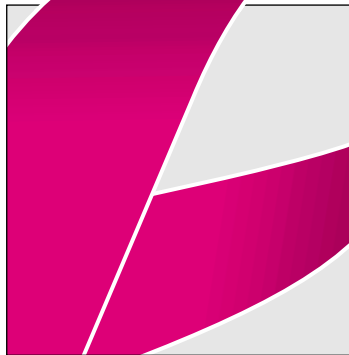


# India : HIV and AIDS-related Discrimination, Stigmatization and Denial



Joint United Nations Programme on HIV/AIDS  
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Prepared for UNAIDS  
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UNAIDS  
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## INTRODUCTION

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In India, as elsewhere, AIDS is perceived as a disease of “others” – of people living on the margins of society, whose lifestyles are considered “perverted” and “sinful.” Discrimination, stigmatization, and denial (DSD) are the expected outcomes of such values, affecting life in families, communities, workplaces, schools, and health care settings. Because of HIV/AIDS-related DSD, appropriate policies and models of good practice remain undeveloped. People living with HIV and AIDS (PLHA) continue to be burdened by poor care and inadequate services, while those with the power to help do little to make the situation better.

Although there have been a small number of recent Indian studies on HIV/AIDS-related DSD, it remains the case that relatively little is known about the causes of these negative responses or how they can best be addressed. For this reason, the Joint United Nations Programme on HIV/AIDS provided financial and technical support to a research team from the Tata Institute of Social Sciences, Mumbai, in order that insights might be gained into the experiences of Indians living with HIV/AIDS, the negative social responses they encounter, and the roots of HIV/AIDS-related DSD. This report describes that research, conducted in Mumbai and Bangalore, India.

We begin with an assessment of the HIV/AIDS situation in India, both in terms of epidemiological and DSD-related research. We then go on to describe the research itself – the objectives, the locations, and the research tools utilized. Next, we describe the research findings, with particular emphasis on forms and determinants of HIV/AIDS-related DSD, and responses to it. In presenting our findings, we wished to move beyond previous research on DSD, which has had a tendency to focus only on individual cases or experiences, or on the role of nongovernmental organizations (NGOs) in exerting pressure on governments and national authorities to act. This report, in contrast, aims to offer an account of how DSD operates, and what causes it, in a range of contexts in two contrasting regions.

Although this account may make depressing reading for those hoping for a more enlightened approach to HIV in India, we make a number of recommendations at the end that are intended to address the core problems and thereby improve the overall situation.

## AIDS IN INDIA

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South and South-East Asia are now an epicentre of the HIV epidemic. Of all countries in this region, India is estimated to have the largest burden, with about 3.7

million infections (UNAIDS, 2000, p.12). Official Indian figures do not yet reveal such a scale of infection, but weaknesses in the serosurveillance system, bias in targeting groups for testing, and the lack of availability of testing services in several parts of the country suggest a significant element of underreporting. Even so, the available data are disturbing.

- Between 1986 and early 1999, the HIV seropositivity rate in India showed a steady increase. Currently, the seropositivity rate is 24.64 per thousand tests (NACO, 1998–99, pp. 8, 10).
- By the end of March 1999, there were 85,312 reported cases of HIV infection and 7,012 cases of AIDS, with cases reported in almost every Indian state (NACO, 1998–99, p. 16).
- Three states – Maharashtra, Tamil Nadu, and Manipur – accounted for almost 75% of reported HIV infections. A majority of cases (76.2%) were contracted heterosexually, followed by infected blood and blood products (7.4%), and needle sharing (6.3%) (NACO, 1998–99, p. 14).
- About 78.6% of infections have been reported in men and 21.3% in women (NACO, 1998–99, p. 14).
- The majority of cases (89%) were in the 15–44 age group (NACO, 1998–99, p. 14).
- Seropositivity in patients with sexually transmitted diseases (STDs) ranged from 5% to 37% in various sites. Among injecting drug users, seropositivity ranged from 24% to 85% (NACO, 1998–99, pp. 14, 15).
- The seropositivity rate among attenders at antenatal sentinel sites ranged from 0.0% to 4.0% (NACO, 1998–99, p. 15), suggesting the spread of infection in the general population in some regions.
- There is evidence that infection is spreading from urban to rural areas, and from infected mothers to their children.
- In the most severely affected state, Maharashtra, seropositivity was 60% among sex workers, 14–60% in sentinel STD clinics, and over 2% among women attending antenatal clinics (NACO, 1999, p. 4).

## RESEARCH ON HIV/AIDS-RELATED DSD

As documented in the relatively few Indian studies of social responses to the epidemic thus far, social reactions to people with AIDS have been overwhelmingly negative. For example, 36 per cent of respondents in one study felt it would be better if infected individuals killed themselves; the same percentage believed that infected people deserved their fate (Ambati, Ambati & Rao, 1997). Furthermore, in this same study, 34 per cent of respondents said they would not associate with people with AIDS, while about one-fifth stated that AIDS was a punishment from God. A hostility index developed in this study revealed that almost 90 per cent of respondents harboured at least one hostile view, and more than half held three or more such views.

Negative responses and attitudes towards PLHA are strongly linked to general levels of knowledge about AIDS and HIV and, in particular, to the causes of AIDS and routes of HIV transmission. In most societies, AIDS is associated with groups whose social and sexual behaviour does not meet with public approval. In the study by Ambati, Ambati, and Rao (1997), 60 per cent of respondents believed that "only gay men, prostitutes, and drug users can get AIDS."

With these findings in mind, it is perhaps not surprising that virtually every Indian setting in which HIV-positive people interact with other people provides a backdrop for discrimination, stigmatization, and denial. Studies have documented HIV/AIDS-related DSD in contexts such as the family, the community, the health care system, and the workplace. Discriminatory restrictions have also been reported in relation to travel, migration, insurance and health benefits.

### Families and communities

In most developing countries, families and communities are generally supportive settings for illness management and treatment (Bharat, 1996; Ankrah, 1993). However, data from some African and Asian countries report both supportive and non-supportive household responses to HIV-positive people. Negative responses are particularly evident in the case of HIV-positive women (Bharat, 1996; Bharat & Aggleton, 1999; Bharat, Singhanetra-Renard & Aggleton 1998; Warwick et al., 1998) and those whose lifestyles and sexual behaviour elicit popular disapproval (Panos, 1990; Warwick et al., 1998).

An Indian study (Bharat, 1996) found that, although a majority of those who had shared their HIV status with their families received care and support, it was largely men rather than women who qualified for such care. Forms of discrimination against women with HIV included being refused shelter; being denied a share of household property; being denied access to treatment and care; and being blamed for a husband's HIV diagnosis, especially when the diagnosis was made soon after marriage. Other factors influencing whether people received support included the quality of past familial relationships, age, economic and educational status, and the apparent or suspected source of infection.

Family responses to infected relatives are heavily influenced by community perceptions of the disease. Families that include an individual with HIV may fear isolation and ostracism within the community (McGrath et al., 1993; Warwick et al, 1998; Bharat & Aggleton, 1999). Consequently, they may try to conceal an HIV diagnosis, which in turn may cause considerable stress and depression within the family (Bharat & Aggleton, 1999). Because most people living with HIV/AIDS in India maintain such secrecy, the epidemic is not socially visible. Given this secrecy and invisibility, it would appear that there have been relatively few actual instances of community-based discriminatory responses. However, stigmatization and discrimination may arise when an individual identified as HIV-positive is seen as a source of infection to others, or when the physical appearance of someone with AIDS produces revulsion or fear. By contrast,

a person who is known to have HIV, but whose behaviour or appearance is “non-threatening,” is sometimes tolerated and may even be offered support in the community (Bharat, 1996). Nevertheless, misconceptions about how HIV is transmitted continue to fuel discrimination.

### Health care

The health care sector is perhaps the most conspicuous context for HIV/AIDS-related discrimination, stigmatization, and denial. Negative attitudes from health care staff generate anxiety and fear among PLHA. Consequently, many keep their serostatus secret, fearing still worse treatment from others (Bharat, 1996). It is not surprising that among a majority of HIV-positive people, AIDS-related fear and anxiety, and at times denial of their HIV status, can be traced to traumatic experiences in health care settings (Bharat, 1996).

Globally, discrimination in these settings can be expressed in a variety of ways. The most commonly reported responses include a refusal to admit or treat HIV-positive patients (Tirelli et al., 1991; Shisam, 1993), the tendency to neglect patients (Daniel & Parker, 1990; Ogola, 1990), the habit of testing for HIV without consent, and breaches of confidentiality (New South Wales Anti-Discrimination Board, 1992; Bermingham & Kippax, 1998).

### Employment

A study of seven large Mumbai-based businesses revealed that none had a policy on AIDS and that mid-level management have adopted a “wait and see” attitude – waiting to see how many workers became infected and whether this had an impact on productivity (Hira, Gupta & Godwin, 1998). At the same time, anecdotal evidence of employment-related discrimination and stigmatization has begun to emerge. Individual cases of job loss, emotional isolation, and denial of employment on the basis of HIV status have been reported in the media (Chinai, 1995), to NGO workers and social counsellors (V. Chitale, personal communication), and to medical practitioners (G. Bhave, personal communication). An industrial body with a specialized role in coordinating industry-based initiatives on the epidemic, the Industrial Response to AIDS (IRTA), has produced a booklet on corporate policy and HIV/AIDS (see Nangia, 1998).

## METHODOLOGY

### RESEARCH OBJECTIVES

This study aimed to examine forms, determinants, and outcomes of HIV/AIDS-related discrimination, stigmatization, and denial in India, and to explore their possible social, demographic, and cultural correlates. This exploration was organized by focusing on a range of key settings, as identified from previous research.

Specific objectives of the research were to:

- examine the forms in which HIV/AIDS-related DSD is experienced and manifested at the levels of individuals, households, and institutions, and for certain marginalized groups such as women, gay men, and commercial sex workers;
- understand the broader sociocultural contexts in which HIV/AIDS-related DSD operates;
- document and analyse the outcomes or responses to DSD associated with HIV/AIDS.

### RESEARCH SITES

This study was carried out in two Indian metropolitan cities: Greater Mumbai in the state of Maharashtra in the west, and Bangalore in Karnataka state in the south of the country.

Brihan Mumbai, or Greater Bombay as it was known until 1996, is the second most populous city in India and the prime commercial and industrial centre. With a high concentration of HIV-positive people, it has also acquired the dubious distinction of being the country's AIDS capital. Mumbai is an island city located along the western coast of India. Comprising the original island city and the suburbs extending to the north, the total area measures approximately 600 sq. km, with a population of 9.9 million (Census of India, 1991). As the hub of commercial and industrial activities, Mumbai has a sizeable migrant population, which is mainly male. A high concentration of people has turned the city into an overcrowded and polluted place with several million homeless people. The city also has a significant problem with illicit drugs and a large sex industry.

Mumbai was selected for this study for two main reasons. First, the city has a high HIV prevalence, both historically and currently. Second, as a result of a previous study (Bharat, 1996), good working relationships and networks were already established with medical practitioners, AIDS workers, NGOs and community-based organizations, as well as groups for HIV-positive people and those living with HIV/AIDS.

An additional site was included to extend the scope of the research. Bangalore, or the “garden city” as it is popularly known, is the capital of Karnataka in the southern region of the country. Spread over a 457 sq. km area, it has a population of 4.1 million (Census of India, 1991). Once a quaint little town, Bangalore today is a vibrant metropolis with a cosmopolitan population. The industrial base of the city is broad, with about 336 medium and large-scale industrial units and about 30,000 small-scale units. Bangalore is well known for its electronics and computer software industries and is the fastest-growing city in South Asia. But its expansion has brought with it unplanned development, disparities in living standards, and large-scale migration. Slums have appeared at several areas of the city. Unlike Mumbai, Bangalore has no well-demarcated red-light area. The sex trade is spread all over the city and is mainly street-based.

Bangalore was included in the study because its HIV prevalence rate is increasing (Karnataka State AIDS Prevention Society, 1998), and because recognition of the epidemic locally has led to AIDS-related interventions, the mobilization of HIV-positive people, networks among individuals and organizations associated with AIDS-related activities, and a growing interest in research on AIDS-related topics.

## RESEARCH TEAM

Data were collected by two teams of researchers, one in each site, each led by the principal investigator (Shalini Bharat). In Mumbai, the main team comprised the principal investigator and one female research officer.<sup>1</sup> In Bangalore, the team consisted of four full-time researchers, with one part-time researcher with the sole remit of collecting data from industry. The research was overseen by a multidisciplinary advisory committee in each site.

## RESEARCH DESIGN

Three main methods were used during the research: key informant interviews, in-depth individual interviews, and focus group discussions.

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<sup>1</sup> The principal investigator and one research officer were engaged in data collection throughout the project duration, while two other staff joined midway for periods of two and three months, respectively, for the support tasks of transcribing, compiling, and data recording.

*Key informant interviews* were conducted with individuals in the voluntary, medical, and employment sectors. In the voluntary sector, the team interviewed NGO staff, AIDS counsellors, and community health workers. In the medical sector, we spoke to deans or heads of hospitals and to medical professionals (two each from the fields of STD, surgery, gynaecology, and general medicine). In the employment sector, we interviewed the heads of personnel and staff in the social welfare department of companies. In addition to staff from the three main sectors, we also spoke to a range of other key informants. A list of key informants is provided in Table 1.

**Table 1:**  
**Sample sizes for each set of respondents, key informant interviews**

KEY INFORMANTS	MUMBAI	BANGALORE	TOTAL
Doctors	11	36	47
NGO staff	4	7	11
Nurses	1	2	3
Industry personnel	8	6	14
Social welfare officers	2	1	3
Lawyers/activists	2	–	2
Patient rights activists	1	–	1
Insurance expert	1	–	1
Gay activists	1	2	3
Total	31	54	85

*In-depth individual interviews* were conducted with two groups. We spoke on a one-to-one basis with people with HIV, specifically the patient population (both men and women). A random sample of PLHA was impossible to draw: enumeration of the entire population of HIV-infected persons is not possible at present. Therefore, a sample was taken from three settings: HIV-positive patients admitted to the hospital wards for treatment; those coming to hospital outpatient departments; and those attending support group meetings. In each situation, attending physicians, senior nurses, or social counsellors were approached and asked to explain the purpose of the study to HIV-positive clients with a view to eliciting their participation in the study.

A total of 31 HIV-positive people were subsequently recruited in Mumbai and 13 in Bangalore. A majority of respondents were between the ages of 20 and 35 and were lower or lower-middle class. A majority of the male respondents were married, while most of the women respondents were widowed.

