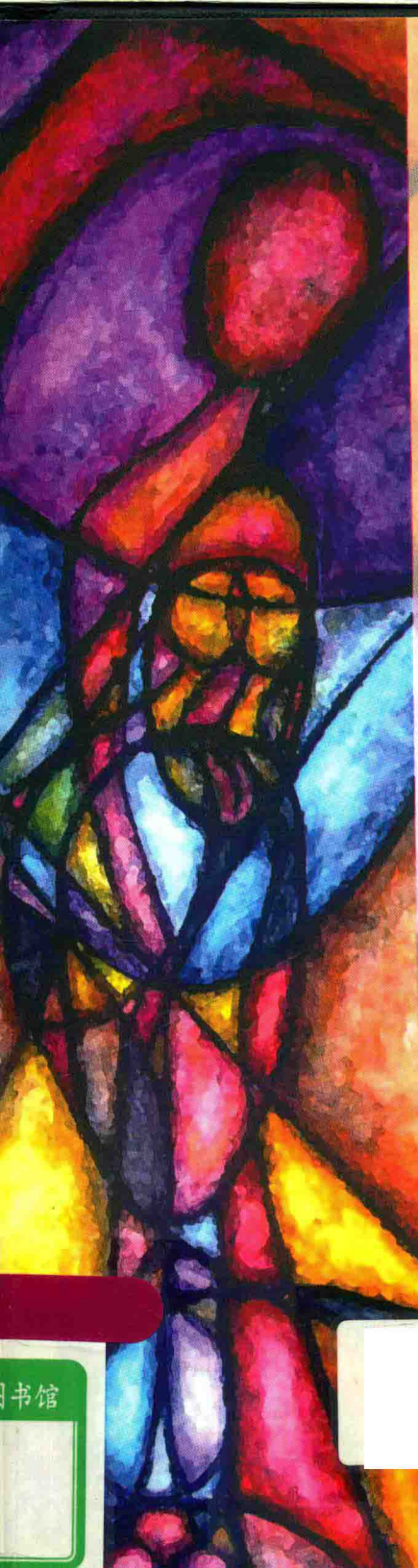

GENDER, SEXUALITY AND HIV/AIDS

Exploring Politics of Women's Health in India

Skylab Sahu

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List of Abbreviations

ACHAN	Asian Community Health Action Network
AIDAN	All India Drugs Action Network
AIDS	Acquired Immune Deficiency Syndrome
AIDWA	All India Democratic Women's Association
AIPSN	All India People's Science Network
ANC	Antinatal Care
ANM	Auxiliary Nurse and Midwife
ART	Antiretroviral Therapy
BGVS	Bharat Gyan Vigyan Samiti
BJP	Bharatiya Janata Party
BKD	Bharatiya Krisak Sangathan
BPL	Below Poverty Level
CEHAT	Centre for Enquiry into and Allied Themes
CHC	Community Health Cell
CINI	Child-In-Need Institute
CPI (M)	Communist Party of India (Marxist)
CSO	Civil Society Organization
DAWN	Development Alternative with Women for a New Era
DFID	Department of International Development
DPSP	Directive Principles of State Policy
FOIRN	Federacao das Organizacoes Indigenas do Rio Negro
FSW	Female Sex Worker
GDP	Gross Domestic Product
GNP	Gross National Product
GSDP	Gross State Domestic Product
HDI	Health Development Index
HDR	Human Development Report
HIV	Human Immunodeficiency Virus
HRLN	Human Rights Law Network
HSDP	Health Systems Development Project
HSR	Health Sector Reforms

ICDS	Integrated Child Development Services
ICPD	International Conference on Population and Development
ICCPR	International Covenant on Civil and Political Right
ICESCR	International Covenant on Economic, Social, and Cultural Rights
ICS	Indian Civil Service
ICTC	Integrated Counselling and Testing Centres
ILO	International Labour Organization
IMF	International Monetary Fund
IMR	Infant Mortality Rate
INSA	International Service Association, India
IT	Information Technology
IUD	Intrauterine Devices
JSA	Jana Swasthya Abhiyan
KHSDP	Karnataka Health System Development Project
KNP+	Karnataka Network of Positive People
Kol.NP+	Kolkata Network of Positive People
KSAPS	Karnataka State AIDS Prevention Society
LPG	Liberalization, Privatization and Globalisation
MFC	Medico Friend Circle
MMR	Maternal Mortality Rate
MSMs	Men Having Sex with Men
NACO	National AIDS Control Organization
NACP	National AIDS Control Programme
NFHS	National Health Family Survey
NGO	Non-governmental Organization
NHA	National Health Assembly
NHRC	National Human Rights Commission
NPC	National Planning Committee
OI	Opportunistic Infection
PC-PNDT	Preconception and Prenatal Diagnostic Techniques
PHC	Primary Health Centres
PHM	People's Health Movement
PLHA	People Living with HIV and AIDS
PMTCT	Prevention of Mother-to-Child Transmission
PNDT	Prenatal Diagnostic Techniques
PR	Panchayati Raj
PSP	Praja Socialist Party

