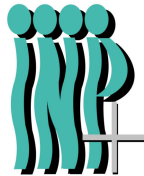


# HIV Testing Barriers and Facilitators among Populations at-risk in Chennai, India

[A Qualitative Study among Men who have Sex with Men, Injecting Drug Users, Aravanis/Transwomen, and Sex Workers]

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INDIAN NETWORK  
FOR PEOPLE LIVING  
WITH HIV/AIDS

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## **Acronyms and Abbreviations**

- AIDS** – Acquired immunodeficiency syndrome
- APCASO** – Asia Pacific Council of AIDS Service Organizations
- ARV** – Antiretrovirals
- ART** – Antiretroviral therapy or treatment
- CBO** – Community-based organization
- FGD** – Focus Group Discussion
- FSW** – Female Sex Workers
- HBC** – Hepatitis-C Virus
- HBV** – Hepatitis-B Virus
- HIV** – Human Immunodeficiency Virus
- ICTC** – Integrated Counseling and Testing Centres
- IDU** – Injecting Drug User
- INP** – Indian Network for People living with HIV
- KII** – Key informant in-depth Interview
- MSM** – Men who have sex with men
- NACO** – National AIDS Control Organization
- NGO** – Nongovernmental organization
- PLHIV** – People living with HIV
- SWAM** - Social Welfare Association for Men
- TNSACS** – Tamil Nadu State AIDS Control Society
- VCTC** – Voluntary Counseling and Testing Centre

## EXECUTIVE SUMMARY

### ***Study purpose***

This qualitative study explored barriers and facilitators to knowing one's HIV status among marginalized populations - men who have sex with men (MSM), Hijras/Aravanis (Transwomen), female sex workers (FSW), and injecting drug users (IDUs) in Chennai, India.

### ***Methodology***

Participants were recruited through voluntary organizations in Chennai. Twelve focus groups (n=84 participants) and 12 key informant interviews were conducted, audiotaped and transcribed. Narrative thematic analysis and a constant comparative method were used to identify themes.

### ***Key findings***

Findings revealed barriers at multiple intersecting levels and contexts. At the individual level, the primary barriers were: fear of adverse consequences if diagnosed as HIV-positive; fear of inability to cope with a positive HIV test result; precedence given to drug use (among IDUs); not being convinced of the benefits of knowing one's HIV status; and low HIV risk perception. At the health care system level, discrimination from providers, unfriendly administrative procedures, long waiting time, and the need to come back to collect test results acted as deterrents. The program, policy and legal barriers include presence of criminal laws against the marginalized groups, inability to follow up with clients because of lack of effective coordination among voluntary organizations, inconsistent funding support for HIV prevention programs, and lack of media campaigns that reach out and appeal to marginalized groups.

### ***Key Recommendations***

- Launch social marketing campaigns to promote HIV testing among marginalized groups
- Address psychological barriers to HIV testing in outreach education & counseling
- Educate about various benefits of knowing one's HIV status
- Ensure that available HIV counseling/testing services are of high quality
- Provide a range of HIV tests (including urine-/saliva-based) with same-day test results
- Reduce stigma/discrimination through public educational programs
- Support establishment of 'community-based HIV counseling and testing centers' run by voluntary agencies

## I. INTRODUCTION

Knowing one's HIV status has myriad health benefits. If one is found to be HIV-positive, this serves as an entry point for regular health screening for early diagnosis of any opportunistic illness and availability of antiretrovirals (anti-HIV medications) to improve the quality and duration of life; it also facilitates early diagnosis of HIV in sexual and needle-sharing partners. Importantly, persons who know their HIV status are also more likely to adopt safer sex and / or safer drug using behaviors. HIV counseling and testing also may motivate HIV-negative people to remain negative and adopt safer behaviors.

Despite the benefits of knowing one's HIV status, it has been estimated that only about 25-30% of people living with HIV in India know their HIV status (NACO, 2007a). There is no information about what proportion of people from marginalized populations such as men who have sex with men (MSM), Hijras/Aravanis (Transwomen), female sex workers (FSWs), and injecting drug users (IDUs) are among people living with HIV who know their HIV status. Experiences from other parts of the world suggest marginalized communities are less likely to access HIV testing services and know their HIV status than the general population (Obermeyer & Osborn, 2007; Ford et al., 2004).

In Tamil Nadu, a southern state in India, currently there are 730 Integrated HIV Counseling and Testing Centers (ICTCs, previously known as voluntary counseling and testing centers or VCTCs), more than 50% of which were formerly serving only as prevention-of-parent-to-child-transmission (PPTCT) counseling centers in government hospitals (Government of Tamil Nadu, 2006). The current client load ranges from 2 to 20 per day per centre (TNSACS, 2007). Most of these clients are referred by health care providers to be tested for HIV and belong to the 'general population'. Similar scenarios exist in other states in India. This led National AIDS Control Organization (NACO), India, recently to articulate that there is a need to increase the number of individuals from 'core high risk groups' (term used by NACO) utilizing government HIV testing centers since a very small proportion of ICTC's clients are from these populations. NACO says, "There are subpopulations which are more vulnerable or practice high risk behavior and HIV prevalence levels are generally higher in them. These subpopulations are the target group for [HIV] counseling and testing services in the country." (NACO, 2007b)

In 2006 alone, through its 718 ICTCs, Tamil Nadu State AIDS Control Society (TNSACS) had tested over one million people (NACO, 2007c). No data is available on what proportion of these people tested in ICTCs are from the marginalized populations (MSM, Aravanis, FSW, and IDUs) but likely to be relatively lower. This lack of subpopulation-specific data on HIV testing utilization from government HIV testing centers is unfortunate given the high HIV prevalence among these marginalized populations (MSM–6.4%; and IDUs–18%) as found in the 2005 HIV sentinel serosurveillance of the Tamil Nadu government (Tamil Nadu government, 2006). (Note: No government HIV serosurveillance data is available for Aravanis and FSWs in Tamil Nadu).

Limited quantitative investigations have documented self-reported HIV testing rates among marginalized populations in Tamil Nadu. In a survey conducted in 2004 among MSM (n=200) in Chennai, about 60% had ever been tested for HIV (Woodford et al., 2007). National Behavioral Sentinel Surveillance (BSS-II) estimated that the percentage of people who ever had tested for HIV among MSM (n=270) and IDUs (n=268) in Chennai, Tamil Nadu were 43% and 22.3%, respectively (NACO, 2006a). Though similar data is not available for FSWs in Chennai, the aggregate percentage of FSWs (n=270) in Tamil Nadu and Puducherry estimated to have ever been tested for HIV was 19.3% (NACO, 2006b). Thus, in general, HIV testing uptake rates are relatively low among marginalized populations at-risk for HIV in Tamil Nadu.

In order to develop strategies to promote voluntary HIV testing among marginalized populations such as MSM, Hijras, FSWs and IDUs, it is crucial to understand the various barriers to and facilitators for HIV testing from the perspectives of these populations. Thus, the ***purpose*** of this study was to explore and understand the barriers and facilitators of knowing one's HIV status - including utilization of government HIV counseling and testing centers - among the marginalized populations such as MSM, Hijras, FSWs, and IDUs in Chennai.