Interviews were not limited to HIV-positive individuals. “Household members” or main care providers were also interviewed in a number of cases. This person

might be a wife, parent, or sibling (Mumbai 9 interviews, Bangalore 5). In-depth interviews were also conducted with commercial sex workers (Mumbai 2 interviews, Bangalore 3), gay men (Mumbai 2 interviews, Bangalore 0), and *hijras*, sometimes referred to as those of the “third gender” (Mumbai 2 interviews, Bangalore 0).

*Focus group discussions* (FGDs) involving approximately five to eight people were held with four main groups: hospital staff, support groups of people with HIV/AIDS, marginalized groups, and people from a range of economic backgrounds.

Different categories of hospital staff were recruited from the four main types of Indian hospital.<sup>2</sup> In each site, staff were drawn from surgery, gynaecology, skin and STD, and general medicine – departments that either had the greatest number of HIV/AIDS patients or used invasive procedures most frequently. Hospital staff respondents included ward boys, *ayahs* (female helpers), sanitary attendants (male and female), laboratory technicians, and nurses. The criterion for staff selection was that they have prior experience with AIDS patients. Twenty FGDs were held in hospitals in Mumbai and 15 in Bangalore.

FGDs were also conducted with support groups for people with HIV. Four such FGDs, segregated by sex, were held in Mumbai, and two in Bangalore.

The research team also attempted to recruit people from marginalized groups for FGDs. In particular, we were interested in speaking with HIV-positive female sex workers, *hijras*, and gay men. In both sites, a formal request was made to counselors or programme coordinators of relevant NGOs to introduce the research to their HIV-positive clients to elicit their cooperation. Initially, the team was interested only in focus groups with HIV-positive clients, but in both sites, the HIV/AIDS status of some individuals was not known to NGO staff. As a compromise, therefore, all clients, irrespective of whether they had disclosed their status, were invited to the focus groups. They were not required to reveal their own HIV status during group discussions.

No participation could be elicited from HIV-positive gay men in either site. There was no response either to appeal letters on NGO notice boards in Mumbai or announcements by staff about the research in Bangalore. Gay activists and social counsellors working with gay men were therefore interviewed to help us to better understand HIV/AIDS-related DSD issues for members of this group.

FGDs were also conducted with community members from low-, middle-, and upper-income communities. In Mumbai, two slum communities were visited for group discussions, one each with men and women aged 20–45 years. In Bangalore, group discussions were held with members of two each, low- and middle-income communities, within the city and with members of two rural communities outside the city limits. The rural communities were chosen because of cases of discrimination in those places that were brought to the notice of investigators during individual interviews.

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<sup>2</sup> Government, corporation, private, and charitable trust hospitals.



Finally, the team also conducted focus groups with truck drivers in Bangalore (3) and doctors and their HIV patients in Mumbai (2). Two FGDS were conducted with *hijras*. For sex workers, four groups were held in Mumbai and one in Bangalore.

Data from these main research methods were supplemented by dummy patient interviews, observations, and case study work. *Dummy patient interviews* were used to find out more about likely responses to HIV-positive patients in smaller private clinics. A researcher posed as a community health worker and presented a fictitious case to a randomly selected set of private practitioners. Cases were varied by gender and age. For women, a case of pregnancy was generally presented; for men, that of an STD; for children, haemophilia. Other fictitious cases involved dental problems, minor surgery, and tuberculosis. Researchers were encouraged to ascertain any reasons for denying treatment, identify attitudes towards HIV-positive patients, and determine whether there was a pattern in refusals and in the proposed transfer of cases to other service providers and facilities. A total of 24 clinics in Mumbai and 13 in Bangalore were approached in this way.

To complement the above information, a small number of *case studies* were conducted with HIV-positive individuals to examine their experience of stigmatization and discrimination at home, in the workplace, in health care settings, and at the community level. A limited amount of *direct observation* provided insight into staff practices in hospitals and the workplace.

## FINDINGS

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We will begin our discussion of findings by identifying the main forms of HIV/AIDS-related DSD encountered during the course of the research. This is followed by more detailed information on the contexts in which HIV/AIDS-related DSD may manifest itself. There then follows discussion of the determinants of HIV/AIDS-related DSD, followed by a consideration of the outcomes of DSD identified in the study. A final section looks at findings from interviews conducted with marginalized groups, in order to highlight their particular concerns.

### FORMS OF HIV/AIDS-RELATED DSD

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Both overt and covert forms of HIV/AIDS-related DSD were reported in each site. The main overt forms of discrimination experienced by respondents are listed below.

#### *Hospitals*

- Refusal to provide treatment for HIV/AIDS-related illness
- Refusal to admit for hospital care/treatment
- Refusal to operate or assist in clinical procedures
- Restricted access to facilities like toilets and common eating and drinking utensils
- Physical isolation in the ward (e.g. separate arrangements for a bed outside the ward in a gallery or corridor)
- Cessation of ongoing treatment
- Early discharge from hospital
- Mandatory testing for HIV before surgery and during pregnancy
- Restrictions on movement around the ward or room
- Unnecessary use of protective gear (gowns, masks, etc.) by health care staff
- Refusal to lift or touch the dead body of an HIV-positive person
- Use of plastic sheeting to wrap the dead body
- Reluctance to provide transport for the body

#### *Home and community*

- Severed relationships, desertion, separation
- Denial of share of property or access to finance
- Blocked access to spouse, children, or other relatives

- Physical isolation at home (e.g. separate sleeping arrangements)
- Blocked entry to common areas or facilities (toilet, etc.)
- Blocked entry to common places like village or a neighbourhood area
- Denial of death rituals
- Labelling and name-calling

### *Workplace*

- Removal from job
- Forced resignation
- Withdrawal of health/insurance benefits
- Poor access to shared facilities
- Social distance
- Labelling and name calling

There were also more covert forms of DSD in these sites.

### *Hospitals*

- Delays in treatment; slow service (e.g. made to wait in queues, asked to come again)
- Excuses or explanations given for non-admission (but admission not directly refused)
- Shunting patient between wards/doctors/hospitals
- Keeping patient under observation without any treatment plan
- Postponed treatment or operations
- Unnecessarily repeated HIV tests
- Conditional treatment (e.g. only on the condition that the patient will come for follow up or join a drug trial programme).

### *Home and community*

- Disparaging remarks about the HIV-positive family member (e.g. "he is paying for past sins")
- "Guilt tripping" for burdening the family economy and for lowering family prestige

## CONTEXTS OF HIV/AIDS-RELATED DSD

In both study locations, HIV/AIDS-related DSD was most often encountered in the health care setting and, to a lesser but still significant extent, in familial and community contexts. Discrimination was also reported in schools, and in relation to life insurance and post-death services. While instances of HIV/AIDS-related DSD were documented at work, in this study the workplace did not emerge as a major setting for negative experiences for HIV-positive people.

### Health care context

A majority of key informants in the medical and NGO fields acknowledged that health care settings were a major source of discrimination and stigma, but these informants nearly always placed the greatest blame elsewhere. For example, a majority of the staff in all hospital types stated that, while they provided “proper and adequate” care to HIV-positive patients, the patients’ families did not. The “family discriminates the most” was a common refrain from health care respondents. Family members, it was alleged, usually abandoned the patient with HIV infection to the health care system or kept a “safe” distance.<sup>3</sup>

Doctors in government hospitals in Bangalore tended to blame those in local private hospitals, claiming that they frequently transferred patients rather than treating them. Staff in private hospitals, on the other hand, argued that government hospitals provided substandard treatment and care and that this led to a rise in the number of inpatients in the private sector.

*“In private hospitals, the news of HIV-positive patients once detected is closely guarded and the patient is conveniently transferred to [a government hospital].” (Surgeon in a government hospital)*

*“Government hospitals are not doing their duty. The quality of care is so poor that the positive patients come to us. We give them all the necessary care without complaining.” (Gynaecologist in a private hospital)*

*“The conditions in government hospitals are bad.” (Doctor in a private hospital)*

Government hospitals were reportedly “under orders” to provide suitable health care facilities to HIV-positive patients, although, in general, the perception was that care in government hospitals was of poor quality. In Bangalore, one hospital was said to be “specially designated” for AIDS care. Staff at this hospital were of the view that because of this designation, all the city’s hospitals “dumped” their AIDS patients on them. Indeed, HIV-positive respondents from corporation hospitals, trust-run hospitals, and a few private hospitals reported that they were routinely asked to seek treatment at this specialist institution. Doctors at these same hospitals also reported transferring seropositive cases there.

In contrast, Catholic church-run hospitals and a few other private hospitals in this same city had opened all their treatment facilities to patients with HIV and AIDS. Indeed, Catholic hospitals were in the unusual position of having a written policy on

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<sup>3</sup> It is important to note, however, that patients themselves did not report neglect and discrimination from family members, apart from keeping vessels and personal items separate.

AIDS that clearly stipulated the provision of unconditional care to patients with HIV. Small private clinics, on the other hand, as was pointed out by doctors at different hospitals and by HIV-positive patients, sometimes denied care and treatment.

Certain kinds of discrimination were also reported in care settings managed by NGOs. Some NGO staff assumed that all their HIV-positive women clients worked in the sex trade; as a result, staff had a casual attitude towards their rights and needs. People with HIV who had once been offered care by an NGO in Bangalore said that their care was provided with “attitude.” One HIV-positive woman, for example, was photographed for an AIDS programme without her knowledge and was later rebuked for questioning the staff about this. “Look you are eating here without any payment, so don’t make any fuss” (HIV-positive woman, age unknown).

Similarly, sex workers who were accessing support from a local NGO reported that the staff talked to them in derogatory terms and denied them services. Conflicts between NGOs often resulted in loss of services for the person with HIV.

*“The HIV-positive woman [who came to our centre] had earlier received counselling from another centre and then had been at a short-stay home. But she had some differences there and so had left the place. When she came to us she was in urgent need of treatment and care, so we admitted her to the government hospital. We informed the NGO who had earlier provided her counselling. But the NGO counsellor didn’t like the fact that we had given services directly to the woman instead of directing her to them. They refused her any further counselling services.” (NGO staff member)*

In Mumbai too, the hospital was the primary care-giving context in which most HIV-positive people experienced DSD. As in Bangalore, one government hospital was generally designated for HIV/AIDS care. All hospitals, including Mumbai corporation hospitals, were expected to provide care, but people with HIV alleged widespread harassment when they tried to access health services there.

In recent years, some private hospitals in Mumbai are reported to have started admitting HIV-positive patients, a development that has come about with the realization that HIV is not a class-specific disease. This has benefited HIV-positive patients generally – with speedy, quality services being provided – but the high cost of treatment is passed directly to the patient. Much of this cost is for fumigating operation theatres or labour rooms used for HIV-positive patients, for double and triple gloving for staff, and for “AIDS kits” for all staff assisting in surgical procedures. As some senior medical professionals pointed out, such precautions are not required and amount to discriminatory practice. As will be seen later, HIV-positive patients felt stigmatized as a result of such unnecessary and selectively followed procedures.

*Private clinics*

Metropolitan areas throughout India are dotted with small private clinics that either offer a single medical specialization or operate as polyclinics. All such clinics are registered health facilities and are generally preferred – even by patients from lower-income groups – for their quick service and better-quality care. An added attraction of private clinics is that they provide more anonymous and confidential service than public hospitals.

In order to better understand HIV/AIDS-related DSD in this health care setting, researchers accessed a small number of private clinics via the dummy patient interview method. Doctors at six types of clinics were visited (see Table 2).

**Table 2: Types of clinic visited**

CLINICS	MUMBAI	BANGALORE
Maternity homes	11	2
Dental clinics	8	3
General physicians	2	4
Children’s centres	3	–
General surgeons	–	2
Dermatologists	–	2
Total	24	13

A clear majority of these clinics refused to admit the “dummy patient” with HIV/AIDS. In Bangalore, 9 of the 13 clinics visited refused, while 4 accepted on certain conditions. In Mumbai, 15 of the 24 clinics refused, 8 accepted with conditions, and only 1 accepted unconditionally. Gynaecologists at all the maternity homes in both sites refused, apart from 3 in Mumbai who agreed on certain conditions. Dentists and general physicians also refused in large numbers. Three children’s specialists in Mumbai said they would admit (2 conditionally) on sympathetic grounds since the patient (in this case, a child) was described as having been infected through blood transfusion. An analysis of the reasons given for refusal is given in Table 3.

**Table 3: Reasons for denial of care**

REASONS	MUMBAI (24)	BANGALORE (13)
Very risky to provide treatment	9	5
Very expensive (safety precautions)	1	1
Will result in loss of clients/business	1	5
Have low opinion of HIV patients	–	1
Will result in loss of reputation of the clinic	2	3
No experience, not sure how to treat	3	2
Fear: HIV is not curable	2	–
Treatment not economical for the patients (because of the cost, etc.)	2	–
Patient can go to government hospital	7	2
Clinic does not specialize in HIV	1	–
Staff will oppose/not trained	2	3
Lack of proper equipment	6	1
Cannot treat knowing that patient has HIV	3	2

*Note: Column totals differ from N because of multiple responses*

Some of those who agreed to admit the patient stipulated the following conditions.

In Bangalore:

- Will give tablets for symptomatic condition, but will not touch or physically examine the patient (1)
- Will treat in a different nursing home (to protect “reputation” of own clinic) and will charge more (for disposables, etc.) (1)
- Will treat only if mode of infection is not sexual (1)
- Will admit only if government makes it compulsory (i.e. until the clinic has no choice, it will not admit such patients) (1)

In Mumbai:

- Will conduct only certain dental procedures (filling and cap fixing – will not do any job which involves blood) (2)
- Will charge 20–30 per cent more (3)
- Will admit only if the patient can pay (1)
- Will not admit if the patient’s health is deemed very poor (1)
- Will not take the child in advanced stage and will charge more for treatment and care (1)

### *Testing and related issues*

In all hospitals, HIV testing was reported as being carried out on patients who did not respond to treatment for “marker diseases” such as tuberculosis, diarrhoea, and persistently swollen lymph nodes. Blood tests were also administered on the “suspicion” that a patient had HIV. Such suspicion could arise because of a patient’s thin physique, weight loss, or skin problems, or because he or she belonged to a perceived “risk group” such as truck drivers and sex workers. As a rule, pregnant women and patients for surgery were also subjected to mandatory testing in private hospitals.

In both study locations, hospitals in general did not ask for consent prior to testing. Instead, doctors acted on the assumption that patients would comply with their instructions. In a Mumbai hospital, one doctor explained that patient consent is implied when the HIV test and its likely outcomes are explained during “counselling.” “There is no written consent taken [for the HIV test] but we explain the test to the patients. Only verbal consent is taken.” Verbal consent here meant a “yes” from the patient when asked if he or she understood what the HIV test meant. However, pre-test counselling was not uniformly practised, and patients were frequently asked to get an HIV test from the microbiology laboratory of the hospital or an outside laboratory before further action would be taken.