QS	Quinacrine Sterilization
RCH	Reproductive and Child Health
RTI	Reproductive Tract Infection
SAP	Structural Adjustment Programmes
SC	Scheduled Cast
SHG	Self-help Group
SPAD	Society for People's Action for Development
SSP	Samyukta Socialist Party
ST	Scheduled Tribe
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
STM	School of Tropical Medicine
TB	Tuberculosis
TI	Target Intervention
UDHR	Universal Declaration of Human Rights
UK	United Kingdom
VCTC	Voluntary Counselling and Testing Centres
VHAI	Voluntary Health Association of India
VRS	Voluntary Retirement Scheme
WB	World Bank
WBNP+	West Bengal Network of Positive People
WBSACS	West Bengal State AIDS Control Society
WHO	World Health Organization
WIA	Women's India Association
WSF	World Social Forum

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Introduction

> Very many people across the world suffer from varieties of unfreedom.... Also a great many people have little access to health care, to sanitary arrangements or to clean water and spend their life fighting unnecessary morbidities, often succumbing to premature mortality.... Further inequality between women and men afflicts—and sometimes prematurely end—the lives of millions of women and in different ways, severely restricts substantive freedom that women enjoy. (**Amartya Sen** 1999: 15)

Health is a multidimensional issue that determines development of people and is used as a vital index for human development. Undoubtedly, growth of any economy depends on the condition of people's health (Bloom et al. 2004; Gupta 2002; Sen 1999), but the process of health provisioning can escalate development, if it is non discriminatory, irrespective of class, caste and gender differences. Quite lately, health has also been demanded as a right of a citizen. Especially in the case of Indian State, health, a welfare need in the past, has recently gained the status of a right. The Indian State had constitutionally categorized health under the Directive Principles of State Policy; the apex court with its directives declared 'right to health' as an extended part of 'right to life' (Article 21). With this, the State's association with health rights became all the more firm, and its responsibility for provisioning of health care to all became an obligation. Health as a right needs to be equitable and holistic such that the health rights of all the citizens irrespective of their socio- economic background could be ensured.

Indian society is heterogeneous and stratified and has huge social differences in terms of caste, class, ethnicity and gender. In such a society, disadvantaged groups like the poor and women face several obstacles in accessing health care. When the health care provisioning is inadequate, unavailable and unaffordable, it further puts people's health rights and especially poor women's health rights in jeopardy. Health rights of people also become unrealizable when public health provisioning fails to cater

to the specific needs of diversified sections of the society. It is mostly the women and poor who are prone to be left out from availing health care. There could be several reasons behind it. Operating within the parameters of a male-dominated society, people tend to give less importance to women's health (Blackburn 1999; Hartigan et al. 2002). The patriarchal system socializes women in such a way that women themselves feel it is unnecessary or even unfair to assign priority to their own health condition and sickness and diseases. This social conditioning makes women to often ignore their own health problems. Further, women get less attention during illness, even from their family members. Women are given partial importance in society and are seen only as bearers of the heir to carry the family forward. General health problems (which are not even female specific) may turn out to be more harmful for women than men due to their socio-economic location (Gilligan 1992). The gender bias prevailing in health care as well as gender role in society creates further hurdles for women, and they lag behind men in availing treatment. In such situations, general health problems like leprosy, tuberculosis and most recently, human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) affect women more adversely than men (Hartigan et al. 2002; Lee 1994; Michelson 1993).

Since independence, the Indian State has been extensively involved in addressing numerous health problems and has taken the initiative to eradicate several diseases. Attempts have also been made to prevent certain health problems[1] or provide immunization for ensuring prevention of selected diseases. The State has intervened in formulating policies and programmes to deal with health in general and women's health in particular. It has allocated finance, built infrastructure and institutions and recruited personnel. Undoubtedly, there have been several achievements in this arena. For instance, the Indian State was successful in establishing a three-tier hospital system in the whole country. Life expectancy for both men and women has increased and death rate has decreased drastically over the past few decades.[2] The State-provided immunization led to prevention of diseases like smallpox, polio and so on.