When designing this study and analyzing the findings, we conceptualized that apart from 'individual-level' factors (such as HIV-related knowledge and risk perception) that influence one's decision to undergo HIV testing, other contextual factors – including access to and utilization of health care services, quality of health care services, social and peer norms, extent of stigma/discrimination faced by people living with HIV or marginalized groups, and criminal laws – could also influence one's decision to undergo HIV testing (Bond & Batson, 2005; Chakrapani et al., 2004, 2007a & 2007b; Sumartojo, 2000; Latkin and Knowlton, 2005).



## II. RESEARCH METHODOLOGY

This qualitative study was implemented with active collaboration of community-based and non-governmental organizations in Chennai, a metropolitan city in the state of Tamil Nadu, India. Prolonged engagement (Lincoln & Guba, 1985) over the course of several years on the part of the research team with these agencies and the populations they serve greatly facilitated study implementation and interpretation of the findings.

The study groups included men who have sex with men (MSM), female sex workers (FSWs), injecting drug users (IDUs), and *Aravanis* (local Tamil language term for transwomen). The common eligibility criteria were being 18 years of age or older, and ability to give informed consent.

Purposive sampling was used to recruit the study participants for focus groups. All recruitment was conducted only by word of mouth in order to avoid potential risks to participants. Sociodemographic questions were asked of all focus group participants. These included questions about age, level of education, occupation, marital status, and living arrangements.

Twelve focus groups, three among each of the four marginalized groups (MSM, Aravanis, IDUs and FSWs) were conducted. Twelve key informants were interviewed, three representing each of the four marginalized groups. Key informants were community leaders, health care providers, directors of the NGOs/CBOs, and program managers of AIDS funding agencies in Tamil Nadu.

Focus group venues were chosen according to the convenience of participants and the safety of participants and research staff. Focus groups were conducted in a private room in the offices of NGOs/CBOs working with these marginalized groups or in a private room of INP+ office. No focus groups were conducted in cruising sites or sex sites, owing to risks to participants and staff. Written informed consent was obtained from all participants, including consent for audiotaping of the interview. This study received approval from the Ethics Review Board of University of Toronto, Canada, and the Community Advisory Board of INP+.

Focus groups and key informant interviews were conducted using a semistructured in-depth interview guide in Tamil with scripted probes. Questions were modified or added over the course of the study in an iterative process to explore and reflect on emerging findings, a technique called progressive focusing (Schutt, 2004). Focus groups facilitators and interviewers were native Tamil-language speakers who received extensive training in interviewing and research ethics. All interviews and communications with participants were conducted in Tamil.

The duration of focus groups ranged from 60 to 120 minutes and key informants interviews approximately 60 minutes. As recommended by INP's community advisory board, an honorarium of 250 Indian rupees (7 American dollars) was given to the study participants who attended focus groups. Key informants did not receive honoraria. Interviews were tape-recorded and transcribed verbatim in Tamil and translated into English for data analysis.

Multiple readings of the transcripts were performed by two independent investigators. Line-by-line review of the transcripts was conducted and first-level codes (descriptors of important components of the focus groups and interviews), including in vivo codes, were noted in the margins (Charmaz, 2006; Glaser, 1978). Next, text corresponding to each of the first-level codes was reviewed by at least two investigators. Using focused coding and a constant comparative method (Charmaz, 2006; Glaser & Strauss, 1967), first-level codes were refined and organized into categories. Finally, theoretical coding was undertaken to identify higher level

codes, relationships among categories, and to ensure saturation of categories (Charmaz, 2006). Member checking was conducted with key informants to increase credibility of the findings (Lincoln & Guba, 1985). Peer debriefing (Lincoln & Guba, 1985) was undertaken with community leaders to increase trustworthiness of the findings. The results correspond to the emergent categories; all quotations are drawn from the focus groups and key informant interviews.

### III. KEY FINDINGS

In this section, we present individual-level barriers; barriers in the health care system; barriers in counseling and testing; and program, policy and legal barriers. It is important to note that there is significant overlap and interaction among the various levels of barriers, as we describe in the discussion section.

#### **Characteristics of the FGD participants**

A total of 84 people participated in the 12 focus groups, 3 within each of the 4 subpopulations.

Among MSM (n=26), ages ranged from 20 to 49 years, with a mean of 32.03 years. About 62% (n=16) had completed high school and 27% (n=7) had completed an undergraduate degree. Nearly half (46%; n=12) were working for a voluntary organization. About two-thirds (62%; n=16) were never married. Eighty-one percent (n=21) engaged in sex work at least part-time during the last one year prior to the date of focus group. Eighty-five percent (n=22) had undergone HIV testing within the 6 months prior to the date of the focus group.

The age of FSWs (n=19) ranged from 22 to 48 years, with a mean of 32.57 years. About one-fourth (21%; n=4) had completed high school. More than two-thirds (74%; n=14) were married. Sixty-eight percent (n=13) of them had undergone HIV testing during the 6 months prior to the date of the focus group.

Among IDUs (n=18), ages ranged from 31 to 48 years, with a mean of 38 years. Thirty-three percent (n=6) had completed high school. Thirty-nine percent (n=7) were working for a voluntary organization and about one-third (n=6) were unemployed. Sixty-one percent (n=11) were married. Seventy-two percent (n=13) had undergone HIV testing during the 6 months prior to the date of the focus group.

Among the transwomen (n=21), ages ranged from 18 to 43 years, with a mean of 27.28 years. Thirty-eight percent (n=8) mentioned 'kai thatturathu' (a Tamil language term that literally means 'clapping hands') as their main source of income. The term refers to the whole process of Aravanis asking money and materials from going shop-to-shop and clapping their hands in a distinct style. Thirty-eight percent (n=8) had completed graduate course. Of those who had completed graduation (n=8), four mentioned 'kai thatturathu' as their main occupation. Almost all study participants engaged in sex work in addition to working in community-based organizations. Thus, even Aravanis who are graduates engaged in 'kai thatturathu' and sex work, presumably because of denial of jobs in the mainstream society. Seventeen (81%) had undergone HIV testing during the 6 months prior to the date of the focus group.

#### **Where do people at-risk from marginalized communities go for HIV testing in Chennai?**

In Chennai, marginalized groups have several options to know their HIV status. In Chennai, there are more than 40 government-supported 'Integrated Counseling and Testing Centres' (ICTCs) (NACO, 2007d). HIV testing facilities are available in government medical college hospitals; a famous TB hospital that treats large number of people living with HIV; STI/HIV screening/treatment facilities run by some NGOs and CBOs; Chennai municipal corporation hospitals; and private clinics and laboratories. HIV testing are available free of charge in government hospitals and for nil or nominal charges in some NGOs and CBOs.

People who are reached out to by NGOs/CBOs working among marginalized groups are usually of lower socioeconomic background and unable to afford payment for HIV testing in private clinics/labs. Often outreach workers or peer educators from NGOs/CBOs refer or accompany

them to government hospitals or NGO/CBO-run clinics for HIV testing. Most often, outreach workers refer or accompany people to the major teaching government hospitals because they are rated better than other government HIV testing centers. Also, many NGOs/CBOs over the years have established good rapport with the health care providers in the teaching government hospitals and some of these hospitals house professional and peer counselors from NGOs/CBOs in their STI/HIV testing facilities. However, some people may prefer to get tested in private clinics – as reported by some of the study participants – since they are afraid of loss of anonymity and confidentiality if they go to government or NGO/CBO-run HIV testing sites.