*“Nobody told me why they were taking my blood.” (HIV-positive hospital ward attendant, aged 32)*

*“No, the doctor did not tell me that he is taking my blood for HIV testing. I thought it was some routine test for malaria.” (HIV-positive male laboratory sweeper, aged 25)*

*“The doctor told me to go and get a blood test done. He didn’t tell me what it was. He just wrote on a piece of paper and asked to get the result.” (HIV-positive barber, age unknown)*

In Bangalore, nearly all public and private hospitals included in the study provided AIDS counselling through a local specialized counselling service. In one private hospital, counselling was provided by doctors. In hospitals where there were no specialist counsellors, counselling was conducted only after HIV reports had been received: in other words, only post-test counselling was available to patients.

In Bangalore too, consent for HIV tests was largely assumed but, compared to Mumbai, many more patients said they were told about the test and what it meant. “Before doing that [the HIV test] the doctor explained me in detail about HIV” (HIV-positive man, age unknown).

In other hospitals, counselling was very much focused on providing information about AIDS, informing patients of their HIV test results and likely future problems.



In some hospitals, respondents argued that such post-test counselling had induced more fear than feelings of reassurance and support.

Private hospitals in both sites had a policy of mandatory testing both for pregnant women and those brought in for surgery (major or minor). Spouses of all HIV-positive men were advised – and sometimes forced – to take an HIV test, irrespective of whether or not they required medical care. As a rule, consent was not requested, and pre- and post-test counselling was not given. Doctors across the hospitals defended such action on the grounds that procedures such as childbirth and surgery were invasive and involved significant contact with blood. Patients argued, though, that in most cases HIV tests were conducted in order to enable the hospitals in question to refuse treatment and care. Several respondents reported that they were refused hospital services following a positive test result.

Another serious issue concerned hospitals' and doctors' demands for repeated HIV testing, even if the patient had already received test reports from another laboratory or hospital. Interviews with some respondents in Mumbai revealed that doctors demanded fresh HIV tests from a particular laboratory, thus putting the patient through further stress and financial hardship. In one AIDS research centre in Mumbai, PLHAs reported that their treatment had been withheld until a new HIV test result had been obtained. Doctors clearly tended to disbelieve the authenticity of HIV reports obtained from other hospitals and laboratories.

Similarly, the women caregivers of HIV-positive husbands and children reported that hospital staff drew blood repeatedly and unnecessarily for testing:

*“He [her husband] was admitted to so many different wards. In each ward blood was extracted, testing was done again and again. As soon as he is admitted, blood is drawn. I don't know what all tests were done but the staff said HIV.” (HIV-positive woman, aged 45)*

*“My blood report was not clear, so the doctor sent it to [a private] hospital. They charged Rs 800. Doctor said this report would finally tell. The testing hospital said it would cost Rs 1500 if you want the report in 2 days, otherwise wait 10–15 days. So I preferred to wait.” (HIV-positive man, aged 28)*

There were also problems relating to confidentiality, especially how and to whom HIV test reports were disclosed. In all hospitals in Mumbai and Bangalore, doctors alone had the right to disclose an HIV test result (although hospitals could also use AIDS counsellors to inform the patient of the results). However, what was told and to whom varied greatly across hospitals. In private hospitals, the most often quoted policy was that test results were disclosed only to the patient and to no one else. But in reality, and in nearly all hospitals, results were also shared with hospital staff, even when they were not directly involved in care (e.g. technical staff): “Confidentiality is maintained, and only the concerned staff – the lab technicians who have done the test, the nurses and

doctors who are caring for the patient and the patient's attendees [family members] only will know of it" (doctor in a private hospital, Bangalore).

Positive test results were also often shared with the family member accompanying the patient. If the patient had come to the hospital alone, relatives were often called in, sometimes from the village, to receive the results. In one Bangalore public hospital, parents, wives, and siblings were called in to receive test results. In the case of married, male patients, doctors had a tendency to share the diagnosis with the man's wife. Unmarried young men were better able to control disclosure of their HIV status. However, when the patient was accompanied by a friend or a relative, the results were often shared with them too. In most Mumbai hospitals, close relatives were given the results ostensibly "to protect the patient from shock and possible self harm": "The patient, as it were, is half-dead. If he is told of the test results, he might commit suicide, so the family members are told" (staff member in a private hospital, Mumbai).

Several patients reported that their results were revealed to their parent(s), sibling, spouse, or other close relatives.

*“My wife was very curious about my sickness, as I had not told her. She showed my case papers to the company's medical doctor and the doctor told her everything about my problem without my knowledge. She was very angry with me and within two days she deserted me.” (HIV-positive man, aged 38)*

*“They [doctors] called my mother from village. She was informed about my disease.” (HIV-positive man, aged 23)*

*“The doctor told my parents first about this disease. We came to know about it later. Only after we came here we knew about it. My parents sent us here.” (Couple, both HIV-positive)*

Health care staff clearly believed that the principle of confidentiality extended to sharing test results with particular groups of people, including other health care staff and family members. However, the principle of confidentiality was often disregarded altogether in the case of women, the less educated, and the poor. In the case of pregnant women, confidentiality did not even appear to be an issue. Women were sometimes not told of their own HIV status. Their husbands, though, were often informed, based on the assumption that it was they who would decide the future course of action – that is, whether or not to continue with the pregnancy and whether or not to get tested for HIV themselves. Yet, the husband was not always the doctor's first contact. Describing how HIV test results were communicated to the patients, one doctor told us:

*“When a young woman who is first time pregnant is found to be HIV-positive, we ask her to call her mother-in-law. We explain the report to the mother-in-law. These patients who come here are from*

*low-income group, and if the girls are newly married, they are really dumb and don't understand anything, so the mother-in-law is called to explain.”” (Gynaecologist in a private hospital, Mumbai)*

Considering the animosity sometimes encountered between daughters-in-law and parents-in-law, this is a particularly worrying development.

The confidentiality of HIV test reports would appear to be strictly observed only for the educated and the relatively well-off:

*“Those who come to the consultants in our hospital [i.e., those who pay fees to the specialists] receive their test reports only from their consultants. Not even the lab technician will know of the results because they are coded. You see these are rich and eminent people, their privacy was to be guarded.”” (Medical superintendent in a private hospital, Mumbai)*

### **Admissions policy**

In all hospitals under study, the management maintained that HIV-positive patients were admitted for treatment on the ward. It was also claimed that a patient found to be HIV-positive after admission would be allowed to remain in the same ward and to continue treatment. While this was stated policy, individual consultants attached to the private hospitals did refuse care, staff did mount protests against having to assist in surgery on HIV-positive patients, and hospitals did transfer HIV-positive patients to other hospitals.

### **Refusing treatment in a private hospital in Mumbai**

“X” hospital is well known for failing to admit HIV-positive patients. The background to this problem is the dismissal of a ward attendant found to be HIV-positive, who alleged that he got the infection from a patient. In protest, hospital staff refused to provide care for HIV-positive patients, alleging job insecurity if the workers were to become infected. The hospital staff, especially those employed in the operating theatre, put up stiff resistance to the admission of HIV-positive patients for surgery and in-ward care. They argued that they did not have protective equipment, that they stood a high risk of infection, and that the hospital did not provide them with job cover for risk from HIV. With a change in management, however, protective gear has been provided and orders issued that all HIV-positive patients are to receive care and treatment. Over the past few months, positive patients have reportedly been admitted for operations, as well as taken care of in the wards. However, resistance continues to be offered by surgical staff, reflected in “delaying tactics,” absenteeism, and unprofessional behaviour. As the surgical officer in charge said, “staff continue to give trouble every time the surgery of an HIV-positive patient is scheduled.” Also, no pregnant women with HIV had been admitted for delivery in the hospital until the time of data collection.

In Bangalore, smaller public hospitals routinely transferred their HIV-positive patients to the main public hospital in the city. "When we do not know the HIV status of a patient, we treat them. But if they are positive, we refer them to other hospitals ... where they treat them. We never conduct any surgery [on HIV-positive patients]" (surgeon in a small public hospital).

Admission and treatment policy with respect to HIV-positive individuals differs across departments within a hospital. For example, in the above-mentioned public hospital of Bangalore, the skin and STD department admitted and treated several HIV-positive patients. Similarly, in a Mumbai-based private hospital, although the management stated that patients with HIV/AIDS were admitted, there were exceptions. A nephrologist attached to the hospital strongly defended her policy of denying treatment and admission to HIV-positive patients requiring kidney transplants or dialysis. She argued:

*“We are not bound by any rule to give treatment to HIV-positive patients. Let the government hospitals take that responsibility. There is a high risk of infection to my staff in the nephrology department and I’m responsible for my staff’s welfare and health. I screen every patient who is referred for diagnosis and do not admit those who are HIV-positive.”*

The medical director of a private hospital in Mumbai agreed that it was ultimately the decision of individual doctors or consultants whether or not to treat HIV-positive patients, even if this went against hospital policy.

Although most hospitals reported having non-discriminatory admission and treatment policies, several discriminatory practices went unchallenged by management. For example, doctors at some hospitals discharged patients found to be HIV-positive even if they had yet to complete a full course of treatment. As a doctor in a public hospital said, "When the patient is not going to gain from the treatment because he is HIV-positive, why should we block a bed? In a public hospital we have to use bed capacity to the maximum. So we provide an early discharge."

In some hospitals, patients for surgery were advised against the procedure once they tested HIV-positive; any prior decision about surgery was reversed on the grounds that it might not be of much use to the patient. Speaking about the forms of discrimination in hospitals, a senior doctor in a Mumbai public hospital remarked, "The same surgeon who advised surgery, on finding out the HIV-positive status of the patient, decided that now it is not needed. The patient will be asked to take medication only. How does one explain this?" Such decisions by medical professionals are questionable because they appear to be based on ignorance about HIV transmission and longer-term prognosis rather than what is best for patients.

### *Patient management*

Most of those interviewed first confronted their serostatus within the hospital context because of illness, surgery, blood transfusion, or pregnancy. Most said that DSD-related problems arose soon after their seropositivity was discovered. A 38-year-old HIV-positive woman told us that “The hospital staff was looking after my husband well, but after they tested his blood for HIV, their behaviour changed, they separated our vessels, pushed him to a corner of the room, and talked about us in hushed tones. I could not understand why their behaviour had become cold. Now I know why.”

The experience of those with HIV receiving treatment for tuberculosis was typical of many others in the same hospital. No consent was requested for HIV tests, and once patients were found to be seropositive, oral medication was introduced in place of injections. No explanations were given for this change in treatment.

*“My blood was tested, and from that day they stopped giving me injections. They didn’t tell me why.” (HIV-positive man, aged 23)*

*“I did not tell anything to the ward staff [about my HIV status]. They took my blood and then they stopped giving me injections completely.” (HIV-positive man, aged 29)*

In many hospitals, common safety measures included the use of gloves, chemical solutions for soaking patient’s garments, linen etc., and disposable syringes and needles. However, other measures such as multiple gloving, the use of AIDS kits, and the fumigation of rooms were also taken, particularly in private hospitals, where the cost of these materials was borne directly by patients. Some of these practices are followed in one Mumbai public hospital as well, where patients also have to pay in order to access services.

*“At our hospital, we do not close down the labour room just because of an HIV-positive patient. But all staff is protected, the patient has to provide 4–5 AIDS kits [gown, 2 gloves, plastic apron, etc.] for the staff assisting in delivery. Each ... [kit] costs approx. Rs 1300 and has to be bought by the patient.” (Gynaecologist in a maternity hospital, Mumbai)*

If patients cannot afford to pay, they have to go to other public hospitals where staff work without such equipment.

None of the hospitals included in the study followed universal precautions for all patients in managing patient care. When precautions like double gloving and masks suddenly began to be used for a patient on the ward, the effect was dramatic both for the patient concerned and for other people on the ward. Hospital practices such as these acted as powerful sources of stigma for patients during hospitalization.

### **Identifying AIDS patients in a private hospital in Mumbai**

In a private hospital in Mumbai, hospital staff described the management of HIV-positive patients thus:

*“At first when a patient is admitted we give him care just like for any other patient. His HIV test result is yet to come back. So we follow normal care practices. But after a few days the nurse cautions us “The patient is HIV-positive, so take care.” Then we understand that we must wear rubber gloves when we go near that patient. We must also keep his vessels separate, his clothes must be put in the chemical solution. So we keep a tub under his bed with the solution. All the waste material from his bed will be thrown in a plastic bag. His clothes and linen are soaked in the chemical solution and washed separately. When we change duty, we inform the staff on duty to take care. Anyhow, even if we don’t do that, the staff comes to know about the patient’s HIV/AIDS status by the tub kept under the bed. This tub is a symbol for the staff. We don’t use any board etc to declare AIDS. But the tub lets us understand. No other patient is told about the patient’s test results.”*

*“When a case of delivery or a surgery is taken, the room is fumigated and closed for several hours. Similarly, after a positive patient dies, the room/ward is fumigated and thoroughly cleaned. It is opened only after 8–10 hours. All the disposable material used for the patient is thrown in a separate bin and sent for incinerating.”*

*“For surgery all the staff (doctors, nurses, and operating theatre staff) wear the AIDS kit. We get good-quality disposable gloves and any number too. The patient pays for all this material. In the general ward, some patients who cannot pay are not charged, but all others are charged.”*

A few senior gynaecologists and surgeons in Mumbai were of the opinion that practices like the fumigation of rooms and the provision of AIDS kit for all staff during surgery were unnecessary. Good-quality gloves, mask, and goggles were enough, they said.

*“Fumigation of the room is not required. This only takes place because of the exaggerated fear of staff and doctors.”*  
(Gynaecologist in a public hospital in Mumbai)

*“Each AIDS gear [kit] costs Rs 400/- and actually they are not required. I mean, ideally one should have them but it is not essential for staff to have the entire gear. They can do with good gloves.”*

*It is costly to provide for all of the staff. The cost of the gear is borne by the patient, but if it is a non-paying patient, the hospitals provide for it. We have given these to all operation theatre staff simply to ensure they don't create problems for us. ”” (Gynaecologist attached to a private hospital, Mumbai)*

In public hospitals, such elaborate procedures and materials are unaffordable. In fact, in a Mumbai public hospital, gloves were the only protective gear available to nurses. Even these were in short supply and were generally oversized and of poor quality – blood had a tendency to seep in during invasive procedures like child delivery.

