UN officials in India are trained, and aware about HIV/AIDS. In Gujarat, the Reliance Group, India’s largest private company, has agreed to sponsor one workshop a month on HIV/AIDS for its own staff, and set up an STD and DOTS (TB treatment) centre. The State Bank has pledged that loans will only be given to those units which have HIV/AIDS prevention, care, and support activities (Chatterjee, 2004).
Care, Support and Treatment

NACO, ICHAP, CIDA and UNAIDS organised a national consultation on community-based care and support for HIV/AIDS. The recommendations were to expand focus to low-prevalence states, explore models of comprehensive care, endeavour to keep people in their communities, train physicians, particularly in the private sector, and increase the capacity of families to care for the infected and affected (Chatterjee, 2004). The provision of free antiretroviral therapy (ART) was introduced through government hospitals in 2003 (Tarakeshwar et al., 2006) although it had been available in the private sector beforehand. However, NACO’s ART initiative reported difficulties in the lack of government infrastructure, lack of finances to access treatment, and lack of access for women. Certainly, the distribution of ART has not been taken up to the full (UNAIDS/WHO/UNICEF, 2007).

Legal and Ethical Issues

The Lawyers Collective has prepared draft legislation to protect the rights of PLWHA. They provide ongoing advocacy in this area. In 2004, UNIFEM supported a consultation with women’s groups to see if gender issues were being addressed in the bill (The Lawyers’ Collective HIV/AIDS Unit, 2009). The Swedish International Development Organization (SIDA) has been working in the area of advocacy of vulnerable populations such as women, MSM, CSW and IDU. Namakkal, Tamil Nadu, has a Positive Living Project aimed at improving access to quality care and support to PLWHA and their families, including home-based care, and outreach services (UNIFEM, 2007).

Healthcare Interventions

In 2007, the World Health Organisation noted that access to treatment for HIV/AIDS has increased gradually in India since 2004. The provision of ART to children has started with a goal of 40,000 children by 2011. Prevention of mother-to-child transmission programmes began in 2002, and were being offered in 2433 health centres by 2006. Voluntary HIV counselling and testing started in 1997, and between 2002 and 2005, 3.03 million people had been tested (WHO/UNAIDS/UNICEF, 2007).

THE NATIONAL AIDS PREVENTION AND CONTROL POLICY

In 1987, the Indian government adopted a national AIDS prevention and control policy which included programmes of condom promotion, behavioural change, community information and education, targeting special groups, blood safety and treatment for sexually transmitted infections (UNAIDS, 2007a). Education and awareness of HIV/AIDS has been undertaken in all states of India through the Department of Education and non-government organisations (NGOs). Film stars and celebrities have spread the messages as well as street plays, songs and dramas. A toll-free national telephone
help-line has been established. Community Popular Opinion Leaders are trained to educate peer groups, and schools have AIDS education programmes (Solomon et al., 2004).

As a result of these and other methods, awareness of AIDS has risen from 54% to 78% in urban populations, and 13% to 64% in rural areas since 1987 (Solomon et al., 2004). However, when the figures for women are separated NACO reports that 15% urban women and 35% rural women lack AIDS awareness (NACO, 2004a). Television is rated as the most effective medium for imparting knowledge, and radio and print have a low effective rate according to Pallikadavath, Sreedharan, and Stones (2006). They suggest using health workers, community level activities such as adult education programmes, and networks of friends and family. In South India, the Positive Women’s Network is seeking to address stigma, fear and paranoia of other individuals (UNAIDS/UNFPA/UNIFEM, 2004).

Discrimination is addressed within the national HIV/AIDS policy, although various states’ policies may differ. Despite the policies, there is no legislation to implement change, although some authors have said that there is an urgent need for such legislation (Arunkumar, Sankar, Archana, & Kochumuttom, 2002). Although all hospitals in Mumbai are expected to provide care for people living with HIV/AIDS (PLWHA), people with HIV report harassment when they try to access health care (UNAIDS, 2007b). HIV prevalence varies widely according to geographical areas and risk groups. There are two different situations – lack of support and care for PLWHA, and also the fear of stigma prevents many people getting tested.

Some examples of programmes to offset the effects of stigma and discrimination are: The Society for Positive Atmosphere and Related Support to HIV/AIDS in Kolkata, in which women learn to sew and sell handicrafts; in Manipur, the Social Awareness Service Organisation helps HIV-infected widows; and The Institute of Health Management employs social workers to intervene in family disputes. PRAYAS is a non-profit organisation which researches the effects of HIV/AIDS stigma on women and their coping abilities (Cohen, 2004). UNAIDS supported a partnership between the Nagaland SACS, NGOs, Nagaland Network of Positive People and Naga People’s Movement for Human Rights to address stigma and discrimination. At a state workshop, representatives from the government, tribal hierarchy, students, church, media and lawyers joined to address stigma and discrimination through community involvement and partnerships (Chatterjee, 2004).