## **A. BARRIERS THAT PREVENT PEOPLE FROM UNDERGOING HIV ANTIBODY TESTING**

### ***INDIVIDUAL-LEVEL BARRIERS TO HIV TESTING***

#### **1. Fear of adverse consequences if found to be HIV-positive**

A major theme that emerged from the focus groups as well key informant interviews was the fear of adverse consequences of being diagnosed as HIV-positive. This was the most common theme across all the subgroups.

For IDUs living with their family members (parents or spouse), the consequences of being diagnosed as HIV-positive could be possible eviction from the house (if they had not already been evicted), and consequent loss of financial, and sometimes emotional, support available to them. Though their family members might have had 'tolerated' their being IDUs, IDU participants mentioned that their family members could no longer take it if they also become HIV-positive. Especially if IDUs are financially dependent on their family members or spouse (since money is needed to buy drugs) then IDUs would not even think about knowing their HIV status. For married MSM as well as married IDUs expressed fear of rejection by their spouse if they are known to be HIV-positive. Thus, marital discord and wife leaving them was another reason that deterred them from going for HIV testing.

Those FSWs who are living with their husband expressed fear of having to face domestic violence if their HIV-positive status and consequently their involvement in sex work came to be known to their husband who would not have otherwise known about it. Also, FSWs expressed that their children would not respect them if their HIV status is known to them since they would be seen as 'immoral' - though they engaged in sex work primarily to support their children. Loss of reputation, shame, and thus not able to face their friends, relatives and family members were other reasons cited by all the subgroups excluding Hijras (who usually do not live with their family members – being evicted or ran away from their home at an early age).

Another major reason was the fear of discrimination from their community members. For example, Kothi-identified MSM were afraid of being rejected by their own kothi friends if found to be HIV-positive. They did not want to lose the psychosocial support they get from their Kothi friends which is not available from any other people – even from their own family members. Similarly, IDUs were afraid of rejection by their drug-using friends circle if they are found to be HIV-positive. FSWs and MSM/Hijras in sex work were afraid of losing their male clients to other sex workers since others would reveal their HIV status and consequently that would affect their income from sex work.

***Fear of rejection from friends and family members if found to be HIV-positive***

'If they [Kothis] are found to be HIV-positive, they are also afraid that other kothis would stop talking to them. Also...afraid of their family members.' (A kothi-identified MSM in a FGD)

***Fear of loss of income and discrimination from other community people***

'Let us take an example. Three of us, who are commercial sex workers, live together. Suppose I am tested HIV-positive. My [aravani] friends will come to know. Then they would say to my 'customer' that she has HIV; don't go to her. Then naturally no one will come. So, Aravanis don't go for test. Discrimination prevails within the [aravani] community itself.' (An aravani in a FGD)

**2. Fear of not being able to cope with a positive HIV test result**

For some people the fear of knowing one is HIV-positive with certainty was worse than living with uncertainty or ignorance in regard to their HIV status. Some felt that fear of whether they could cope with an HIV-positive diagnosis prevented them from going for HIV testing. This was especially when they have no or limited psychosocial support from other people. Also, some convinced themselves that they must be already HIV-positive and thus there is no need to go for HIV testing. However, it seems that even in these people there is a fear of confirming their belief – to know for sure - that they might be already HIV-positive.

***Do not want 'mental torture'***

'[Kothis] want to live happily without 'mental torture' [English term as used]. So they don't prefer [HIV] testing.' (A key informant who is a kothi community leader)

***What is the benefit in knowing?***

'If they [IDUs] are found to be [HIV] positive then acceptance [from society] will not be there. In case if they are positive they [IDUs] do not have the strength to bear it. "Why should we know that through testing? Leave us. We don't want to know" - they will say like that.' (A former drug user in a FGD)

**3. No perceived benefits of finding out that one is HIV-positive**

Some IDUs are not convinced or could not see the benefits of knowing one's HIV status. It seems that they are not well-informed about the effectiveness of antiretroviral therapy since some mentioned that if they are already HIV-positive then anyway they would eventually die – because of HIV itself or because of overdose or other drug-related complications. Hence they see no point in knowing their HIV status now. Some IDUs felt that the current antiretroviral treatment (ART) regimens given in government hospitals are not suitable for HIV-positive IDUs since they have seen many complications faced by HIV-positive IDUs after they started taking those regimens. They reasoned that since the liver of HIV-positive IDUs might have already been damaged by alcohol abuse and co-infections with Hepatitis-B and –C viruses, ART regimens that contain drugs that could damage liver (such as nevirapine) – could further worsen the condition of IDUs. Thus, the lack of appropriate treatment for IDUs and lack of treatment for associated alcohol dependence and Hepatitis co-infections, apparently prevent many IDUs from knowing their HIV status.

In addition, some people from all subgroups have witnessed the discrimination faced by people living with HIV and how they had been isolated from the social circle of even their own communities. Thus, the perceived lack of psychosocial support from their own community members as well their family members is another reason that prevent people from knowing their HIV status.

***No one will help in the 'last stage'***

'There is a man near my house - HIV-positive. No... I am not tested yet. He went to an 'NGO' [non-governmental organization] asking for help – when he became very ill. Last news - Nobody bothered about him. When it is like this, how will I go for test? At the last stage he is not getting help from any place. So others [IDUs] are scared. What is the use of testing for me? When he is in such a stage what guarantee that I will be helped.' (A 'recovering' IDU in a FGD)

**4. IDUs give precedence to drug use and not to health/HIV**

Former drug users mentioned that current drug users are mainly obsessed with their thinking about how to get drugs, where to get money to buy drugs, and how to get prevent or get rid of 'turkey' and withdrawal symptoms. Hence their concern is not to take care of themselves and protect their health. Knowing their HIV status is not their priority though they might know very well about HIV and even aware about of their risk of contracting it. This observation of many ex-users made them to argue for the need to immediately link the current drug users to "detox" (drug dependence treatment) programs rather than enrolling them in needle syringe supply programs or even oral (sublingual) buprenorphine therapy.

***Will be thinking about getting drugs only***

'Because his [IDU] first priority is in drugs, he needs to find money. He will not think of anything else. ...First he has to come out of drugs. Only [then] he will go voluntarily for [HIV] testing.' (A former drug user in a FGD)

**5. Lack of supportive social and peer norms for HIV testing**

In general, though basic knowledge about HIV/AIDS seems to be present in the society, often people who are known to have undergone HIV testing are looked down upon by society since they are then seen as or suspected to be immoral and "bad". For example, a FSW mentioned how she felt bad when one of her neighbors – a lady friend of hers – told her by pointing to a billboard advertisement on HIV, "It [HIV] comes to those who are bad in character – you know?" This negative attitude from her neighbour acted as an additional barrier to even consider going for HIV testing. Similarly, the fear of being seen by others (family members, relatives or friends) when they go to HIV testing centers prevented many people from going to HIV testing centers that are nearby their residential or working places.