*“Being in a public hospital I don't think we nurses can even think of getting good-quality gloves in adequate numbers. Often, after a delivery I find that my hands are soaked in blood because the gloves are so ill fitting and large, or because they have got torn in the urgency to put them on. And then when I learn that the woman was HIV-positive – I quickly check my hands to see if there is any cut or wound. On such days I go home and pray to God. That is all we can do being in a public hospital. ”” (Nurse in a public hospital, Mumbai)*

A similar story was heard in Bangalore. There, private hospitals were able to afford most safety gear, while in public hospitals conditions were dismal. “We use gloves and disposable syringes. But the supply is very less. For example we get two packets of gloves [i.e., 50 for 6 months]. Most of our nurses and *ayahs* do not use them” (doctor in a small public hospital, Bangalore).

The practice of identifying HIV-positive patients in the wards by using boards proclaiming their status was reported as having been discontinued in most hospitals. In both private and public hospitals in Mumbai, however, medical files of patients were being marked “HIV-positive” in red ink. Although these files were in the safe-keeping of the ward nurse, staff in one private hospital reported that the identity of HIV-positive patients in the general ward (mainly for poorer patients) was public knowledge. “I can see the patient file. When the patient comes to our ward, it's written on the file ‘HIV’ in big letters. Anybody can see it. It's kept next to the patient. Even relatives can see it” (ward attendant in a private hospital).

The status of HIV-positive hospital staff also becomes common knowledge very easily. During group discussions in a private hospital, staff members freely referred to the ward and bed numbers of HIV-positive colleagues admitted for treatment. Although it is probably difficult to avoid such identification in a closely knit hospital setting, the lack of a culture of patient confidentiality among hospital staff was very noticeable.

Within any one hospital, departments differed in terms of how they identified people with HIV. For example in a public hospital in Mumbai, the skin and STD department followed the practice of writing “Immuno-compromised patient” on notes and on the bed head, and kept two empty beds between the HIV-positive patient and oth-

ers. The crowded labour ward of the same hospital used a symbol (a cross within a circle) to identify the HIV patient's bed because "in a crowded gynaecology ward where patients are put on the floor [for lack of space], staff have to quickly identify the positive patient in order to take precautions." In other departments of the same hospital, the use of any symbols or boards was forbidden. However, in yet another department of this same hospital, a separate, small room inside the ward was used to isolate HIV-positive patients. The staff pointed out that the room had been meant for patients with infections like gangrene, but it was now being used for HIV.

The unstated intention behind all such practices was to inform staff about the need to take special precautions with patients with HIV/AIDS. While this information was meant to be displayed unobtrusively so that other patients did not know, in congested public hospitals some staff members revealed the information by their words or actions: "Earlier in the wards a board used to be hanged from the bed, now it is not put. Still, in the ward nurses shout out to the ward boys 'Take this HIV patient for X-ray.'... All heads turn and everybody comes to know who the HIV patient is" (senior doctor in a public hospital, Mumbai).

In Bangalore, one public hospital set aside certain beds for HIV/AIDS patients.

*“After we know that a person is HIV-positive, we shift him to a separate cabin meant for them. It has eight beds. In the male ward we have this facility. In the female general ward we have kept ten beds separate for HIV/AIDS patients [these are the last five beds in each of the two rows in the ward]; we never keep them in the middle of other patients because they may also contract the infection. But we do not tell other patients [about positive patients]. This way our staff can be careful with precautions.”* (Senior doctor in a public hospital, Bangalore)

### *Insiders' perspective*

It is sometimes argued that HIV-positive people's assessment of health care is influenced by excessive vulnerability and fear. In order to provide a balanced picture, therefore, the research team asked medical professionals for their perspectives. Seventeen medical professionals – eleven from public and six from private hospitals – were interviewed in-depth and asked to give an account of HIV/AIDS-related discrimination and stigmatization in their hospitals. Nine senior doctors, two resident doctors, and two medical directors of hospitals in Mumbai, and two senior doctors and two medical superintendents in Bangalore, were interviewed. A majority affirmed that discrimination took place, quoting examples of the neglect and harassment they had witnessed:

*“There is definitely a great deal of discrimination and stigmatization in this hospital. Patients are quietly referred to “X” hospital. The surgeons especially do this. It is a myth that has been created*



*that the “X” hospital takes all the HIV patients but actually this is not correct. All municipal hospitals are supposed to provide services. But these doctors take the easy way out. ”” (Senior doctor at a public hospital, Mumbai)*

Supporting these comments, another senior doctor currently working at a private hospital spoke from his experience of several years’ prior work in a public hospital:

*“There is an almost hysterical kind of fear ... at all levels, starting from the humblest, the sweeper or the ward boy, up to the heads of departments, which make them pathologically scared of having to deal with an HIV-positive patient. Wherever they have an HIV patient, the responses are shameful. ”” (Retired senior doctor from a public hospital, currently working at a private hospital).*

### A doctor’s view of public hospitals

A doctor working in a public hospital made the following observations:

*“We also have some very bizarre kind of experiences. At the hospital where I worked, we had a patient sent from another department ... who [needed an] operation. So he was sent for various tests before the operation. At our department, we never ask for HIV test because it does not make any difference to us whether he is HIV-positive or negative. We take precautions for all the patients. And then they sent the patient back with all the reports and we said, OK the patient is fit for surgery and please transfer this patient after a couple of days as we do not have a free bed now. After a few days, a doctor from that department came down and said, “Sir, this patient is HIV-positive... So what should we do? Shall we discharge the patient?”... I said, how can you discharge him, he has got a condition that needs an operation and we are prepared to operate upon him. So, here was this young doctor who was willing to send the patient away simply because he was HIV-positive, and when he knew very well that ... most of our operations are those which cannot be put off. If you [do], then after a few months the patient will either become blind or paralysed or he will die. And here is this young doctor who has somehow imbibed this culture which says that if the guy is HIV-positive, send him out of the hospital.*

Researcher: *Can you say how long ago back was this incident?*

Doctor: *Just a month ago. ””*

Fearful responses are not restricted to public hospitals. A senior gynaecologist attached to both public and private hospitals reported that her colleagues from private hospitals routinely sent HIV-positive pregnant woman to the public hospital because they would not undertake such deliveries at their own hospitals. Although the private hospitals named by her have recently revised their policies, elaborate precautions such as fumigating the labour rooms and keeping them locked for 3–8 days afterwards were still reported. A senior gynaecologist at one private hospital reported that the risk of infection justified such precautions.

Other cited examples of discrimination included delays in surgical procedures, shunting patients between outpatient departments or public hospitals, isolating people in wards, and refusing to perform pathological investigations:

*“The pathology department does not accept positive people’s papers for various tests. They will not conduct the blood test until HIV tests results are shown to them. I don’t know what this means and how it helps them to know the results of HIV test. But this happens. They will [then] ask the HIV patient to wait till all other patients have left. So the patient will be called in the morning but will be taken in only last.”* (Senior doctor in a public hospital).

Interviews made it clear that some doctors faced problems getting their HIV-positive patients admitted for treatment at clinics. One doctor, who was associated with an HIV-positive people’s support group in Mumbai, recalled several cases where he had struggled to get medical care for his patients. Doctors providing treatment to HIV-positive patients were becoming identified as “AIDS doctors” and were acquiring the status of specialists, which enabled other doctors to shirk their professional responsibilities. In Bangalore, one private practitioner to whom several HIV-positive patients were referred, both from the private and public hospitals, commented that patients were frequently referred to a handful of “HIV/AIDS specialists”: “There is no such thing as AIDS specialists, yet they tell their patients, ‘I’m not a specialist for this disease, so please go to doctor “X” who is a specialist.’ The patient is unable to question the doctor’s judgement” (doctor at a private hospital, Bangalore). But doctors in private hospitals in both cities tended to defend their professional colleagues. The recent opening up of some private hospitals to HIV/AIDS patients was cited by them as a major development in medical care.

Among all health care professionals, it was the doctors and senior doctors who were felt to discriminate most against HIV-positive patients.

*“Discrimination is greatest among senior doctors. They don’t change their opinion even though they are well aware. Ward boys can change after training is given [but not the doctors].”* (Senior doctor from a private hospital, Mumbai)

**“Even today some negative attitudes exist among the senior doctors who ask questions like – “If you have two patients, one HIV-positive and the other HIV negative, and you have limited drugs, who will you try to save? Why not save the HIV-negative patient because the positive patient is anyway going to die?” ” (Resident doctor in a public hospital, Mumbai)**

The apprehension of senior doctors was attributed to the fear of the unknown: during their training period, they had received minimal or no exposure to patients with HIV. Younger doctors’ greater exposure to HIV cases is now expected to result in a more open and less prejudiced approach.

Among specialists, surgeons and gynaecologists were said to be the most rigid in their practices towards HIV/AIDS patients. In Bangalore and Mumbai, mandatory testing for HIV was reported for both surgery and child deliveries at all private hospitals and in a few public hospitals as well. While these specialists were seen as having a higher risk of infection compared to other medical professionals, because of the invasive nature of their work, they were also regarded as the major source of discrimination towards HIV-positive patients.

The situation was seen to be improving, albeit slowly. Increasingly, greater experience in managing HIV-related care was helping orient the younger generation of doctors to the epidemic, and lessening their fears about it.

**“Now we can say that the fear is slowly getting reduced. Doctors do not react so strongly now to HIV/AIDS. We can say that we are in a way being immunized against HIV. We are seeing so many patients that we do not have the fear of the unknown now. The students of today ... will fear the disease less as they become the caregivers of tomorrow. ” (Resident doctor in a public hospital).**

Indeed, each of the selected hospitals, public or private, had an appreciable number of doctors, nurses, and supportive staff who were committed to providing good-quality patient care. “I certainly belong to the set of doctors who have not reacted irrationally to the problem of AIDS. At my hospital there are a few of us, yes only a few, but significant in numbers, who take on all cases – no matter what their HIV status” (doctor in a private hospital in Bangalore).

In both sites, research staff also came across doctors who worked alongside AIDS NGOs, providing free medical consultations to AIDS patients, helping to frame guidelines for care and treatment at short-stay homes, being part of community-based AIDS education programmes, and serving on national or state government programmes. Several NGO staff and HIV-positive people spoke highly of these individuals, calling them “doctors in the true sense”. Doctors who led from front in providing care for HIV-positive patients served as role model for other staff who were in turn able to reduce their anxieties about HIV.

### Employment context

In both study sites, employment did not emerge as a major setting for discrimination and stigmatization – probably because most respondents had not disclosed their HIV/AIDS status at work. Many had a strong fear of social isolation and stigmatization, and they worried about losing their job if they were to reveal their status. This fear was validated by those who had shared their HIV/AIDS diagnoses with work colleagues and management.

Felt stigma in relation to HIV/AIDS-related DSD clearly presents serious problems for people with HIV in the workplace. A majority of HIV-positive respondents, even those who were open at home, said they would not disclose their status to their colleagues or employers. They mentioned fear of social discrimination and isolation, lowered prestige, and possible job loss as reasons for keeping their status secret. Indeed, many asymptomatic individuals felt there was no need to reveal their status at work as long as they remained physically healthy. Business and industry by and large do not have AIDS policies, and no special benefits are offered to workers with HIV. As a result, respondents had to make up other excuses whenever they needed to take leave for medical treatment or because of opportunistic infections. Such secrecy interfered with daily treatment schedules – for example, some workers avoided taking medication in the presence of colleagues. It also affected health and safety precautions: respondents were concerned that if they took particular care, they might make others curious.

Respondents were also worried about what would happen if their status were revealed to work colleagues: one widely expressed fear was that they would become “untouchable.” In a society that is very concerned with social image, the prospect of damaging one’s reputation and family name was extremely worrying.

**“People may not behave badly towards me, but my reputation would certainly go down. Who then will take the risk of telling others? People out there have dirty minds, they will only think of one thing – that I went “out” – and this will spoil my family name. ”** (HIV-positive man, aged 30)

**“Nobody will come near me, eat with me in the canteen, nobody will want to work with me, I’ll be an outcast there. ”** (HIV-positive man, aged 27)

Such fears and doubts were common among respondents in both sites. Many HIV-positive workers said that they either kept silent or left their jobs in anticipation of social rejection at work. “After I got my HIV test result, I never went back to work. How will I face colleagues who currently think I am a very ‘nice’ person? They will stop interacting with me” (HIV-positive man, aged 32, printing-press worker). Job loss and ensuing economic hardship were among the most feared outcomes of AIDS, especially among poorer people at both sites.

These fears and anxieties were not unfounded, as was evident from the personal experiences of those few respondents whose sero-status had become known at work. Social isolation, hostility, and attempts to dismiss HIV-positive workers were reported from both sites. Often this hostility came from co-workers and other staff, who put pressure on management to fire HIV-positive employees. Labelling and isolation sometimes forced HIV-positive workers to leave their jobs and either settle for poorer-paying work or keep moving between jobs to avoid being stigmatized at successive workplaces. The following case in Mumbai reflects anxieties typically experienced by HIV-positive employees.

*“Those staff members who know about me, talk about it. They point out at me and say “Look, he is the one with AIDS.” There has been some difference in the way they behave towards me now – keep distance from me and remain aloof [lamba rahate hain]. I don’t share my tiffin box with them now. I don’t feel like coming to work. I remain absent for 10–15 days and then I lose wages.”* (HIV-positive hospital ward attendant, aged 38)

Respondents felt that HIV transmission via everyday contact at work was a general workplace anxiety. Group discussions in workplaces mentioned the following as perceived possible transmission routes: sharing utensils in the canteen, drinking water from the same glass, sitting in close proximity while operating machinery, or having infected people as group members. Anxieties such as these led some HIV-positive workers to quit their jobs rather than risk the humiliation of being removed by employers or colleagues. The physical distance maintained by co-workers at meal times or general working hours was reported to be particularly stigmatizing. During focus group discussions, hospital staff also admitted that they didn’t feel comfortable being close to their HIV-positive colleagues.

*“We behave with them as before but there is some distance that we now maintain. This is natural, isn’t it – I mean it’s caused by our anxiety?”* (Male sweeper in a Mumbai private hospital, age unknown)

*“I am speaking for myself; I don’t have very close contact with the staff members who have AIDS. I feel I have to take special care of myself when working with infected workers.”* (Male ward staff member in a Mumbai private hospital, age unknown)

Hostility from co-workers sometimes led management to terminate the employment of HIV-positive workers. In one case, the refusal of others to work alongside an HIV-infected employee persuaded management to ask the worker to stay at home while drawing full pay. The doctor who intervened on his behalf stated, “My patient was extremely disturbed at this insult but as he needed rest, I advised him to accept the situation and continue to be paid while sitting at home.”