Chatterjee (2004) in his UNAIDS report on the responses to HIV in India, details examples of the use of HIV positive people to spread the prevention and education message. For example, the Gujarat State AIDS Control Society has undertaken a comprehensive needs assessment in six urban settings with the help of people who are HIV positive. This has resulted in building networks and enhancing research capacities. UNIFEM has supported the participation of three HIV positive women in a national consultation on Domestic Violence Bill organised by Action India and the Lawyers Collective. The Indian Network for People living with HIV/AIDS (INP+) launched the Positive Speakers Bureau. This is designed to empower PLWHA to tell their stories, in order to reduce stigma and discrimination (Chatterjee, 2004).
Highlights of Initiatives and Achievements by the NACO

The NACO (2010) report highlighted some key initiatives and achievements, a summary of which are listed below:

**Targeted Intervention for High Risk Group Population:** Interventions for high risk groups are a core component of the control strategy to ensure that people, who are at high risk due to frequent exposure to HIV and higher levels of STIs, do not transmit the infection. Targeted Interventions projects provide prevention and care services covering **53 percent** of Female Sex Workers (FSW), **74 percent** of Injecting Drug Users (IDU) and **78 percent** of Men having Sex with Men (MSM) and transgender populations (NACO, 2010, pp. 7 & 8).

**Link Workers Scheme:** This community-based intervention addresses HIV prevention and care needs of the rural community with special focus on High Risk populations and other vulnerable groups. The scheme is operational in 100 selected villages in 126 identified districts in 18 states.

**Blood Safety:** Access to safe blood has been ensured through a national network of 1,103 Blood Banks including 130 Blood Component Separation Units and 10 Model Blood Banks.

**Integrated Counseling and Testing Centres (ICTC):** Counseling and testing services have been phenomenally scaled up with 5,135 ICTCs and 608,000 general clients and 440,000 pregnant women were counselled and tested at ICTCs as of December 2009. Among the 15,089 positive pregnant women, 9,398 (62.28%), received Nevirapine prophylaxis to prevent the mother to child transmission of HIV. 37,196 patients with HIV-TB co-infection were identified and treatment commenced.

**Management of Sexually Transmitted Infections:** The Department of AIDS Control supports 916 designated STI/RTI clinics at District and Teaching hospitals, 1,290 STI Clinics in Targeted Interventions, 5,744 private preferred providers for community-based STI services delivery to the high risk population.

**Information Education & Communication (IEC):** An ambitious communication strategy has been implemented, aimed at effecting behaviour change and creating an empowering environment. The IEC strategy focuses on stigma and discrimination reduction, giving special emphasis to youth and women who are more vulnerable to HIV infection. A multi-media campaign in September 2009 targeted youth through music and sports in Manipur, Mizoram and Nagaland. 7,677 Red Ribbon Clubs in colleges across the country encourage peer-to-peer messaging on HIV prevention. 208 drop-in-centres supported by NACO are run by PLWHA networks to promote positive living and improve quality of life.

**The Red Ribbon Express (RRE):** The world’s largest mass mobilisation against HIV/AIDS. In its second phase in India, the RRE train was flagged off by the Hon’ble Smt. Sonia Gandhi on World AIDS Day, 1 December, 2009. During its year long run, RRE will cover 152 stations in 22 states. Services for HIV testing, treatment of STI and general health check-up have been added at the stations. IEC exhibition vans and folk troupes are taking the messages to rural areas.
The Tribal Action Plan was finalised and launched in 44 Integrated Tribal Development Project areas in A & B category districts; 21 more areas will also be covered. During 2009–10, about one lakh Self Help Groups in 15 states are being trained on HIV/AIDS issues.

Condom Promotion: Condom is the most effective prophylaxis for preventing HIV transmission. During 2009–10, the condom social marketing programme has been successfully scaled up to 294 districts; 4.64 lakh condom outlets serviced by the programme distributed 23.4 crore (234 million) pieces of condoms till January 2010.

Care, Support and Treatment: The programme provides comprehensive management of PLWHA with respect to prevention and treatment of opportunistic infections, Antiretroviral therapy (ART), psychosocial support, home-based care, positive prevention and impact mitigation.