Though some FSWs and MSM/Hijras in sex work would like to know their HIV status, the fear of being labeled as 'HIV-positive' by the other sex workers - even if one just go for HIV testing - prevented many from testing themselves. They were afraid that such rumours will affect their income since clients will not come to them.

### ***Fear of being seen by neighbors***

'What if our neighbors see us there [in the government hospital where they go for HIV testing]? Some others might see. So, I don't go.' (A FSW in a FGD)

'Now, general hospital is there. There will be a board outside...It will be written *HIV testing centre*. Near that other centers will be there. Those who have come for going to other centers will be sitting there...four people belonging to the same area could also be there. Then you know what one among the four will do... He will enter into the 'VCTC'. If the other three see this person entering into that center they will go and tell that news in their area. ...news becomes 'public'.' (A former IDU in a FGD)

### ***Fear of possible spread of false rumors by own community people***

'If I go to GH [government hospital] for 'HIV test', other kothis who come there might see me. Then, *that's all*. They will go all over Chennai and tell I have [HIV]. So we are afraid to go to GH.' (A kothi-identified MSM in a FGD)

## **6. Denial of risk and low HIV risk perception**

While in general, participants mentioned that these days many people (including those from marginalized groups) have good knowledge about HIV and understand the risk of contracting HIV, IDU participants felt that there are still some IDUs who deny any risk of contracting HIV. For example, a FGD participant said that he knew of one IDU who would say, "It will not come to me. I look very healthy and I share with my friends who are healthy-looking". In other subgroups, this reason was not mentioned and denied even if questioned about this possibility.

## **7. Lack of correct knowledge about STIs/HIV**

Participants mentioned that some people from marginalized groups still do not have adequate knowledge about STI/HIV. Often these are people who are: not reached by NGOs/CBOs; not attached to their respective communities; and not attending educational/training programs organized by the NGOs/CBOs. Some also do not have adequate knowledge to recognize STI-related symptoms and they misattribute such symptoms to having eaten beef or having drunk too much alcohol. Consequently they are unlikely to go for HIV testing.

## **HEALTH CARE SYSTEM BARRIERS TO HIV TESTING**

### **1. Health care provider attitude and discrimination**

Though in some government hospitals, the attitude of health care providers are considered positive by the study participants and key informants, several incidents of discrimination in some centers against people from various marginalized groups were narrated. Having had prior negative experiences and having heard from people who had faced discrimination in the government health care system act as a strong deterrent for some people to go to government HIV testing centers.

### ***Breach of confidentiality***

'When we go for getting [HIV] test result, they ask us to wait saying that it would take only a very little time. Then they would not reveal the result in an indirect way. In front of the others they will say that I am positive and ask me to come later. All these acts hurt us. The doctors treat us like this way.' (A FSW in a FGD) (Mentioning that sometimes test results are revealed by doctors in

STI clinic, not by counselors, without proper post-test counseling)

***Looked down by health care providers***

'In hospital they look at us differently when they come to know that we are [MSM] - they mock at us ... When they also come to know that I [engage in] sex work they share gestures among themselves and laugh. But in 'NGO' [provider] ask questions without hurting us.' (A kothi-identified MSM who engages in sex work)

***Not getting consent before 'showing them' to medical interns***

'The worst thing is we will be made to stand nude... and all trainee doctors will be invited to see the [lesions] we have... They won't ask us our permission. Do you think I will ask others to go to [government hospital] after this?' (A kothi-identified MSM) [Talking about the physical examination in the government STI clinic before referring them for HIV testing]

***Providers use harsh language***

'When we go there [STI clinic], they ask us to show our body parts [genitalia]. If we hesitate they hurt us by saying, 'Why do you feel shy here? You didn't [feel shy] when you had sex?' (An aravani in a FGD)

**2. Location of HIV testing centers**

Many people preferred to go to HIV testing centers that are far away from their residential or working places so that their acquaintances do not see them entering HIV testing centers. However, if the HIV testing center is too far, that also posed problem in terms of not being able to afford the travel fare as well as the longer time it takes to reach the site.

***If center is closer to residence then risk of being seen by acquaintances***

'An acquaintance of me had seen me crying there [STI clinic] and informed my family about my visit to that [STI] department. My brother questioned me ... I wished to have a place where there would be confidentiality, reliability, hygiene....' (A kothi-identified MSM in a FGD)

**3. Restricted service hours in government hospitals**

All government hospitals in Chennai close their outpatient services by noon. People who are daily-wage laborers find it difficult to find time to go to these clinics as they are worried about loss of daily-wages if they must come in the morning hours. Sex workers, who work mainly at night, also find it difficult to come during the morning hours. Thus, limited duration and lack of convenient timing for marginalized groups create obstacles to HIV testing at government hospitals.

***Restricted service hours***

'I had to take 3 buses to come to GH. By the time I reached it was 11'O clock and they asked me to come the next day.' (A kothi-identified MSM in a FGD)



#### **4. Registration and navigation difficulties in major government hospitals**

For people who are unfamiliar with the bureaucratic procedures of registering as outpatients and navigation inside the major government teaching hospitals, visiting those hospitals on their own may be a nightmare. Many expect and need the outreach workers of NGOs/CBOs to accompany them, in addition to demanding that they pay for travel expenses and provide snacks during their visit to the HIV/STI testing center. This may be because knowing their HIV status is not seen as personally beneficial but more as a responsibility of the NGOs/CBOs since they receive funds to work among these communities. Aravanis expressed particular concern that even those Aravanis in saris (traditional attire for women in Tamil Nadu) are registered as males and asked to stand in the line for males, which is humiliating to them and invite snide remarks from other patients. Aravanis want to be recognized and registered as woman.

Lack of a visible reception area and friendly reception staff, and lack of clear signposts directing people to respective departments inside the hospital prevent many from going to major government hospitals alone or, even if they had visited once, from visiting again (which has specific implications for whether people come back to get their HIV test results). While some participants complained about lack of clear signposts, some participants were worried about the implications of entering buildings that are clearly labeled as 'STD department' or 'voluntary [HIV] counseling and testing'. They were afraid they might be seen by others known to them when they enter these buildings and later questioned about why they were there. They suggested removal of name-boards and red ribbon logos (that shows those buildings to be associated with HIV/AIDS).

#### ***Problems for Aravanis starts from registration and there is no end***

'We are questioned as to in what gender should we be enrolled while getting the OP [outpatient] slip, while standing in the queue. When we say that we are 'ladies' [English term] and stand in the queue for women, other women look at us in a disapproving manner. [Then] when we go inside the clinic ... the doctor would sign others to go out and check us. He would seriously instruct us and ask us to give blood for test. He would call again and now 10 to 15 people [medical interns] would surround us, to whom we would be instructed to show our organs again. So, right from the beginning till the end, we face embarrassment. So we go to private hospitals.' (An Aravani in a FGD)

#### ***Roaming around***

'[From the STI clinic] we are asked to go to the new building for [HIV] testing. Then, we would be asked to go to some other place for urine and other tests. This makes us feel that we should not have come: instead of roaming like that we can better die.' (A FSW in a FGD)

#### **5. Waiting time for counseling / testing and getting test result**

Since government hospitals have a huge patient load there is usually a long waiting time for getting registered; seen by a doctor; counseled by a professional counselor; giving blood for testing; and getting drugs for STI treatment. Thus, for people who have never visited government hospitals and even those who have visited previously, the very thought of having to wait for long hours prevents them from coming for HIV testing or coming back to collect their HIV test result. Typically, HIV test results are supposed to be collected after about three to five days. Participants expressed their concern about the anxiety experienced by some people while they wait for their HIV test result. They argued that if the test results are given on the same day, that anxiety would be reduced and they would also know their result without having to come back again, also avoiding loss of additional daily wages.