A contrasting picture, however, reveals that despite these achievements, the State is grappling with several problems. Diseases like malaria, flu, cancer, tuberculosis (TB) and several others continue to remain a cause of concern. Apart from these, a relatively new epidemic, that is, HIV/AIDS, which emerged during the late 1980s, has put forth an enormous challenge before the State, especially with regard to women's health and

their rights. Despite several initiatives taken by the State, there have been intrinsic inadequacies attached to its approach towards women's health. The State mostly adopted a medical approach for women's health through several health and population policies that targeted women (Hartmann 1987). In the process, it neglected the socio-economic aspect of women's health, and such an approach has led to medicalization.[3] The public health system intending to provide health services to women in an equitable way has also indeed remained gendered.[4] Current state of affairs in women's health care indicates that only a few female doctors, gynaecologists and hospital beds are allocated for providing treatment to women.

Until the mid-1990s, the State's approach to women's health remained narrow; that is, it focused only on maternal health, a sign that enough focus has not been given to general health problems faced by women. A major shift in government approach towards women's health took place in the era of globalization. During the 1990s, there was a change in the discourse or the language that the State has been using in relation to women's health. Several national and international initiatives like Swaminathan Committee report, Cairo Conference and civil society activisms influenced the State to change its approach towards women's health. India, being the signatory of Cairo Declarations (International Conference on Population and Development [ICPD] Action Plan), adopted a reproductive health approach. With this, the Indian State changed its approach from maternal health to reproductive and child health. With the neoliberal economy becoming popular during the 1990s, many nations willingly or unwillingly adopted structural reforms, and the role of international agencies became prominent in policy formulation as well as in policy changes. In light of structural reforms, the role of State has shrunk in terms of reduction in financial allocation to social service sectors. There has been increased privatization, retrenchment (full or partial through contracting, outsourcing and voluntary retirement services [VRS]), cut in subsidies, introduction of user fee, cut in other welfare programmes and so on (Dev and Mooij 2002; Patnaik and Chandrasekhar 2007; Prabhu 1994). Moreover, there was a change of discourse that converged rights with development (Marks 2004). All these changes were aimed to have a significant impact on the issue of health, particularly on women's health.

Along with State, parallel interventions by CSOs and health movements were also taking place. Though historically, the civil society was socially active and concentrated more on the service delivery aspect of health care, it was only in the mid-1970s its nature underwent change; several CSOs

joined hands with women's groups (leading women's movements) for the common cause of addressing health issues. Several health issues such as sex selective abortion, use of reproductive technologies, health implications of reproductive technologies on women and so on were discussed (Contractor et al. 2003; Gandhi and Shah 1993; Lingam 2002). During the National Emergency, the Indian State acted as a coercive authority in implementing birth control measures. As a result, these CSOs and women's groups, together as a movement, criticized the State for its coercive family planning policy and its faulty target-specific population policy (Chacko 2001). The politically active role of CSOs and women's groups continued even during the 1980s. In the 1990s, especially with the phenomenon of globalization setting in and through an improved communication system (Bhagwati 2004), the civil society started playing a more active role; CSOs and activists built their strength through networking with organizations within and outside the country. The changing scenario, thus, influenced the already existing health movements and provided impetus for a new health movement called Jana Swasthya Abhiyan (JSA) to emerge. Along with that, in the 1990s, the involvement of CSOs got new legitimacy as they were invited by international organizations as well as by the State for service delivery in development issues, including health (Helmich and Lemmers 1998).

Among several diseases, HIV/AIDS has emerged as one of the major health diseases of the time ever since it was reported in Tamil Nadu in the year 1986. HIV/AIDS, as a general health problem, posed several threats to the health of people in general and women's health in particular. Though, during the early years of the epidemic, HIV was rampant among men, subsequently a large number of HIV-positive cases were detected among women (Amaro 1993; Gorna 1996; Karim et al. 2010; Lepri et al. 1994; UNAIDS 2008). There could be several implications of HIV/AIDs not only for women's health but also for their rights. In case of HIV, there is a high chance that women also lag behind men in seeking information about health care. A 'culture of silence' surrounding sex in Indian society demands a 'good woman' to be ignorant of her sexuality and this cultural conditioning makes it difficult for women to understand their own body. It increases their helplessness to understand and inform others about their problems relating to sexuality like sexually transmitted diseases (STDs) or HIV/AIDS transmission (Carovano 1992; Rao Gupta 2000; United Nations Economic and Social Commission for Asia and the Pacific [UNESCAP] 2005). Living with a sense of socio-economic powerlessness, women can