The free ART programme for PLHA has been scaled up to 239 centres - 300,743 patients are being provided free ART as of January, 2010, including 18,889 children. The Department of AIDS Control is in the process of implementing the “Smart Card” Project. This card will act as a portable medical record and facilitate analysis of data. The rollout of second line ART commenced and expanded from January 2009, and currently there are 970 patients on second line ART provided through 10 Centres of Excellence.

Addressing HIV/AIDS in children especially infants below 18 months is a significant global challenge. Recent evidence demonstrates that early HIV diagnosis and ART are critical for infants, and a significant number of lives can be saved by initiating ART for HIV infected infants immediately after diagnosis within the first 12 weeks of life. In India, the programme has been rolled out from 1 March 2010 at 760 ICTCs and 180 ART centres.

Laboratory Services: Capacity of laboratories for CD4 testing has been strengthened with 209 CD4 machines. Quality assurance in kit evaluation and assessment of HIV testing services has been enhanced through the implementation of an External Quality Assessment Scheme (EQAS).

The ‘National Ethics Guidelines for Research in HIV/AIDS’ were reviewed and finalised at a joint meeting of the NACO Ethics Committee and the Technical Resource Group on R&D on 8 January, 2010. The ‘Network of Indian Institutions for HIV/AIDS Research’ has 35 institutions as members.

The HIV Sentinel Surveillance 2008–09 was completed in August, 2009. The Behavioural Surveillance Survey was carried out in six states. The epidemiological profiling of HIV in district/sub-district level was carried out in 182 districts of seven states from July to November 2009. A plan is being developed for initiating Integrated Biological and Behavioural Surveillance in a phased manner.

Finance: Against the revised estimate of Rs.980.15 crores for FY 2009–10, an expenditure of Rs 890.77 crores (90.88%) was incurred (as on 15 March, 2010). Special efforts were taken to build in systems for effectively managing resource mobilisation and fund utilisation (these highlights have been paraphrased from the NACO report 2010, pp. 7 & 8).
International Contribution to HIV/AIDS in India

The World Bank has worked with the Government of India through NACO to ensure collaboration with overseas partners such as UNAIDS, WHO, USAID, DFID and CIDA. Overseas funding for HIV/AIDS projects totalled US$328 million in 2005 (The World Bank Group, 2005). The World Bank has stressed that India must move quickly to target high-risk groups such as CSWs, MSM, migrant labourers, and IDUs to contain the spread of the epidemic. Strategies promoted are peer counselling, condom promotion, treatment of STDs, and patient programmes.

Prevention strategies, which have proved successful, are information and awareness campaigns with an emphasis on behaviour change, voluntary testing and counselling through blood banks and STD clinics, and the reduction of transmission through blood transfusions and exposure through occupations. Funding through the World Bank provides low cost treatment for PLWHA, home and community-based care and treatment of opportunistic infections. Another facet is the strengthening of the effectiveness of programmes across the country, and improving surveillance and data collection (World Bank, 2005).

Figure 1. Map of India and of the 6 high prevalence states (map obtained from http://www.avert.org/aidsindia.htm)
CHAPTER 2

It is important to focus on the state of Maharashtra, because different states in India have varying responses to HIV, as seen above. The following section details the pertinent issues and challenges facing the state, and, in particular, the city of Mumbai, its capital.

![Map of Maharashtra and the high prevalence districts](http://mahasacs.org/ahvaan].htm)

THE STATE OF MAHARASHTRA

Maharashtra is the third largest state of India, (see Figure 2 above) and leads the country in industry, contributing 13% of the national output, producing chemical and allied products, electrical and non-electrical machinery, textiles and petroleum (Chatterjee, 2004). However, over 64% of the state’s population are employed in agricultural areas. Maharashtra is one of six states with a high prevalence rate of HIV/AIDS - over 5% among groups with high-risk behaviour, and 1% among women attending antenatal clinics in public hospitals (Chatterjee, 2004).

THE MEGA CITY OF MUMBAI

Maharashtra’s main city, Mumbai, has a HIV prevalence rate of over 2% of the population (Solomon et al., 2004), compared to the national prevalence rate of 0.3% –0 0.5% (UNGASS, 2008). Situated on the western seaboard of India, Mumbai is the financial capital of India with a population of 20.04 million (UN, DESA, 2009). The bustling, thriving metropolis attracts migrant workers, and transient truck drivers from all over the country (Bharat & Aggleton, 1999). Mumbai is located on a peninsular with little space (440 square km) to expand, resulting in overcrowding and poor socio-economic conditions for a majority of the inhabitants (Eliot, 1998).
OVERVIEW OF HIV/AIDS GLOBALLY AND IN INDIA

Mehta (2004, p. 14) describes the mega city thus: Greater Bombay’s population, currently 19 million, is bigger than that of 173 countries in the world. Singapore has a density of 2,535 people per square mile; Berlin, the most crowded city in Europe has 1,130 per square mile. Some parts of central Bombay have a population density of 1 million people per square mile. This is the highest number of individuals massed together at any spot in the world. Due to its mobile migrant population it is difficult to actually provide accurate numbers for the population of Mumbai.