***Takes a whole day to complete all the procedures***

‘It takes one full day to get [HIV] testing done. Then we are asked to come after four days. We have to wait there for more than one to two hours to get the [HIV] test result.’ (A FSW in a FGD)

***Test result not given on the scheduled date***

‘They [hospital staff] make us come again and again. How many times can we do so? It takes one week for us to get the [HIV test] result. They ignore us. They don’t give the result immediately fixing a separate date for that. So, we lose interest in going again [to get the test result]. (A FSW in a FGD)

***Need for same-day HIV testing method***

‘It is good if the test result is given on the same day. They need not come again.’ (A key informant who is a kothi community leader)

***BARRIERS RELATED TO COUNSELING AND TESTING***

***1. Counselors: Competency & Sensitivity***

In general, over the years, peer educators among the FGD participants have witnessed a relative improvement in the counseling offered to marginalized groups. However, they reported that there are still counselors who are ignorant about conducting competent risk assessment among marginalized groups in a sensitive and nonjudgemental manner, and who have limited skills in providing appropriate risk reduction counseling.

Participants complained that some counselors do not even ask questions about same-sex behavior to MSM if they are apparently masculine-looking (thus pass as ‘heterosexuals’) or even if they are ‘obviously feminine’. However, some counselors asked curious or irrelevant questions that were hurtful to participants. For example, asking MSM about why they are having sex with men when they themselves are men, and asking FSWs in an insensitive manner/ tone about why they could not leave sex work and how much they earn through sex work. Such experiences prevent some from accepting HIV testing or from coming back to get HIV test results. Similarly since injecting drug use is not asked about as a routine practice, often IDUs who go for counseling have to report their injecting drug use behavior on their own.

Participants also complained about not having both male and female counselors in many government HIV testing centers. They also expressed that it would be better if they have access to a peer/community counselor in at least selected government HIV testing centers since that might increase HIV testing uptake by the marginalized groups. Lack of open dialogue with the professional counselors at VCTCs was another reason cited for the need for community/peer counselors.

***Breach of confidentiality and lack of privacy***

‘Some [counselors] don’t tell anything in private when we go to [government] hospital. They reveal things immediately in the public. They embarrass us saying in front of others – “You have this disease [HIV], what are you going to do?”...’ (A FSW in a FGD)

***Using insensitive language offends clients***

‘Some [counselors] ask questions in a vulgar manner. They don’t ask us about our feelings or

try to find out what is in our mind. Instead, they make us feel bad. They ignore our feelings. Then, can we go there again for blood test? No. So, you see we don't even go there to collect the blood test report because of the way they have spoken to us.' (An aravani in a FGD)

## **2. Rapid HIV antibody screening tests: Knowledge & Availability**

Many participants have heard the English term 'ELISA' for HIV test. Some even mentioned western blot and some have undergone it. However, very few participants have undergone, or even heard about, rapid blood-based HIV screening tests. People who have taken those tests have invariably taken them in private clinics or labs – with results given to them in an hour or so, even before they go to doctors. However, participants also reported that some of these private centers did not give them proper pre-test counseling and results were given directly to the patient without any counseling or follow-up.

Blood-based HIV tests are widely available. However, they have their own disadvantages: the need for venipuncture (sometimes more than once); serum separation; storage in fridge; and at least a day to give test results. In some countries non-blood-based HIV tests are widely available. These include HIV testing based on saliva and urine. When asked about whether they knew about any HIV tests that are not blood-based, many FGD participants just blinked and shook their hands. When we asked whether they have heard about HIV testing using urine and saliva, many could not control their laughter thinking that it was meant to be a joke. When explained that one's urine and saliva can be tested for HIV, people expressed surprise as well as enthusiasm regarding the availability of such tests. However, as some participants pointed out there is a need to educate the public that presence of HIV antibodies are tested in the urine/saliva and the test does not detect viruses in saliva and urine. It is important to stress that information since otherwise people might erroneously assume that if HIV testing can be done on urine and saliva then HIV must be present in them and there is a risk of getting HIV from coming into contact with urine/saliva.

Participants noted several advantages of urine- and saliva-based tests: more people will come forward since non-invasive; results available immediately; specimens can be given on the 'field' itself to outreach workers; and no need to travel to clinics/VCTCs. IDUs expressed that these tests can be made available through mobile vans that could visit the drug users' sites.

### ***Freedom from 'prick'***

'I would bring everyone in my family for [HIV] testing if these tests [urine or saliva-based HIV tests] tests are introduced instead of getting pricked here and there.' (A FSW in a FGD)

### ***Why they would prefer non-blood based HIV tests?***

A group of MSM in a FGD, when talking about why they would prefer saliva- or urine-based HIV testing:

- 'Spitting is easier than giving blood.'
- 'Blood is essential for our strength whereas saliva and urine are not like that; they are "waste".'
- 'Many fear at the thought of giving blood. Needle [disposable] requires money. So this saliva method would be better.'

## **PROGRAM, POLICY AND LEGAL BARRIERS**

### **1. Criminal laws against marginalized groups and HIV testing**

In India, being a same-sex attracted male, Hijra, sex worker or injecting drug user is not criminal. However, current laws that criminalize people who have non-vaginal penetrative sex, who 'solicit' a person for having sex for money, and who carry drugs on their person - all effectively criminalize groups of people who engage in these behaviors. Thus, acknowledging that one is engaging in these behaviors to a third person takes a considerable amount of courage and involves a degree of risk.

The negative consequences of being exposed in the media if one is found to be HIV-positive was one of the reasons expressed by some female sex workers. While it may sound naïve, since photos of female sex workers are routinely published in leading local and regional newspapers after they are 'caught red-handed' by the police, the rationale behind FSW's fear of being outed in the media is not hard to understand. Similarly, police in civilian clothes who almost ambush IDUs who come to needle syringe programs or drop-in centers discourage IDUs from visiting these places; consequently HIV prevention activities and referrals for HIV testing suffer. While interruption of outreach activities by the police on 'beats' has reportedly decreased in general, new police officers who come to those beats may suspect that outreach workers are actually drug peddlers or sex workers. Consequently, they pose problems to outreach workers and interrupt their outreach educational activities on HIV prevention.

A key informant also mentioned that when an IDU is locked up in a police station or sent to prison, withdrawal symptoms are not treated and there is no referral to drug dependence treatment, oral substitution therapy or provision of voluntary HIV counseling and testing inside prisons. IDUs are treated as criminals and not seen as people who require understanding, compassion and assistance in dealing with drug dependence.

Another key informant opined that presence of criminal laws against MSM, Hijras, IDUs and sex workers were likely to influence the attitudes of health care providers, which is then expressed - as prejudice and blatant discrimination against people from those communities.