Levels of discrimination and stigma might be expected to be greater in the non-organized work sector, where unskilled or semi-skilled workers have no employment rights.

*“I was with my employer [a barber] for 15 years and so felt confident to tell him about my AIDS result. But clearly I made a mistake. He just asked me to pack up. He was afraid of losing his customers. He allows me to clean his place and cut his hair but the fear of losing business made him very disturbed.” (Nabi, HIV-positive man, aged 42)*

Fear of AIDS is prevalent in India. Workers in the food business are especially vulnerable to discrimination. The present research highlighted the case of a food vendor in Mumbai, who sold BhelPuri<sup>4</sup> in an upper-middle-class residential area. When the man tested HIV-positive, his doctor informed the police; the next day, police officers removed him, as he was felt to “pose a risk” to the health of his affluent customers. He tried explaining that he could not infect others by selling snack-foods, but the police were not convinced.

### *Discrimination by management*

Management discrimination against HIV-positive workers seemed to be due to lack of knowledge and/or the absence of protective policies. Discrimination and stigmatization from management made it particularly difficult for individual workers to have their rights respected and to earn a living.

### A bus conductor

N.K. is a 38-year-old conductor in a Mumbai transport company. He found out about his HIV-positive status five years ago. In the past three years, he has been falling sick with diarrhoea, fever, coughs, and colds, and he feels weak. His conductor’s job demands physical fitness: he has to be on his feet for nearly eight hours a day in a moving and jolting bus. He has been absent for long periods due to weakness. After he finished his allotted quota of leave, he was put on “leave without pay” for three months. Because he was unable to carry out his conductor’s duties, yet felt strong enough to manage other tasks, N.K. asked management to transfer him to a lighter post or a desk job. He then requested medical leave on grounds of “weakness” but was informed that this was not a listed condition for which medical leave can be given. He was given two options, either to resign or to face dismissal due to long-term absenteeism.

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<sup>4</sup> BhelPuri is a popular local snack.

N.K. has nineteen years of service behind him, but is still young. He has no major AIDS-related illness as yet, but bouts of weakness prevent him from doing his job on a regular basis. The company has no policy on medical conditions related to HIV – like weakness – or on shifting infected workers to other, more suitable jobs. The medical officer, who is otherwise very supportive, is unable to help because AIDS is not yet recognized as a problem in the company. According to N.K., other medical staff are unsupportive, saying for example, “This disease is because of your mistake.”

Because N.K. does not want his name to be identified with AIDS outside the medical unit of his company, his situation cannot be taken up as a special case with the personnel department of the same company. To avoid the humiliation of being dismissed from his job, N.K. chose to resign. Recently he handed over his conductor’s badge to the company and is now looking for a less demanding job that will help preserve his health.

It is not uncommon for HIV-positive workers to find themselves unable to do their usual job. They may no longer have the stamina, or the job may expose them to substances or activities that make them sick. Two respondents who worked in a transportation department were finding it difficult to work on buses moving through polluted areas of the city. Both kept falling sick due to throat infections and asthma. Although they had requested lighter jobs, neither was confident of receiving a favourable response from management (see box above).

### *Denial*

The response of employers to the AIDS epidemic in both sites was largely one of denial. As part of this study, fifty small, medium, or large public and private industries in Mumbai were sent a questionnaire about their AIDS-related policy or measures taken to deal with cases of HIV/AIDS in the workplace. Only four companies returned their questionnaires, and none of these had a written policy on AIDS. In response to a question about policy on HIV-positive staff, one private company stated, “No known cases of HIV and hence no need felt so far.” One public-sector company said that it allowed infected workers to remain in their job positions, while one in the private sector accepted requests for a change of job.

In Bangalore, initial attempts to collect information on AIDS-related policies and programmes from local industries were not successful. However, after several attempts, six of the nine small and large-scale industries contacted from both the private and public sector eventually responded.

### A local transportation company

Company "X" has no written policy on AIDS; supposedly, there is "not a single case of HIV reported in the company so far". The welfare officer as well as the head of human resources development were largely ignorant about the magnitude of the epidemic in the city and about the existence of the AIDS Cell created by the State Government. Since their staff are better paid and do not stay away from their families for more than three days at a stretch, they felt that they were not likely to have had unsafe sex. Further, they did not think the epidemic would affect their company greatly as surplus labour is readily available.

About a week after company officials denied that HIV was a issue, a local newspaper revealed that there had been HIV cases in the company. At the same time, the paper reported a declaration by the State government of its intent to screen all employees for HIV. When research staff again contacted company officials, they were told that the unions were very strong in the company and would not like management acting on HIV issues because such action might lead to job losses. Management has been aware that a large number of drivers and conductors had had treatment for STDs and that some of the men had been found to be HIV-positive. With the educational requirement for drivers being only Grade 4, the training manager said that "it was quite difficult to make them realize the seriousness of the situation; instead they view the management with suspicion." Some of his colleagues in the personnel department had even been beaten up, and nothing could be done to take the issue forward because the union had threatened strike action.

The company recently devised a plan to screen all employees for HIV. It was explained to them by the research investigators that it was not ethical to screen all employees, and that the National AIDS Control Organization had issued directives against such measures. Management is now in a dilemma about to deal with such a potentially explosive issue within the company.

Denial of the epidemic was not restricted to small or medium-sized industries employing semi-skilled and less educated workers. In one computer software company, the human resource development officer believed that staff, being among the highest-paid professionals in the country, were at very low risk of HIV. In his own words:

*“Our staff is very highly paid. They come from the most highly regarded institutes [of higher education] and we are sure that they do not have behaviour that would make them a suspect for AIDS. They are very well educated and have easy access to the sources of information, so cannot easily fall for “such” things.”*

In one large-scale private manufacturing company that employed around 5,000 people, the chief of human resources said there was no written policy on AIDS. So far, no cases of HIV/AIDS had been reported among the workers. The social counsellor and medical officer of the company supported this view. The company, they said, was welfare focused; it provided free meals, good working conditions, and medical coverage;



and its workers were among the highest paid in the city. The chief of human resources was confident that workers would have no hesitation in reporting their sero-status to the company if they tested positive. He also believed that HIV/AIDS cases could not be kept confidential since any long-term absence of workers was noticed.

**“We are in the highly competitive business of manufacturing equipment. HIV/AIDS is a low priority area for me. There are others to take care of this. We are facing recession at the moment and so all efforts are to be at the shop floor to maximize production. HIV/AIDS is not yet an issue for the local industry and so there is no written policy on AIDS.”**

The social counsellor of the company agreed. She did not acknowledge the vulnerability of the workforce to HIV/AIDS (since reported cases of alcoholism, tuberculosis, and STDs were said to be low) and paid little attention to any connection between AIDS and productivity. She asked, “Where is the need for a policy on AIDS when there are no reported cases and there is no cure and no clear benefits to HIV-positive workers?” The company medical officer was more realistic in his assessment of the situation. He stated that a few cases of STDs had been reported, but he felt that workers would not report their HIV sero-status to the company for fear of discrimination.

Denial of HIV/AIDS in the private sector seems to emerge for two main reasons. First, there have been few reported cases of HIV/AIDS in the workforce. Second, management seems to believe that workers who are well educated, better paid, or well covered by company health insurance schemes will not engage in risk behaviour. By contrast, in the state sector, pressure from unions, fear of adverse publicity, and a desire to sweep such problems under the carpet were the main reasons for inaction.

### *Acknowledgement of the epidemic*

While there was some acknowledgement of the importance of AIDS in two Bangalore companies (one public, one private), the concerns and the focus of the two companies differed markedly. In a large public-sector manufacturing unit, the threat of the epidemic was seen largely from the workers' perspective. Management recognized the importance of organizing AIDS awareness workshops, providing counselling services, and making free condoms available. The HIV test was included in the annual medical check-up of workers. Pre- and post-test counselling was provided and confidentiality of results maintained. The stated objective of such annual check-ups was “to identify positive workers and for individuals to know their HIV status so that they do not spread the infection.” However, there was no written policy on AIDS, and although there was no pre-employment testing for HIV, the chief of personnel was strongly against employing a HIV-positive worker.

In contrast, a large-scale private company appeared to focus on HIV in class terms. The perception of AIDS as a threat to the company came about after the detection of two HIV-positive cases in the ranks of senior management. The acknowledgement of

the threat of HIV to the workforce of the company stemmed from this discovery. As the head of human resource development put it:

*“We did nothing [about the epidemic] until a couple of months back. Like any other industry we too didn’t think this [HIV/AIDS] was a problem ... and then one of our senior executives was reported to be HIV-positive.... Some time ago there was one more case brought to my notice among the executive class. As a company we were taken aback. Then I knew we had a problem on our hands.”*

The company did everything to maintain the confidentiality of the two individuals concerned and provide practical and emotional support. However, the company’s major concern was protection of its market position. “We are in a competitive business. Our competitors can falsely allege that the [person] in charge of quality control at our company is infected with HIV. [Then] our sales will just drop.”

Although the potential threat of HIV to the workforce had now been made clear, “We have done nothing about it. So far we have organized one AIDS workshop but I know that this needs to be done at different points of time.” Even while accepting that the company had to formulate a policy on AIDS, perceptions of people with AIDS remained biased. “We have to think about the compensation to the workers. Even if it is his fault, yes it is his fault, we will work out the compensation.”

On the question of pre-employment screening for HIV, the head of human resource development said:

*“Though we do not have a policy so far, I can say that if at the time of recruitment there is a person with HIV, I will not take him. I’ll certainly not buy a problem for the company. If I was in the steel industry, I would not bother, but I am in “this” business. I see recruitment as a buying–selling relationship. If I don’t find the product attractive, I’ll not buy it.”*

To sum up, HIV-positive workers do not disclose their HIV/AIDS status at work because of fear of discrimination, job loss, lack of support, and loss of benefits in the absence of a clearly defined corporate policy on AIDS. Thus, the epidemic remains invisible, in the workplace at least. Because it is not visible, management denies its seriousness and sees no need to frame a policy. This vicious circle of silence and denial needs to be broken.

Where cases of HIV have been identified, the response of management is patchy, at best. The case for hiring people with HIV has not been won.

Despite this situation in both sites, the welfare departments in two leading Mumbai-based private industries are involved in responding to the epidemic in major ways. Welfare officers in both these industries spoke about a supportive management that

acknowledged the threat of the epidemic in the work sector. In 1996, these two leading industries had initiated the process of bringing the corporate world to face the challenge of AIDS. This initiative was named the Industrial Response to AIDS (IRTA). However, out of thirteen companies that pledged support to the formulation of an AIDS policy in the corporate sector, and to donate funds for it, only two showed interest in taking forward the initiative (see Nangia, 1998).

### Family context

A majority of respondents had disclosed their seropositive status only within close familial relationships – parental, spousal, or sibling. Within each of these, gender was a significant factor determining the likely response. Daughters, wives, and daughters-in-law experienced greater levels of DSD than sons, husbands, and sons-in-law. The relationship most strained by HIV status was that between parents-in-law and daughter-in-law, followed by the spousal relationship (these observations held true in both study sites). Discrimination against daughters-in-law was blatant even when sons received good familial care. In both sites, women were stigmatized as being of “loose character” and a potential source of infection to their husbands, at the same time as they were expected to provide care:

*“My in-laws do not have good opinion about me. They say that my husband got this disease from me. I sometimes feel “Why should I live with this insult? It is better to die.” But I am living for the sake of my children.”* (HIV-positive woman, aged 40)

*“My mother-in-law tells everybody, “Because of her, my son got this disease. My son is a simple boy as good as gold – but she brought him this disease.”* (HIV-positive woman, aged 26)

In most cases, after the death of the son, parents refused to take responsibility for the well-being of their daughter-in-law and asked her to leave. She either had to return to her birth family or was forced to support herself.

### Sundari

Sundari was not told of her husband’s disease by her family. When the doctor explained to her what the disease was she was very worried. She was her husband’s sole caregiver, and he had recently developed skin lesions and suffered from diarrhoea and vomiting. Both she and her son were also found to be HIV-positive. After her husband’s death she was abandoned by her parents-in-law. “After my husband’s death, my mother-in-law and sister-in-law stopped talking to me. I was not allowed inside the kitchen. One day she asked me to go on a pilgrimage. My father accompanied me and my son. After we returned I found my mother-in-law had vacated the house.” (Sundari, HIV-positive woman, aged 25)

Even when the parents knew that their son had visited sex workers, it was the wife who was blamed for not keeping her husband “under control.” She had failed in her role as a wife, thereby justifying the family’s rejection.

For their part, most husbands acknowledged that their wives were the main caregivers, and many felt guilty for potentially having infected their wives by their “wrong deeds.” In a few cases, wives took the initiative and left their husbands, an experience described by two male Mumbai respondents:

*“My wife left me when she came to know of my disease. She said, “You have this disease, living with you will be a trouble.” She is frightened and I also know that she is very angry with me for my behaviour.” (HIV-positive man, aged 28)*

*“My wife has left in anger, she blames me, and she feels I have gone and brought this disease home. (HIV-positive man, aged 27)”*

In Bangalore, none of the male respondents reported desertion by their wives, but some spoke about their wives’ negative behaviour:

*“My wife has taken this disease very much to heart. She keeps my plate, glass, soap, towel, brush all separate. She doesn’t come near me. Sometimes she makes sarcastic remarks and says, “Bad deeds produce bad results. If we do what we shouldn’t do, we get what we shouldn’t get.” These words hurt a lot.” (HIV-positive man, aged 45)*

### *Other gendered experiences*

For both men and women, the contexts and forms of HIV/AIDS-related discrimination, stigmatization, and denial appear to be influenced by wider social expectations and relationships. Women in particular tended to be seen as wives, mothers, daughters, and daughters-in-law before they were seen as HIV-positive women in their own right. The impact of HIV/AIDS for most men was cushioned by their privileged position in society, while for women it was intensified.

In pregnancy, many women were discriminated against on the grounds of assumed HIV status. These were the wives of men suspected of high-risk sexual behaviour and were targeted for HIV testing before labour. There was a high probability that if found HIV-positive these women would be refused hospital care. No such case was reported by the respondents, but in Mumbai several women, and even men whose wives were pregnant, spoke of their high levels of stress as they went from hospital to nursing home trying to register for maternity services. One man spoke of his sense of despair when nursing homes refused to register his pregnant wife:

**“When they got her HIV report and it was positive, the nursing home told me to take her to hospital. Another nursing home also refused. Then I took her to a public hospital. There they again tested her. I was worried, if they don't [admit her] what next? Thankfully, they agreed to do the delivery.”**

For HIV-positive women, pregnancy itself was stressful because of the fear that medical care during labour might be denied.