The Unique Place of Migrants in Mumbai

The density of the female population living in Indian rural areas has declined from 70% to 50% because of migration away from rural areas and villages. Thus, according to Feldman (1998), female migration to the cities is rarely voluntary, but...
as a result of decreasing rural viability. The factors contributing to the increasing poverty amongst rural women include a decrease in per capita food availability. This has meant losses in the traditional employment of women in their subsistence occupations of sheep rearing, dairying, wool-making and weaving. Tribes such as the Halkars, who are sheep rearers, have disappeared in 19 districts in Maharashtra (Mishra, 1999). Singh (1999, p. 21) terms this migration the “feminization of poverty,” and claims that the centrally sponsored poverty eradication programmes have also meant that women have become more impoverished, and moved to the cities as programmes may not have favoured or reached them.

Instead of dreams of economic liberation and employment in the city, the reality for many women is the exchange of rural hardship for urban squalor. Poverty and low status make women especially vulnerable, and despite the gains made by middle to upper class women in India, tradition and poverty are still major obstacles for most women (Schaffer & Mitra, 2004). In addition to the migration from rural to urban areas, poverty and its attendant overcrowding among the male population in Mumbai has contributed to men seeking work outside the crowded city. This has resulted in a vast army of truck drivers traversing the whole country (Stansbury & Sierra, 2004). They are away from home for prolonged periods of time, and are known to be major carriers of HIV/AIDS, as they are reported to have up to 200 sexual encounters in one year, although these figures are said to be reducing, for example, 48% to 27% from 1996 to 2002. Seventy per cent of male migrant workers are reported to have STIs and 30% to have AIDS. The men return to urban and rural households where they pass on the infection to their wives and ultimately, children, through mother-to-child transmission (Mohan, 2007; Solomon et al., 2004).

The Sex Worker Industry in Mumbai

The migration to big cities such as Mumbai is especially hard on women. Uprooted from their families and village traditions, they become embroiled in the traumas of cash-commodity-flesh-trading in order to survive. This results in criminal activities such as prostitution, bootlegging, and trade in contraband. Since the first AIDS case was detected in Chennai, Tamil Nadu, in 1986, there has been an alarming growth in the number of HIV positive people in Mumbai, which has the largest brothel-based sex industry in India, with an estimated 15,000 sex workers (Gomare, Bamne, & Thanekar, 2002), 62–70% of whom are HIV positive (Shankaran, 2002).

The primary drivers of the HIV epidemic in India as reported previously are unprotected paid sex, commercial female sex work, unprotected sex between men and injecting drug use. It is estimated that there are 12.6 lakh (120,000) Female Sex Workers, 3.5 lakh (350,000) Men who have Sex with Men with high risk and 1.9 lakh (190,000) Injecting Drug Users in India. Though sex workers account for about 0.5 percent of adult female population, they account for 7% of HIV infected females. Sex work continues to act as the most important source of HIV infections in India due to the large numbers of clients that get infected from sex workers (NACO. 2010). India’s cultural diversity, regional differences and taboos may hinder the collection of exact data, so the figures may be even higher (Chatterjee, 2004; Solomon et al., 2004).
OVERVIEW OF HIV/AIDS GLOBALLY AND IN INDIA

SUMMARY

The literature regarding HIV/AIDS in India is now extensive. There are national government departments and organisations, state societies for the prevention of HIV/AIDS, and many internationally funded organisations. Married women have not been a focus of attention until recently, and because of the low status of women in the slums, are unlikely to attract attention. Although India’s HIV/AIDS epidemic is small in prevalence, the huge population means that even a small increment leads to millions of people being affected. India has implemented successful interventions and strategies; however, structural problems in the allocation of funds, corruption and mismanagement, mean that even the distribution of lifesaving medication is delayed. Stigma and discrimination play an important role in the epidemic because of structural and cultural factors. The following chapter discusses the ubiquity of stigma, discrimination and prejudice; and how understanding of the concepts is necessary in order to strategise responses in the area of HIV/AIDS.