be prevented from taking decisions even regarding their own body and reproductive issues (Sen et al. 2002). In such society, women's low socio-economic status refrain them from realizing their rights, which can in turn increase their vulnerability towards health problems like HIV/AIDS. HIV/AIDS makes women even more vulnerable socially, politically and economically after the infection.

In the context of HIV being closely related to women's health and their rights, a major thrust of the study is to understand the role of the State towards health in general and women's health in particular, especially in the case of HIV/AIDS from both gender and human rights perspective. The study explores several issues: How far has the State exercised its power while dealing with women's health in India? What has been the role of CSOs and health movements in defining women's health? What are the constraints that women with HIV/AIDS face in accessing health rights? Does the growing privatization of health care affect women's health rights? What is the history of health movements, their strengths, their weaknesses and the effect in widening gender health rights discourse?

To address these objectives, the study was conducted in two Indian states, namely, Karnataka and West Bengal. In these two states, the study attempted to make a comparative analysis of vulnerability of women to HIV/AIDS and examine the role of states and role of civil society in ensuring health rights to women. The selection of the states was done on the basis of prevalence of HIV/AIDS—Karnataka among the high-risk states and West Bengal among the low-risk states. West Bengal is a state that has been ruled by a left-leaning political coalition while Karnataka has been ruled by either right- or centre-oriented (e.g., Janata Dal or Congress) or right-winged parties (e.g., Bharatiya Janata Party [BJP]). However, civil society is active in both the states and they have a history of active civil society participation. The study included women participants who were HIV infected, CSOs and government officials and policymakers engaged in policy formulation and implementation on HIV/AIDS.

The first chapter of the book outlines the concept and discourse on health rights in India and focuses on theoretical framework. The second chapter analyses state's policy towards women's health. The chapter deals with the major health committees in India like the National Planning Committee and Bhore Committee from gender rights perspective and includes analysis of population policies, health policies and national AIDS policy in India. The steps taken by Indian government in terms of its approach, strategies and so on are also discussed in the chapter.

The third chapter explores the socio-cultural conditioning underlying the physical vulnerabilities of women to HIV/AIDS. This chapter also focuses on women's vulnerability after the HIV/AIDS infection and analyses resistance (if any) by HIV-positive women against their suppression in a patriarchal society. The fourth chapter outlines on women's and social sector's spending and health measures taken in select states. Women's health conditions are also discussed. It also attempts to analyse the approach and attitude of states towards HIV/AIDS people in general and HIV-positive women in particular.

The fifth chapter deals with the role of civil society working on health issues in India. Approach of CSOs towards HIV/AIDS-affected people in the states of Karnataka and West Bengal is outlined. The chapter discusses the different types of roles played by CSOs in both the states. The chapter includes both case studies and qualitative analysis to identify the difference in the role of CSOs operating in both the states. It also analyses the limitations associated with the CSOs. The sixth chapter deals with the area of overlap and exclusion coming out of the interaction between health movements and CSOs. The chapter also attempts to analyse health movements and CSOs' politically active function towards HIV/AIDS. It further focuses on the role and limitations of CSOs and health movements in the light of a social movement. The concluding chapter enumerates the major findings of the study.

Notes

1. The epidemiological shift during the post-independence period shows that the Indian State could, to a large extent, control the spread of certain diseases like malaria. In 1951, there were 7.5 per cent cases, which fell to 2.7 per cent and 2.2 per cent in 1981 and 2000, respectively. However, the recent times have witnessed increase in the incidence of malaria in few states in India. A few diseases, including smallpox, have been completely eradicated (National Health Policy 2002).
2. In the year 1951, life expectancy in India was 36.07 years which has subsequently increased to 64.6 years by the year 2000. As far as crude death rate (per 1,000 population) is concerned, in the year 1951, it was 25 per cent, which reduced substantively to 8.7 per cent by the year 2000 (National Health Policy 2002).
3. Medical approach is defined as addressing health problems through the expansion of institutional facilities, introduction of medical technologies, and so on. In the context of this study, medicalization is referred by three