**“I was pregnant. It was my third month I remember well. I went for a check up. The doctor said they would check my blood. Next time when I went to the doctor she said the hospital would not take me for delivery. “There is mistake in the blood, bring your husband.” Then they checked his blood also and said “It is AIDS. We cannot take you here for delivery.” For the next three months I cried. Then with the help of a doctor in that hospital, they agreed to admit me.”** (HIV-positive woman, aged 23)

Some pregnant women were advised to seek an abortion, yet no counselling was offered. “The doctor said I should think of ‘dropping the child’ [*baccha gira do*]. I was confused. When I looked at sister [the nurse] she said ‘Your husband has HIV, so...’.”

The narratives of some women revealed the stigma they experienced during their husbands’ hospitalization for HIV-related conditions.

**“In the hospital the staff used to say, “Why are you coming to the hospital. Didn't you know when you first made the ‘mistake’?” I used to feel so embarrassed and also angry with my husband. But what's the use of getting angry now?”** (HIV-positive woman, aged 32)

**“The nurse would say to me, “He did many ‘wrong’ deeds, now you have to pay for them,” and she would keep instructing me – “Don't sit too close to your husband, don't do this – don't do that.”** (woman, aged 41, HIV status not known).

Many married women were forced to have sexual intercourse even when the husband’s HIV status was known to them. One woman spoke of her powerlessness: “My husband had AIDS explained to him but he had sex with me that same night. I asked him if it was OK but he said there was no problem. Under the influence of alcohol, he doesn't listen to me. What could I do?” (HIV-positive woman, aged 28).

For HIV-positive mothers, discrimination was often experienced in the form of physical separation from their children. One woman’s children (a daughter aged nine and a son seven) were looked after by her mother-in-law after her husband died of AIDS, while she herself was forced to leave and stay with her parents.

**“They [in-laws] keep my children with them. They let me visit them but do not allow me to get too close to them. They think I’ll pass the infection to the children and they will in turn pass it on to them. I visit my children on weekends. My mother-in-law tells the children, “Don’t go close to the mother,” but how can you tell the kids? When they see me, they come running to me. I pay for the children’s books etc; they only give them food. I have to be satisfied with this arrangement. ”** (HIV-positive woman, aged 32)

Some mothers were forced to give up their babies either because they were too weak to look after them, or because they hoped that if a child tested HIV-negative he or she would be adopted.

**“I have sacrificed my child for this [AIDS]. I have kept him away from me so that he can live a happy life. He should learn to live by himself. Some children become HIV negative and then they go for adoption. I pray to God to give him long life – then I don’t mind dying. ”** (HIV-positive woman, aged 28)

Women experienced DSD from their parents-in-law after a husband’s death. A clear distinction was made between the son and the daughter-in-law, even when both shared the same HIV status. In Mumbai, several HIV-positive women spoke about being denied medical treatment and a share in the husband’s property, pension, or insurance. Discrimination was also evident in the quality of food provided and in the attitude of family members. Widows were often blamed for the son’s death and told to leave the family home; some were not welcome in their birth homes either. They then faced the prospect of being both HIV-positive and homeless.

### Asma

Asma is a 23-year-old widow. Her husband died of AIDS about six months previously. He tested HIV-positive in September 1996 and soon after she, too, was found to be infected. Asma provided all possible care to her husband. After the death of her husband, she experienced AIDS-related stigma in her home.

**“My mother-in-law has kept everything separate for me – my glass, my plate, they never discriminated like this with their son. They used to eat together with him. For me, it’s don’t do this, don’t touch that and even if I use a bucket to bathe, they yell – “wash it, wash it.” They really harass me. I wish nobody comes to be in my situation and I wish nobody does this to anybody. But what can I do? My parents and brother also do not want me back. ”**

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Asma quickly learned not to expect anything from her parents-in-law, and that, as daughter-in-law, she would not be treated fairly:

*“My in-laws never paid for my treatment, only for their son. They have not given me a share of his property. They say there was a lot of expenditure on his treatment. But the loan I had taken for his illness I paid that by selling my jewellery.”*

She was forced to seek shelter with her sister, but here too she found fear and anxiety.

*“My sister keeps her clothes separate. Her husband keeps saying to her “Your sister has this awful disease.” But my in-laws have said, “Now we have no use of you in our home” – I wish I could die, then I won’t have to think where to go.”*

Despite the repeated reports of hardship, a few HIV-positive women’s narratives in Bangalore revealed experiences of support and care from parents-in-law.

*“My husband’s family is looking after me well even now. I prepare lunch and breakfast. If I get a cut my mother-in-law says, “Put on a bandage quickly.” My husband used to tell me, “You got this disease from me. You have earned a bad name because of me.”” (HIV-positive woman, aged 28)*

Such support and care tended to be observed in homes where the husband had been open in admitting his risk behaviour to the wife and where the in-laws and other family members had been counselled about HIV/AIDS. In such cases, fear of infection did not create a rift between the infected daughter-in-law and others, and the daughter-in-law tended not to be blamed.

Most HIV-positive women were not as fortunate, and the care given to sons with HIV reveals the gendered nature of HIV-related discrimination. Men usually had more positive stories of support to narrate:

*“My mother consoled me. She said, “What had to happen has already happened. Be a good person here after. Till I live I will look after you well.”” (HIV-positive man, aged 26)*

*“My mother is of a very caring nature. Even on my death bed she will be the one to pour water into my mouth.” (HIV-positive man, aged 26)*

## Other contexts

### ***Discrimination and stigmatization at the time of death***

Discrimination was reported in the community wherever people's HIV status was known. However, differential treatment at the time of death was one of the greatest sources of distress for HIV-positive people in Mumbai. The bodies of people with AIDS are reportedly packed in black plastic bags or sheets and handled with disrespect because of the fears of mortuary and ambulance staff.

During a group discussion with HIV-positive men, many spoke with agitation about what they called "stigma in death." They spoke of the irony of maintaining secrecy in life in order to protect their reputation, while in death their plastic-wrapped body effectively revealed their AIDS status to everyone. The plastic sheet was seen as a symbol of the shame and stigma associated with AIDS, and there was a strong demand that this practice be discontinued.

### **A friend's funeral**

I have just returned from my friend's funeral – we are all friends in this group of positive people – he died of AIDS two days back. I can tell you how badly he was treated in death. In this very hospital, he died of a high fever and respiratory problems. His family did not come forward to claim the body as they had been given so many instructions by the doctors. They were afraid, so I and a few other group members decided to give him decent last rites. At the mortuary we found the staff standing, waiting for us to do something. They wouldn't lift the body. "We know he has died of AIDS, the body is covered with plastic," they said. The driver refused to help unless we paid him twice the normal fare. We agreed to do that. We were afraid what impact the plastic-covered body would have on the onlookers and other relatives so I covered the body with a bed sheet to make it look like a "normal" body. During the journey, the driver cautioned me about the risk I was taking – I wondered what he would do if he knew of my HIV status. At the cremation ground, the relatives didn't come forward to help and the father-in-law of the boy didn't want to come near the body. The wife and her son were among the few relatives who touched the body. The priest was curious as to why some relatives stayed away. I asked the priest to hurry up for I was afraid that he may see the plastic sheet and ask about it. Throughout the rituals I was tense and very, very, very depressed. I don't feel like living any more. I feel I have lost the battle against AIDS. (Hari, HIV-positive member of a support group)

Although plastic sheeting was used in some hospitals in Bangalore, it was not referred to by anyone with HIV as a source of stigma, nor was it mentioned during



community group discussions. However, it was pointed out that bodies were taken straight for cremation or burial because doctors advised against any rituals. People with HIV were angry and upset that they were not allowed the customary rituals at the time of death. "Society and the family don't think we are worthy of proper rituals at the time of death. I know they follow the doctor's advice, but I feel very bad about it" (HIV-positive man, aged 42).

The mother of a young boy who died of AIDS said, "We didn't do any rituals, because we felt people will start suspecting if we kept the plastic-covered body too long at home. But now we feel so bad that nothing was done for him. His elder sisters lament that he didn't even get some wood from us [wood is used by Hindu people to build the funeral pyre]."

### *Schools*

NGOs in both study locations are beginning to acknowledge schools as a setting for HIV/AIDS-related DSD. Problems – both for the HIV-positive parents of HIV-negative children and for HIV-positive children – were beginning to be observed at the time of the study. In Mumbai, one HIV-positive couple and one widow of a man who had had AIDS were forced to withdraw their HIV-negative children from school. No specific reasons were offered by school management, and the affected parents were too afraid to pursue the matter – in one case, reluctant to have their identity become known to others. As the grandmother of one child said, "I was afraid that people would talk more if I argued with the school principal. So we moved the child to a municipal school."

Another school displayed complete ignorance about HIV transmission routes when refusing to accept an HIV-negative child of positive parents. The management of the school insisted that the child's presence would adversely affect the other students, even though they were aware that he was HIV-negative. In yet another case, an HIV-positive widow had to get help from social workers to enable her six-year-old son to attend a boarding school in a suburb of Mumbai, which had initially been worried about the possible impact on other children.

Where a child was HIV-positive, school staff were generally worried about possible HIV transmission from cuts or injuries following playground fights or in the event of an accident. In Bangalore, such fears made one NGO conceal from the school authorities the sero-status of children in their care. In Mumbai, however, another NGO has been successful in educating the staff of a municipal school about transmission routes and health and safety precautions. As a result, all school-aged children in the care-home are now allowed into the school.

Other childcare institutions, however, continue to discriminate against children with HIV. In a few institutions in Mumbai, destitute children are tested for HIV at the time of admission; if positive – and despite adequate staffing levels and space in the childcare centre – they are either segregated or transferred to an NGO with a designated shelter programme.

### *Life insurance*

The denial of life insurance to HIV-positive individuals was yet another issue raised during individual interviews. The Life Insurance Company (LIC) of India has added the HIV antibody test to the list of medical tests required for a policy application. HIV-positive people are denied life insurance on the grounds that it is supposed to cover “risk of loss” rather than actual loss. Since there is no effective treatment for HIV, the risk of loss of life is taken as “definite,” compared to, for example, cancer or heart disease, for which there are well-established medical interventions. HIV-positive individuals feel that this is discriminatory.

One senior LIC official defended the company's decision as being no more discriminatory than for other patients with terminal diseases. Policy-holders who tested HIV-positive after taking out life insurance would, it was claimed, have their policies honoured. Yet a significant number of respondents worried that their premature death due to AIDS would result in the policy being revoked. Some respondents had consequently discontinued payment of their LIC premium. While the LIC rules seem clear, fear of disclosure and stigmatization prevented people from seeking clarification directly from the company, with the result that some infected people were likely to forgo claims to their policies. More data are required to assess the impact of life insurance policies on HIV-positive individuals.

## DETERMINANTS OF HIV/AIDS-RELATED DSD

In order to counteract HIV/AIDS-related DSD, it is important to understand more about the factors that enable it to thrive. Here, we will discuss some of the determinants identified in the course of the investigation, with special reference to the health care sector, where levels of information, risk assessment, and attitudes were found to be particularly variable.

### Low levels of HIV/AIDS knowledge

In all hospitals in Mumbai and Bangalore, most nurses, technical staff, and medical doctors appeared well informed about HIV/AIDS. Several of them had attended training programmes on AIDS. However, ward staff in most hospitals generally lacked adequate information. They knew some basic facts, but there were a number of serious misconceptions. First, despite working in a health care setting, several staff did not know the difference between HIV and AIDS.

**“HIV and AIDS are same. HIV means AIDS. HIV is in English and AIDS in Marathi [the local language of Mumbai].” (Ward attendants and sweepers in a Mumbai Private Hospital)**

*“If doctor says HIV, we know he means AIDS.” (Ward attendants in the operating theatre of a Mumbai private hospital)*

*“Acquired means, which is transmitted from mother to a child. Acquired means, which is there since birth.” (Nurses in a private hospital, Bangalore)*

*“HIV is when the virus is infected and it turns into AIDS after a long time. At that stage there are chances of communicating the disease.” (Technician in a private hospital in Bangalore)*

Second, there were serious questions about routes of transmission. In theory, staff knowledge about the major modes of transmission was adequate. A majority of staff across hospitals said they were aware that everyday contact and sharing meals, drinking vessels, or clothes were not sources of infection. Yet, in practice, staff had significant anxieties about casual contact with people with HIV. Most staff knew that they needed to take care with needles, blood, and other fluids of an HIV-positive patient, but several other precautions mentioned showed an exaggerated sense of HIV's infectiousness. “Their blood should not touch us, even if one-drop touches our body, we can be in danger” (ward staff in a private hospital in Bangalore).

Management and senior doctors in most of the hospitals spoke about the need for periodic training programmes for staff. However, ward attendants, *ayahs*, and sweepers generally said that no special lectures had so far been given. Staff in a private and a public hospital in Mumbai claimed that the researcher's visit was their first chance to have any informed discussion about AIDS.<sup>5</sup> This claim was refuted by senior doctors, but in some hospitals deliberate attempts were made to withhold information from staff in order that they would not ask for safety kits or compensation. In a Bangalore public hospital, the chief medical officer declared,

*“So far as any training programme, or orientation groups or whatever is to be conducted in our hospital, we do not allow any such things. Recently, somebody conducted a programme. We allowed only the doctors to attend it. Our other staff like our nurses and ayahs, we will not allow them to be involved. During the groups you may talk about gloves, extra allowances, risk, and so on. If they come to know more about these things they will demand them, and it will be very difficult for the management to run the hospital. Our staff has sufficient information about it. But if there is any additional information they require, we prefer to give it to them ourselves rather than a third person or an outsider coming and talking about it.”*

<sup>5</sup> At the end of several group discussions, the researcher was asked to give information on HIV and AIDS.

### Risk assessment

When dealing with general health and safety matters, staff members in both public and private hospitals accepted that there was always some general risk of cross-infection. However, there was a specific and major fear of infection when it came to HIV. A majority of the ancillary staff – ward attendants, sweepers, and *ayahs* – said they were at high risk of infection. Risk perception was considerably higher among the staff of hospitals in Bangalore than in Mumbai. In Mumbai, there were differences in risk assessment between ward staff and sweepers and nurses. Here, it appeared that staff who provided close care, or who handled body fluids, had lower anxiety levels than those who provided more distant or superficial care (making beds, giving food, and wheeling patients around). Although it was the sweepers and *ayahs* who worked with bodily fluids, it was the ward staff who feared infection most. The nurse in charge of an operating theatre in a private hospital in Mumbai stated:

*“All that the [theatre] staff has to do is to move the lights or wheel the patient. But they say “Blood will splash in our eyes, we have cracks in our feet, we are at risk.” This is basically the class 3 and 4 staff. They assist only indirectly in operations. They have to lift the body and turn it on its side. The sweepers have to help in the post-operation period in washing the floor, in disposing the waste. But whenever we have patients for surgery, we face stiff resistance from the staff. They say “If we get infected what will happen to our children?””*

In a few public and private hospitals, staff members in particular departments are aware that HIV does not pose a major risk if adequate precautions are taken. Doctors who are proactive and supportive seem to become role models for these workers.