#### ***FSWs afraid of their photos released in media***

'Some don't come forward for [HIV] testing to [government] hospital as they are afraid that their photos would be flashed in newspapers and TV.' (A FSW in a FGD)

### **2. Lack of effective coordination and linkages among various programs and services**

Key informants explained that although there are many NGOs/CBOs working with marginalized groups in Chennai, there is a lack of coordination and collaboration among these agencies. Different viewpoints of the funding agencies as well as the leaders of these NGOs/CBOs also seem to impact HIV testing. For example, among NGOs working with IDUs, the viewpoint on whether 'harm reduction' (seen as merely needle syringe supply programs and sublingual buprenorphine substitution therapy) or "detox" (i.e., drug dependence treatment) should be supported prevents service providers from seeing the need for a range of services and the need to establish effective referral linkages to HIV testing centers.

NACO (Ministry of Health) is supporting needle syringe supply programs and the Ministry of Social Justice and Empowerment (MSJE) is supporting 'detox'/rehabilitation programs for drug users. This means that these vertical programs have different priorities and there are currently

no effective linkages among these services at the ground level. Thus, there is a missed opportunity for HIV testing among IDUs in the detox and rehabilitation programs of MSJE.

[Note: Recently, NACO and MSJE are trying to establish better linkages: UNODC website states that 100 MSJE de-addiction centers have an additional fieldworker supported by NACO (<http://ncdap.nisd.gov.in/map/map8.html>) and NACO website lists its plan for 'mainstreaming HIV' into several ministries including MSJE ([http://www.nacoonline.org/Partnerships/Ministries\\_and\\_Departments/](http://www.nacoonline.org/Partnerships/Ministries_and_Departments/))].

### **3. Government policy restricting appointment of peer counselors in government HIV testing centers**

The current policy of NACO to appoint only counselors with post-graduate degrees was criticized by key informants. They pointed out that trained peer counselors from the respective marginalized communities are best suited to conduct sensitive and competent risk assessment and risk-reduction counseling for marginalized groups. Key informants as well as FGD participants expressed their willingness to have peer counselors in at least the major HIV testing centers frequented by the marginalized groups and that this would increase uptake of HIV testing among marginalized groups.

#### ***Lack of peer counselors in government hospitals***

A former IDU when talking about how a counselor who was a former drug user provided him quality and sensitive counseling:

'In one hospital, an NGO has placed peer counselors [former drug users]...They give good counseling... We listened to them with interest...They discussed with us in an understanding manner...and give good counseling...But government is not employing peers [in HIV testing centers].'

### **4. Allocation of specific areas to NGOs/CBOs working with marginalized groups**

As there are many NGOs serving marginalized groups in Chennai, funding agencies have divided Chennai into various zones, with NGOs 'allocated' to particular zones. Nevertheless, 'territorial disputes' may occur. Key informants suggested that though in principle this system seems efficient, it makes it difficult for the NGOs/CBOs to keep track of their clients who 'migrate' across territories. For example, an IDU who has just given blood for HIV testing may move to another area (e.g., if there are problems with police due to using drugs in the streets in that area) before he collects the test result. In another area, he might be approached by an outreach worker from another agency and asked to be tested again, and he may not resist because of the monetary incentive that comes with HIV testing. Thus, territorial demarcation may effectively prevent follow-up of clients who were motivated by outreach workers to have HIV testing or who have already given blood for HIV testing. Also, there is 'duplication' of services (the client is tested in two different sites) and thus duplication of the number of IDUs tested and possible inaccuracy in relation to HIV prevalence data among IDUs in Chennai.

### **5. Funding agency policies to support HIV testing in STI clinics run by NGOs**

Some NGOs are supported by funding agencies for running STI clinics for marginalized groups but HIV testing is not supported in those clinics. After requests from the marginalized groups as well as considering the logic that it would be better to offer HIV testing when people periodically come for STI screening/treatment, certain NGOs have begun to offer HIV testing in those STI clinics, mobilizing funds from other sources. Thus, funding agencies who support STI clinics for marginalized populations should also consider supporting HIV counseling and testing services in those clinics since that would be cost-effective (a 'one stop-shop') and beneficial to the marginalized communities.

## **6. Erratic fund disbursement and abrupt cessation of funds from funding agencies**

Funding agencies (including government agencies) abrupt termination of HIV prevention projects was seen by key informants as another major impediment for sustaining HIV preventive behaviors among marginalized groups. Delays in receiving funds as well as abrupt cessation of funding were seen as wasting the efforts of NGOs since it makes it difficult to sustain preventive outreach education and HIV testing referrals. This shows the need to assist NGOs/CBOs in preparing a plan to manage delays in getting funds and in developing sustainability plans to enable continuation of services even if funding stops abruptly. Such mechanisms need to be built in from the beginning of prevention projects.

## **7. Government IEC/Mass media campaigns**

In discussing mass media HIV testing campaigns of NACO (such as the 'know your status' campaign) and that of local government agencies (such as bill board advertisements about HIV testing), key informants and FGD participants were quick to point out that people from marginalized groups are not explicitly targeted in these campaigns. They argued that these campaigns primarily reach out to educated urban residents who are from the 'general population'. Participants expressed that one-to-one communication with the marginalized communities about HIV testing is more likely to be effective than such mass media campaigns. If the latter is necessary, they suggested finding out innovative ways of reaching out to the groups at-risk without increasing the stigma associated with those groups.

## **8. Why some people do not return to get their HIV test results?**

There are several reasons that people who give blood for HIV testing do not come back to collect their results. One important possibility suggested by participants was that the fear of negative or unknown consequences of knowing their HIV status might have overridden their initial intention to know their HIV status. Other practical problems expressed by some persons were lack of time or not being able to get 'leave' to come back and collect results, though some saw these as just 'excuses'. Also, the experience of the bureaucracy in the government health care settings, long waiting times, and loss of wages for daily-wage earners (or people having a small business) prevented people from coming back to get their results. Participants mentioned that if the test result could be given on the same-day (within a few hours) it would enable many people to collect the result during a single visit. Decreasing the anxiety in waiting for the test result was another reason given by the participants to give the test results on the same day.

### ***Fear of being diagnosed as HIV-positive***

'IDUs are not interested to go back to the [government] hospital to get the result. They hesitate. They are afraid that the result might be positive and they might be infected. They don't want to go.' (A key informant who is a NGO service provider for IDUs)

## **B. FACILITATORS OF HIV TESTING**

In spite of the so many barriers, many people do undergo HIV testing, some even on a periodical basis. What can we learn from those who have undergone HIV testing?

### **1. Accurate knowledge about HIV testing**

Sound knowledge seems to be an essential component of the need to undergo HIV testing.

While participants mentioned having heard or seen HIV-related messages in the mass media, one-to-one communication between people from the marginalized communities and outreach worker/peer educator was indicated as a significant factor that enhances HIV knowledge among these populations. Outreach workers provided information that went beyond the basics of HIV/AIDS. They also included information about: why one should get tested for HIV?; what are

the benefits in knowing one's HIV status?; and what are the treatment facilities that are available even if one is found to be HIV-positive?