### General staff attitudes

Hospital staff who were most anxious about HIV were generally those who had a derogatory attitude towards HIV-positive people. In Bangalore, staff members across hospitals targeted truck drivers and sex workers as the major sources of HIV transmission in their city or state, labelling them as “bad” men or women with “dirty” habits, who were “not satisfied with what they have at home.” The poor, the slum-dwellers, and the illiterate were commonly believed to be “AIDS infected” in larger proportions than the rest of the population. The migrant population from neighbouring states was targeted even more frequently.

*“This illness is more in lower-income group as well as in backward classes. Also it will be more in higher-economic groups.”* (Nursing staff in a small public hospital, Bangalore)

**“Village people will have more of this illness. Those who come to us [in this hospital] come from Andhra and Tamil Nadu border. Among them 75 per cent are truck drivers.”** (Nursing staff in a small public hospital, Bangalore)

For a few staff, people with HIV introduced an element of curiosity and interest into otherwise humdrum jobs. There was an eagerness to learn how infection had occurred. “We get more cases from Andhra Pradesh. That too, people who go on tour to Maharashtra will surely be having it. We can make out as soon as we see them. Our guess will be 90 per cent true. We ask him where did he go and what did he do. It is very interesting” (technician in a public hospital, Bangalore).

An overwhelming proportion of hospital staff from both sites supported the idea of separate hospitals and wards for HIV-positive patients. They argued that specialized hospitals would have:

- better patient management, since all patients suffer from the same disease
- better infection control
- greater ease in dealing with safety precautions
- no threat of infection to other patients
- better mental preparedness of staff.

At the same time, none of the staff wanted to work in the separate ward or hospital, because of fear and risk of infection. As a counter-measure, therefore, they argued for the mandatory testing for all patients in all hospitals so that precautions could be taken from the beginning. Another demand was for extra benefits for “risking their lives” caring for HIV-positive patients. These demands were more forceful in Bangalore than in Mumbai.

### Attitudes of doctors

In Mumbai, doctors generally acknowledged the right of people living with HIV and AIDS to adequate care and treatment, and did not feel that separate hospital facilities were needed. In Bangalore, in contrast, doctors’ general perception was that HIV-positive people had “bad habits” – of visiting prostitutes, of smoking and drinking – and were “promiscuous” and “immoral.” Certain sections of the population were singled out for blame:

**“When a truck driver comes, we are sure he is HIV-positive and we get him tested for HIV. Especially those who travel between Bombay and Bangalore are the most risky lot.”**

**“Some special groups like cooks in Chinese hotels and even cleaners, mostly they have HIV. So we should be very careful when they are admitted.”**

These doctors also largely excused the behaviour of those who stigmatized people living with HIV and AIDS:

*“They have bad habits, so people don’t like them. We can’t blame the people for this.”*

*“When a person does something wrong, he will be naturally looked down upon. There is nothing wrong with it.”*

A majority of medical professionals in Bangalore justified the need to know the mode of infection in order to take better precautions. They also justified a doctor’s fear of infection, saying that “doctors too are human beings.” Displaying solidarity with fellow professionals, a majority of the doctors rated nurses, surgeons, and gynaecologists especially high on risk of HIV infection. The doctors claimed that these people’s fears, and their refusals to treat AIDS patients, were largely valid.

## OUTCOMES OF HIV/AIDS-RELATED DSD

Individuals with HIV/AIDS widely reported fear of social isolation, judgmental attitudes, severing of relationships, and denial of support and care. As the number of negative experiences increased, HIV-positive individuals became more and more distrustful of relationships, both personal and social.

*“I have seen people around me change. Earlier when my health was okay my family was supportive, but now I have recurrent bouts of fever, diarrhoea, and I can see that everyone is fed up. My [step] mother was very caring, but now I guess she too is tired. My toilet is separate – nobody comes to clean it, nobody cleans my room or even looks into it, my younger brother dares to answer me back. I have no faith left in relations with doctors and friends. I can see distances created between us. I feel their indifference and avoidance of me. Before I was struggling bravely with my problem, but now I have no will to fight anymore. It’s like I have lost my trust to AIDS.” (HIV-positive man, aged 28)*

Depression, anxiety, isolation, and suicidal thoughts or self-harming tendencies were recurrent themes in individual interviews. The fear of others effectively prevented people with HIV from accessing help and support.

Self-imposed isolation and the tendency to hide one’s HIV status contribute to a “hidden epidemic.” The most worrisome result of this is the silent spread of infection: many HIV-infected people, in their desire to remain undetected, may have difficulty with safer sex and safe injecting drug use practices. Another concern is that healthy, asymptomatic patients may conceal their HIV status in health settings as part of an effort to receive good care.

**“I have learned [to cope] the difficult way. In this same hospital where the dispensary for AIDS patients is located, I can point out so many staff who have discriminated against AIDS patients. I decided not to disclose my HIV status when I visit a doctor here. So far no doctor has asked me for HIV test, so I don't tell – if they ask to see my HIV test results or want to make me get tested, I will change hospital. ”** (HIV-positive man, aged 28)

Some of those who were unable to conceal their seropositive status, on the other hand, avoided visiting doctors or hospitals or delayed treatment, harming their health in the process. In order to avoid hospital-based discrimination, respondents also reported buying over-the-counter drugs for recurring problems like fever and diarrhoea. “I avoid going to doctors for regular problems like a fever, a cold or a cough. I get very disturbed by their behaviour and the hospital depresses me. Anyway, how long I am going to carry on? I can buy some medicines from the store directly” (HIV-positive man, aged 34).

Shame and stigma seem to have been internalized by many HIV-positive respondents, and they have a tendency to feel guilty and to tolerate the judgmental behaviour of others.

**“People are not to be blamed [for how they behave towards us]. I think this was to happen – I mean nobody will tolerate “wrong” kinds of behaviour [galat kaam], and this is an incurable disease [lailaaj bimari] – so who wouldn't be afraid?”** (HIV-positive man, aged 21)

**“I feel I've done something very wrong – it is a very “bad” thing [galat kaam kiya]. But I went only once to Kamathipura from college – it is a shameful thing [sharamnak kaam]. I think God is punishing me. ”** (HIV-positive man, aged 21)

Some do not accept such responses and are beginning to challenge discrimination. Although this attitude is still restricted to a small proportion of HIV-positive people, it is gradually gaining more support. At the societal level, it is taking shape in the form of a positive people's support movement, the Indian Network of Positive People (INP+). However, the movement is still in the early stages of development and has yet to establish itself as a viable social force. Furthermore, there is still a considerable degree of secrecy and mistrust among INP+ members. State- and national-level meetings, for example, are “members only” affairs, with participation by only select legal and health invitees.

## MARGINALIZED GROUPS

Our research suggests that sex workers, *hijras*, and openly gay men experience AIDS-related discrimination and stigma in ways that marginalize them not only from the mainstream, but also from their own communities.

### Sex workers

For sex workers, social discrimination and stigmatization were not new experiences. The daily business of sex work had already stigmatized them as “loose” or “dirty” women, and as “women who break up homes and families.” In the context of the epidemic, women who sold sex were perceived as the main source of HIV infection, with most interventions being targeted at them.

Sex workers’ experiences in seeking medical treatment revealed much about prejudice in the health care system. Those women interviewed said that they preferred private doctors because treatment could be accessed on payment, even though prejudice was also likely to be experienced. In government hospitals, on the other hand, sex workers were not only discriminated against and stigmatized, but also denied treatment, or given unsatisfactory care. They reported that medical staff made fun of them, commenting negatively upon their clothes or makeup. They also said that staff generally made them wait longer than other patients. For example, one public hospital had one line for “housewives” and another for sex workers. Clinic staff instructed sex workers to sit on one side: “Let these women from decent homes come first. They need to go back home in time. What is your hurry?” Furthermore, sex workers reported that medical staff typically advised them to terminate pregnancies on the grounds that they would set a bad example to their children.

Health care professionals recommended HIV testing for sex workers whenever they presented with a recurrent fever, tuberculosis, diarrhoea, or an STD. Although these are indicators used for HIV testing in the general community, any single episode of such an illness for sex workers was taken as suggestive of HIV infection. This attitude, sex workers in Mumbai alleged, stigmatized them and caused them stress. As one said, “Even before asking me what health problem I had, the doctor asked me, ‘Do you have AIDS? Go for an HIV test first.’” Physically weak and thin-looking sex workers were frequently singled out for such questioning in medical settings.

In one of the women’s hospitals in Mumbai, blood samples were taken without any explanation from every sex worker seeking treatment. When the women asked for their test results, staff explanations were unsatisfactory – “There is some mistake in the blood, don’t worry.” When HIV test results were given, there was no post-test counselling, and information was not given discreetly.

One peer educator who often accompanied sick sex workers to hospitals, described her experience: “The nurse just tells the *dhandewali* [sex worker] ‘You have



AIDS' without explaining whether it is HIV or AIDS. Getting admission for a sick woman is a major task. Each time I have to fight for a bed for a very sick woman, and their [hospital staff's] general attitude is one of prejudice."

Several sex workers reported that doctors tried to avoid touching them, and that when they were known to be HIV-positive, the situation became worse. Doctors refused to admit destitute and chronically ill sex workers, arguing that the unit could not function if they started "admitting everyone who comes." Of the three public hospitals close to Mumbai's red light area, only one was cited as providing adequate services to sex workers both in terms of admission and treatment.

Disclosure of HIV status to other sex-workers and to *gharwalis* (literally house owner, but in regard to sex workers, the woman who owns them because she has bought them for a price) was very rare. Reasons included fear of isolation, ostracism, loss of income, and destitution. The first reaction of most sex workers to a positive HIV test result was one of denial. Peer educators reported that they came to know about infected sex workers only when they started falling sick. The *gharwali* was feared most by HIV-positive sex workers since she controlled access to customers – their source of income. Nevertheless, it was reported that many *gharwalis* themselves wished to deny the reality of AIDS as a major health problem. One peer educator shared her experience:

*“The gharwalis generally get irritated when we mention HIV/AIDS. Many of them like to deny the problem, saying we are unnecessarily creating a fuss. They say things like, “We have been doing this business since British times. There has been no problem until now. Now you women come and keep talking to the girls, educating them about condoms and AIDS, and what not.” They feel we are creating unnecessary panic.”*

Much as the *gharwalis* liked to deny AIDS as a problem, they were being confronted with HIV-positive sex workers on a regular basis. Few were reported as displaying a supportive attitude.

*“When a gharwali learns of a girl's positive HIV report she asks her to keep quiet and lets her entertain customers, with or without condoms. Once the girl starts falling sick she sells her to another unsuspecting gharwali. If the girl becomes too sick she is given back her things and shown the door. The girl is then literally on the road. Sometimes the gharwali takes the girl to a bus or train going to any destination, gives her some pocket money and leaves her to her fate. The girl may or may not reach her village, but even if she does, discrimination at home often brings her back to Mumbai to die on the city streets – the life of a dog.”* (Peer educator)

Researchers were told that the sight of a sex worker dying on the streets was not unusual. This form of destitution was one of the worst fears among women in the sex trade. As one HIV-positive sex worker pointed out,

*“There is discrimination for us from all quarters. The staff of some organizations also call us AIDS wali [ones with AIDS]. If a sex worker goes from here to where she came from, and falls sick, she is suspected of having AIDS because in the minds of local doctors she has come from Bombay so this is what it must be. She is first labelled a “dhandewali” and then with the stamp of HIV.”*

Thus, sex workers with HIV/AIDS face double discrimination during the course of their working lives.

### Homosexually active and gay men

Gay and other homosexually active men are a marginalized and hidden population in Indian society. The few support groups that have been set up for them work secretly. Despite numerous attempts over several months, eliciting the voluntary participation of HIV-positive gay men in this study proved unsuccessful. In Mumbai, two gay groups – the Humsafar Trust and Udaan – were contacted. At the Humsafar Trust, a meeting was arranged during a festival party at which the aims of the research were explained and the participation of eligible members requested. Additionally, an appeal letter was put up on the notice board of the office for members to approach the principal investigator individually over the phone, but no one called. At Udaan, despite assurances given by its coordinator that cooperation would be forthcoming, meetings with potential respondents proved difficult. In Bangalore, the gay group Good as You and a group called SABRANG, which provides a meeting point for people of all sexual orientations who wish to promote individuals' right to choose their own sexuality, were approached. None of their members volunteered to participate in the study.

The following discussion is therefore based on interviews and conversations with two gay activists in Bangalore, and one gay activist and one social counsellor working with a gay support group in Mumbai. In addition, relevant information collected from two HIV-positive gay men in the course of an earlier study (Bharat, 1996) was also included. One HIV-positive gay man from that study participated in the current research to provide follow-up information about his experiences of discrimination in household and health care settings.

In both sites, HIV-positive gay men were hard to identify as a group or a community. According to one gay activist, once they discover they are HIV-positive, gay men tend to take on a heterosexual identity to escape being “found out.” Coping with two stigmatized identities – as a gay man and as HIV-positive – was understandably seen as difficult in a closed, homophobic society. As a 28-year-old HIV-positive gay man explained, there is a far greater stigma attached to homosexuality than to AIDS in India. “I dare not let my people know about my sexual identity. They won't accept it. So, I have only told them about my HIV-positive result.”

A gay activist in Mumbai confirmed this view. He told researchers that once a gay man discovered he was HIV-positive, he would stop coming to the counselling centre for gay men and would instead join a group for HIV-positive people, where typically he would conceal his gay identity. As health complications increased, so this seropositive identification intensified. "I used to party a lot ... was a favourite with senior men in the corporate world.... Now, no more. My own problems keep me away from such groups. I'm also more and more drawn towards positive people's group as I feel I now belong there" (HIV-positive man, aged 28).

In Bangalore too, gay HIV-positive men were a hidden population. One gay activist said, "In Bangalore I don't know a single person who is gay and who is HIV-positive. I don't think anyone can have any figures on this." This is an important issue. There are no statistics on gay HIV-positive men because gay men understandably do not disclose this information. Yet in Mumbai, there were indications of a high number of gay HIV-positive men, based on a recent survey and on the numbers of men who come for AIDS counselling but do not return after confirming their HIV status (Ashok Row Kavi, personal communication).

Social prejudices and attitudes offer an explanation as to why gay men act this way. On the whole, gay men in India are seen as "sexually deviant" and "perverted" individuals preoccupied by sex. No space is made for them in society, and talking about "gay identity" in public is extremely difficult. Gay men risk social ridicule and ostracism, fear rejection from family and violence and aggression from the police and the general community, and worry about losing their jobs. Society discriminates against gay men in terms of inheritance and benefit rights. On a personal level, it is extremely difficult for gay men to form long-term relationships because there is no support for or acknowledgement of these. Moreover, there are very few counsellors and NGOs to help when gay relationships break up. "In a heterosexual relationship ... there are so many mechanisms that keep it going. You have counsellors, you have family and ... to try to repair it. In the case of gay people there is no support like that" (gay activist in Bangalore).

Against this general background, gay men also find that the health care system is oriented towards providing services only to those who fit traditional definitions of sexuality. A gay men's counsellor reported that medical practitioners' questioning was highly offensive to gay men. STDs among men were generally presumed to be a result of sex with female sex workers. Thus, all STD patients were asked standard questions such as, "When did you last visit a woman?" or "How often have you been visiting women?" For gay men, doctors' assumptions that all men are heterosexual often resulted in difficulty. Because most doctors were unaware of or ignored the fact that many married men in India may also have sex with other men, issues of male-to-male sex tended to be overlooked.

This blindness to the existence of gay men has resulted in continuing ignorance among doctors about the gay STD profile. Gay men felt discouraged from consulting doctors in health care settings, especially in public hospitals. For them, discrimination, stigmatization, and denial began with the very first questions put to them by medical professionals.

## Hijras

For *hijras* (sometimes referred to as those of the “third gender,” previously known as “eunuchs”), discrimination and stigmatization stemmed mainly from attitudes to their sexuality. Those in the sex trade (some earn their living through begging) were also stigmatized for earning money via “unnatural sex.” AIDS only added to their sense of isolation and marginalization. In Mumbai, interviews took place with two *hijras* living with HIV/AIDS and a group of seven *hijras* (some of these were HIV-positive, but their status was not revealed to research staff). In Bangalore, interviews took place with a group of four *hijras* (serostatus unknown).

For *hijra* respondents, discrimination and stigmatization had started early in life. Some had been denied a normal childhood and education. As one 40-year-old put it, “I used to be made fun of by village children. I wanted to study. But the school head master told my father ‘Why are you sending your child to school? He’s not fit to study with other children. Take him home’” (HIV-positive *hijra* sex worker).

As they grew older, they learned to take these insults in their stride. Street life, they felt, was their only option, as they were denied jobs or stigmatized when they did manage to get one. “We have to live with our heads bowed. If we take up jobs people mock at us, we feel this work [sex work] suits us best” (HIV-positive *hijra*, aged 40). *Hijra* respondents told us that people had continually heaped abuse upon them. Anjum, a sex worker of 32, showed researchers her *paan*-stained sari on which some men had spat betel leaf paste that morning. She said, “These are common experiences for us.”

*Hijra* respondents reported that before they had tested HIV-positive, they did not have many problems in health care settings. Services were provided to them in private health clinics as well as in public hospitals like other patients, although they preferred private clinics as the doctors and other staff there were less likely to subject them to verbal abuse. But after being told their HIV status, they had found it difficult to access medical treatment.

*“I had a boil. Then I had problems with my tonsils. The doctor in the private clinic asked for several tests including the HIV test. He saw the HIV test report and said that he could not do the operation [on my tonsils] and asked me to go to a government hospital. He did not tell me what the report said. I took my papers to a government hospital where, on seeing my report, the doctor said no operation could be done and sent me away after prescribing some medicines. Now no doctor is willing to operate on me for tonsils. So I just take medicines from shops and suppress the problem.”* (HIV-positive *hijra*, aged 40)

Anjum’s experience as a peer educator in one NGO programme had been the same. HIV-positive *hijras*, she said, were denied surgery and interventions involving injections at government hospitals even when these had been previously recom-

mended. “‘You don’t need injections, you’ll be all right with tablets alone.’ This is what the doctors tell us if we go to them for treatment” (HIV-positive *hijra*, aged 32).

Injections were generally perceived as superior forms of treatment, quicker and more effective than oral medicines. But medical professionals reduced the use of injections to prevent any possible infection to themselves or other staff through needle scratches or punctures. Such actions were perceived as discriminatory by individuals, such as sex workers, who had become accustomed to having injections, especially for STDs. In small private clinics, injections were still available at a price. “The doctor asked me Rs 5 more for an injection [with a disposable syringe], or else he’ll boil the needle which he uses for all patients” (HIV-positive *hijra*, aged 40).

Anjum’s experience seeking hospital services for other HIV-positive *hijras* had made her depressed and anxious. Refusal to admit HIV-positive *hijras*, denial of invasive treatments, and poor care during hospitalization were among her experiences of discrimination in the health care sphere. Discrimination was likely after death too. Ambulance staff refused to carry the dead bodies of HIV-positive *hijras* or did so only for a higher fee. The plastic-covered body was a clear symbol of an AIDS death, it was said. The stigmatization was complete when the usual death rituals were not observed.

## CONCLUSIONS

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By examining responses to HIV and AIDS in two contrasting sites in India – Bangalore and Mumbai – it has been possible to identify some of the ways in which people with HIV/AIDS are stigmatized and discriminated against in different situations.

In both sites, significant levels of discrimination, both overt and covert, were identified in the health care setting. In an attempt to avoid having to provide care, health care staff passed patients from hospital to hospital. There was uncertainty among health care staff about basic HIV-transmission information and about the need for, and purpose of, universal precautions. Staff, particularly those with a secondary care role, held exaggerated fears about the infectiousness of HIV, which profoundly affected their ability to provide good care. No matter how miniscule the risk of infection, treatment interventions were often selected not on the basis of what was best for the patient, but on what would prevent any risk of infection whatsoever. Staff's negative views about people with HIV also affected the care provided. In sum, the study reveals a depressing picture of widespread labelling and stereotyping and lack of care throughout the health sector, with the possible exception of a small number of hospitals where good policies and practices have been established.

There was clear evidence that HIV/AIDS-related DSD in India is in some respects a gendered phenomenon. Issues such as inheritance, housing, and caregiving were found to be particularly fraught for women. Moreover, women were often blamed by their parents-in-law for infecting their husbands, or for not "controlling" their partners' urges to have sex with other women. The quality of care provided to women in the family was significantly poorer than the care provided to men. While a small number of cases were cited in which women had abandoned their husbands, more common was the neglect and maltreatment of women by husbands and parents-in-law.

Schools, the insurance business, and post-death services were also found to be contexts in which HIV/AIDS-related DSD could and did take place. Children of HIV-positive parents, whether positive or negative themselves, were often denied the right to go to school or were segregated from other children. Life insurance companies were not trusted by people with HIV, despite assurances that benefits would be paid if the policyholder had tested positive after taking out a policy. Concern was expressed by people with HIV that they faced harsher treatment from insurers than did people with other serious health conditions.

The treatment of the bodies of people who had died of HIV-related illnesses was another matter of serious concern to HIV-positive respondents. The practice in Mumbai of placing such bodies in black plastic bags was felt to be an affront to human dignity and an effective breach of confidentiality, making it very difficult to access good undertaker and funeral services. Concern was also expressed in both sites that traditional rites were no longer being administered to people who had died of HIV/AIDS-related conditions.

Detailed interviews with female sex workers, *hijras*, and gay men revealed the extent to which HIV/AIDS-related DSD can lead to double discrimination. People in these marginalized groups are stigmatized not only on the grounds of HIV status but also for being members of a socially denigrated group. Stigmatization for members of marginalized groups was also felt to be more severe, because the stigma arose from two sources: fear of HIV and fear or hatred of the group in question.

While fewer cases of overt HIV/AIDS-related DSD were identified in employment than in other settings, data suggest that many industries and businesses are in serious denial about the spread of the epidemic and its potential impact.

HIV/AIDS-related DSD generates numerous fears for people living with HIV. These include:

- fear of AIDS stigma (of being identified with “deviant,” “morally sinful” behaviour, mainly sexual promiscuity and visiting sex workers)
- fear of loss of reputation in the family and society
- fear of damaging the family’s social reputation
- fear that HIV serostatus will be revealed and of being identified as sexually deviant
- fear of social discrimination and isolation, of being avoided or shunned by others
- fear of being judged and categorized as a member of a “deviant” group such as promiscuous people and gay men
- fear of death and of dying early
- fear of dying uncared for, and being denied last rites
- fear of social ridicule
- fear of various illnesses and debilitating ill-health, of painful conditions, of not receiving medical attention, and of being denied admission to hospital
- fear of being deserted, of loss of significant relationships, and of loss of trust and confidence
- fear of losing one’s job or source of income
- fear of passing the infection to others, whether spouse, children, or other family members

## RECOMMENDATIONS

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The following recommendations seek to address many of the points made in this study and to establish the grounds for proper dialogue about how effectively to challenge HIV/AIDS-related DSD in India. Not only is HIV/AIDS-related DSD a scourge upon Indian society, it serves, we believe, as a badge of shame, bringing the reputations of basic social institutions into question. Discrimination, stigmatization, and denial must be dealt with if India is to effectively tackle its broader crisis of possibly 3.7 million HIV infections. Failure to act now, this research would suggest, will have the severest consequences.

In order to reduce levels of discrimination, stigmatization, and denial associated with HIV/AIDS in India, a number of interrelated actions are needed.

### ***AMONG PEOPLE LIVING WITH HIV/AIDS***

- People living with HIV/AIDS need to be better educated about their rights as patients and about how to get help to challenge the discrimination and stigmatization they face in health care settings.
- People living with HIV/AIDS need legal education and access to the justice system to address the violation of their rights in the context of employment and education.
- A more enabling environment needs to be created to increase the visibility of people with HIV/AIDS and to facilitate the formation of support groups so that discrimination, stigmatization, and denial can be challenged collectively.

### ***FOR MEMBERS OF MARGINALIZED GROUPS***

- The further social marginalization of members of infected minority groups will only intensify the spread of HIV infection. It is therefore imperative to act to protect the rights of minority group members and address their needs specifically so they are not overlooked in more generic approaches to reducing HIV/AIDS-related DSD.
- The stigmatization of women who are the wives of HIV-positive men or who are pregnant must be given special attention in relation to testing, pregnancy, abortion, and breastfeeding. Discrimination in the form of early discharge from, or denial of, services on grounds of gender must be strongly challenged.



**IN THE HEALTH CARE SECTOR**

- Within the health care system, the concept of universal precautions needs to be promoted and the irrational and selective use of inappropriate “safety measures” reduced. The latter not only create a false sense of security among health care workers, but also adversely affect the emotional health of HIV patients.
- Human rights principles of informed consent and confidentiality need to be more widely adhered to in medical practice so that health care staff and professionals do not violate patients’ rights to informed choice, privacy, and counselling.
- Newer concepts and labels such as “barrier nursing” or “immune-compromised patient” are becoming synonymous with HIV/AIDS and hence serve the same function as the label “AIDS.” These concepts need to be used for all types of infections without revealing the nature of infection to staff involved in providing care.
- There is an urgent need to extend awareness among health care staff concerning their legal duties and responsibilities towards patients in general, and patients with HIV/AIDS in particular.
- Necessary protective gear, including good-quality gloves, must be supplied in adequate quantities to all staff in government hospitals so that the non-availability of such items is not used as an excuse to deny care to HIV-positive patients.
- Mandatory testing must be strongly discouraged for individuals, including pregnant women, regardless of what treatment (invasive or otherwise) they seek, as it often leads to denial of services to those found to be HIV-positive.
- Counselling services must be made available in all health facilities to provide for the psychosocial needs of HIV-positive patients.
- To help individuals who wish to learn of their HIV status without the fear of disclosure to others, voluntary testing accompanied by counselling must be provided in all cities and districts.
- Lack of adequate AIDS education can give rise to irrational fears and inappropriate care practices. Hospital staff at all levels need access to appropriate HIV/AIDS education. No medical institution should be allowed to withhold or limit HIV/AIDS education to any groups of staff.
- HIV testing should not be carried out without the informed consent of the patient and without pre- and post-test counselling. Treatment and care must be provided following positive test results.
- Above all, in order to reduce levels of discrimination within the health care sector, it is important to challenge beliefs about casual modes of HIV transmission and address the diffuse and irrational sense of personal risk among ancillary staff.

### ***ANTI-DISCRIMINATION LEGISLATION AND OTHER LEGAL MEASURES***

- Legislation is needed to reduce discrimination and stigmatization of PLHA in all areas, but particularly in relation to health care and employment.
- An effective complaints mechanism should be put in place in the health care sector for HIV-positive people to seek protection of their rights as patients.
- Fear-based AIDS messages and biased social attitudes towards infected people urgently need to be tackled, as fear and prejudice lie at the core of DSD.
- It is not enough to raise awareness about HIV/AIDS, its transmission routes, or even about legal rights. What is urgently needed is anti-discrimination policy supported by a law that will ensure the protection of HIV-positive people's rights.

### ***OTHER***

- The employment sector must develop policy guidelines on AIDS to help and support HIV-positive workers. HIV testing, when beginning a job or as part of routine medical check-ups for existing staff, must be strongly discouraged, as such tests prevent individuals from earning a living, and can lead to social isolation and rejection for those found to be HIV-positive.
- Childcare institutions must not be allowed to transfer responsibility for care and protection of HIV-infected children to other institutions. Existing institutions must add special facilities to provide all necessary care and treatment to infected and sick children.
- Life insurance policies must be expanded in appropriate ways to address the needs of HIV-positive people desiring insurance cover, and efforts must be made to dispel misconceptions and fears about claims to existing insurance policies.
- Research on drug trials or any aspect of HIV patients' lives within the health care sector may be conducted only after the informed consent of the patient is secured.

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The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.

Discrimination, stigmatization and denial have been recognized as important issues to be addressed in the context of HIV/AIDS. Discrimination against those living with HIV/AIDS, or presumed to be infected, is a violation of human rights. All individuals deserve equal respect and dignity, whatever their situation and whatever their health status.

This *Key Material* describes the findings from a study of the nature, determinants and effects of HIV/AIDS-related discrimination, stigmatization and denial in India. The findings demonstrate the profound consequences of these negative processes for the individuals, families and communities involved. Programmatic and policy issues are also highlighted.



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