Participants who have undergone HIV testing (irrespective of their HIV status) articulated the benefits of early diagnosis of HIV-positive status and also had good knowledge about antiretroviral therapy. Participants also expressed that they trust peer outreach workers that their information would be kept confidentially – which also encouraged them in going for HIV testing.

### ***Knowledge and overcoming fear***

'They advertise about this [HIV] in [news]papers, and announce about AIDS in bus stand - places where we roam around; and we hear [about HIV] from our office [community organization]. Seeing and hearing those messages we have overcome our fear and feel that we should maintain good health and go for [HIV] testing.' (A FSW in a FGD)

## **2. Accurate risk perceptions**

Knowledge alone, however, does not seem to be sufficient. There also is a need for accurate risk perception. Among the participants who have gone for HIV testing were people who have had multiple sex partners and used condoms inconsistently; people victimized by forced sex from ruffians or policemen; and people who experienced symptoms suggestive of STI/HIV disease. All among these who went for HIV testing realized their risks for contracting HIV.

### ***Wants to undergo HIV testing after condom breakage***

'In case the condom gets worn out during sex, I go for [HIV] testing after two days - out of fear. I do not want to get [HIV] germ and spoil my health.' (A FSW in a FGD)

### ***HIV-positive status of needle-sharing partner motivates one to undergo HIV testing***

'Then he [person with whom one shared needle] will say - I went for a testing, they said I have it [HIV]. Then the [other] person will think ... I have also done it [shared needles] with him. So let me go and do it [undergo HIV testing]. That is also one reason. Some will not go...Some people will boldly go. That boldness will not come to everyone.' (A former IDU in a FGD)

## **3. Overcoming systemic barriers**

How are the system barriers faced in the government health care settings overcome? Outreach workers usually accompany people from key populations – thus saving them from the trouble of having to roam around the government hospital with apparently no one to guide them where they have to go. Also, many times the travel fare for HIV or STI testing/treatment are borne by the NGOs/CBOs – making it accessible for people from marginalized groups with poor economic backgrounds. IDUs are usually told that they will be given monetary incentives if they are willing to go for HIV testing. Some participants and key informants were against giving monetary incentives for HIV testing since they believed it to decrease self-motivation and thus might not result in changing risky behaviors. However, other participants suggested that though they initially went for HIV testing only to get the monetary incentive, after they received counseling they did change their risky sexual and drug-use related practices. Participants from FSWs and MSM/Hijra communities also mentioned having received monetary or non-monetary incentives from certain NGOs for undergoing STI and HIV screening/treatment.

**Reasons given by some participants for why they prefer NGO-run STI clinics or HIV testing centers over government settings**

**Privacy assured**

'In private hospitals and 'NGO' there will be a separate room..... in which there will be only one doctor and we can frankly speak.' (A kothi-identified MSM in a FGD) [Participant was comparing this with the scenario in the government hospitals where there is no privacy, and where many medical students come and see the patients who have STI lesions - without getting the explicit consent of the patients.]

**Good non-clinical atmosphere**

'In [non-governmental organization] people from different communities come there. There are chances to mingle with them. They have some games for us. We can take part in those games. So, we can talk to them. It actually gives us confidence and so we don't want to go anywhere else.' (An aravani in a FGD)

**Presence of Community-friendly health care providers**

'We will prefer [name of an NGO-run STI clinic]. Our community people will go there. Because the doctor there co-operates well. He will not behave like a doctor but like a friend... Trained counselors would be there.' (A kothi-identified MSM in a FGD)

**4. Drug treatment, recovery and support**

Ex-drug users mentioned that only after they recovered from drug use did they become concerned about their health and want to know their HIV status. They reasoned that since now they are not under the influence of drugs they could think rationally and are thus concerned about their health and their responsibility to protect their sexual partners/spouse. Thus health-seeking behavior and responsibility to protect their sexual partners seems to come to IDUs who have recovered or who are under drug-dependence treatment programs. Some IDUs were willing to undergo HIV testing if their spouse or drug-sharing friends seemed supportive of their decision to undergo HIV testing or if they felt they would not be rejected even if they are found to be HIV-positive.

**5. Knowing someone who is HIV positive**

Another common theme expressed by participants from all subgroups is, if they knew someone who is HIV-positive it motivated them to undergo HIV testing. In the case of FSWs or MSM/Hijras in sex work, if they knew that there are some HIV-positive sex workers in their 'field' and their clients overlap, then they wanted to know their HIV status. Even for those who are not engaging in sex work, having seen their own friends die of HIV-related illness or having seen a person living with HIV as a positive role model motivated many to undergo HIV testing.

'But now they [Aravanis] are aware of "HIV / AIDS". So they would come for test automatically. Because when they see, they develop fear. Even yesterday people saw the death of a person who had HIV. So, naturally people [aravanis] develop fear and they would come.'  
(An aravani in a FGD)

**6. Characteristics of an ideal HIV testing center**

When asked what should be the characteristics of an ideal HIV testing center for their communities, participants and key informants listed the following:



- Friendly atmosphere in the testing center.
- Friendly staff (at all levels – doctors, counselors, and lab/clinic assistants) who have adequate knowledge and skills to deal with various marginalized groups.
- Confidentiality of client information – especially HIV status – is guaranteed.
- Convenient timings so that they are able to drop-in at a time that is suitable for them.
- Effective referral linkages with treatment, care and support services if diagnosed HIV-positive.
- Assistance in explaining to spouse/sexual partners about their HIV risk and motivating them to undergo HIV testing.

## 7. Repeat testing

While some people do not want to get tested for HIV even a single time, there are some others who have undergone HIV testing more than once or even do it periodically. The reasons behind repeating testing are diverse. For example, if they have engaged in HIV-related risk behavior within the last three months, then during counseling they are told about the ‘window period’ (during which HIV tests may not detect HIV infection in the body) and they are asked to come back after three months for repeat testing. Sex workers (women in sex work or MSM/Hijras who engage in sex work) periodically encounter male clients who do not want to use condoms or experience non-consensual/forced sex with ruffians and policemen who do not use condoms. Thus, this ongoing risk makes sex workers undergo HIV/STI testing repeatedly since they see this ‘repeat testing’ as an investment to maintain their health, thus maintaining their ability to earn a living.

For some others, especially expressed by MSM, repeat testing may become almost a ritual to just check whether safer sex behaviors adopted by them are working. Sometimes they are not sure whether their partners used condoms or threw away when they turned their back. Condom breakage also makes some MSM go for repeat testing.

<b>Tab Column-1: HIV Testing Barriers and Facilitators among marginalized groups (Based on study findings)</b>		
<b>Level</b>	<b>Barriers</b>	<b>Facilitators</b>
<b>A. Individual-level</b>	Fear of adverse consequences if found to be HIV-positive (rejection, stigma and discrimination)  Fear of not being able to cope with a positive HIV test result  No perceived benefits of finding out that one is HIV-positive  Low perceived HIV risk  Lack of correct knowledge about HIV/STIs  Primacy of drug use renders health/HIV a low priority	Accurate knowledge about HIV testing  Accurate HIV risk perceptions  Knowing someone who is HIV positive  Willingness to undergo drug dependence treatment, and rehabilitation

<b>B. Health Care Systems level</b>		
<b>Administrative procedures &amp; infrastructure</b>	<p>Registration difficulties (especially transwomen) and lack of continuum of care among services in major government hospitals</p> <p>Perceived (or actual) lack of privacy and confidentiality</p> <p>Restricted service hours in government hospitals</p>	<p>Friendly environment in NGO-/CBO-run HIV testing centers</p> <p>Privacy and confidentiality assured</p>
<b>Health care staff</b>	<p>Perceived (and experienced) discrimination from doctors and counselors</p> <p>Perceived incompetence and discrimination on the part of lab technicians in taking blood from IDUs for HIV testing</p>	<p>Sensitive, competent and non-discriminatory health care providers</p> <p>Peers (former drug users) assist in withdrawing blood from IDUs</p>
<b>HIV antibody testing</b>	<p>Prolonged waiting time for counseling and testing</p> <p>Lack of knowledge and availability of rapid HIV antibody screening tests</p> <p>Lack of same-day test results</p>	<p>Peer referrals to labs that offer rapid HIV testing</p>
<b>C. Community-level</b>		
<b>Peer norms</b>	<p>Lack of supportive social and peer norms for HIV testing</p>	<p>Supportive peer norms for HIV testing (e.g., among transgender women)</p> <p>Peers accompany people to HIV testing centers</p>
<b>Visibility of people living with HIV</b>		<p>High visibility of people living with HIV among marginalized groups</p>

<b>D. Program, Policy and Legal</b>		
	<p>Criminal laws against marginalized groups</p> <p>Lack of effective coordination and linkages among various services (such as drug dependence treatment) and HIV testing</p> <p>Government policy restricting appointment of peer counselors in government HIV testing centers</p> <p>Certain funding agencies' support NGOs for running STI clinics but not HIV testing in those clinics.</p> <p>Erratic fund disbursement and abrupt cessation of funds from funding agencies</p> <p>Government IEC/mass media campaigns only target the "general public"</p>	(No supportive policies were explicitly stated or identified)

#### IV. DISCUSSION

This study identified various barriers and facilitators to HIV testing among four marginalized groups – men who have sex with men, Aravanis/transwomen, female sex workers and injecting drug users.

Though the findings have been presented as analytically distinct, in reality there is considerable interaction among the various levels of barriers and facilitators – sometimes obvious and sometimes not so. For example, it is understandable that provider discrimination at HIV testing centers may deter people from going there because of fear of discrimination. Provider discrimination in turn happens because of ignorance, prejudice and misconceptions about marginalized groups. Similarly the apparently individual-level barrier of fear of adverse consequences of being diagnosed as HIV-positive, a predominant theme that emerged across all marginalized groups, is in turn related to perceived and actual stigma and discrimination faced by people living with HIV and marginalized groups in Indian society – an important structural barrier. *Hence, blaming the individual for not going for HIV testing is both inaccurate and counterproductive: we must focus on the various contextual factors that influence an individual's decision as to whether or not to undergo HIV testing.* Simultaneously, we need to focus on how to eliminate or reduce the various contextual factors that lead individuals not to get tested and know their HIV status.

At the individual level, fear of negative consequences of being diagnosed as HIV-positive needs to be explicitly asked and addressed – by appropriate service providers, such as outreach workers, HIV testing counselors, and doctors. Some researchers have come to a similar conclusion and emphasized that one should focus on ‘hopes and fears’ during one-to-one interactions (of outreach workers or counselors) and also stress the need to introduce a module on ‘hopes and fears’ to train service providers (Downing et al., 2001). This focus acknowledges the reality of fear underlying HIV testing for most people and helps to mitigate these barriers by addressing them at the outset.

At the system level, in general, doctors and counselors lack the necessary sensitivity and competence to deal with the issues experienced and expressed by these marginalized groups. Thus, there is a need to provide training to health care providers to inculcate a better and unbiased understanding of marginalized groups and also to make them competent in providing quality counseling services tailored to individuals from those groups. This means there is a need to explicitly train health care providers on sexuality, gender identity, human rights, and substance abuse. Staff training alone may not be sufficient. It is also important that the testing site atmosphere and infrastructure provide real assurances of privacy and confidentiality to the clients. While prolonged waiting times for getting things done in government hospitals may reflect the tardiness in the government working culture, it may be also due to the lack of adequate number of trained staff and necessary administrative infrastructure. Thus, ameliorating these systemic barriers could benefit all of the public who make use of government health facilities.

Several barriers at the program, policy and legal levels were identified that directly or indirectly affect HIV testing uptake among marginalized groups. The presence of laws that effectively criminalize the individuals belonging to these marginalized groups results in: interruption of HIV outreach education; fostering negative attitude and justifying discrimination from health care providers; and prevents people from revealing their risky behaviors that are considered criminal. Consequently these laws influence HIV testing uptake among marginalized groups. *Narrowly focusing on promoting HIV testing among these marginalized populations – thinking only in*

*terms of HIV prevention — is unlikely to be effective without addressing these criminal laws that affect the lives of marginalized groups and violate their rights.*

At the program level, lack of partnerships among NGOs serving marginalized groups in the same city, erratic supply of funds or abrupt cessation of funds with no prior sustainability plan drastically affects the momentum built by the NGOs/CBOs to promote HIV preventive behaviors (including promoting HIV testing) among marginalized groups. Additionally, Indian government's policy (at the time of this publication) that prevents posting a trained peer counselor in government HIV testing centers – on the premise of the need for a post-graduate degree – needs to be relaxed given the strong recommendation of the key informants and study participants based on their broad experience and unique insights on what works best for their communities.

### *Limitations*

As a qualitative study, the primary aim was not to generalize the study findings, but rather to explore in depth the unique perspectives and lived experiences of persons from various marginalized communities in terms of HIV testing. All study participants were recruited through NGOs/CBOs that work with marginalized communities. Association of the study participants with NGOs/CBOs could account for the sound knowledge among them about HIV and the benefits of undergoing HIV testing. Since the clientele of the NGOs/CBOs are people from lower socioeconomic background and lower educational status, one cannot 'transfer' the findings to marginalized people from relatively good economic or educational background. Additionally, these NGOs/CBOs were predominantly reaching out to specific subgroups within marginalized populations. However, participants were ideally positioned to identify barriers to HIV testing given their hands-on knowledge of persons from various marginalized populations, including those at highest risk for HIV infection and with the greatest need for being tested. The venue-based strategy is also a benefit in that it represents a connection to the various subpopulations that will enable recommendations to be implemented in an effective manner.

A related limitation is that we may not have captured all the diversity in the barriers to HIV testing among various subgroups of these marginalized communities. For example, because of the nature of clientele of the NGOs/CBOs working with MSM, our study participants were predominantly Kothi- or Doubledecker-identified MSM. We could not recruit gay- or bisexual-identified MSM. Similarly, female sex workers who are reached by NGOs/CBOs and who participated in the focus groups were predominantly street-based sex workers – many of whom are living with their husband and children. Thus the barriers faced by other subgroups of female sex workers (such as 'high class' sex workers who are not street-based or others who operate through internet advertisements) could not be identified. Thus, when interpreting these findings one should understand that the study has mainly captured the experiences of specific subgroups of marginalized communities: Kothi- or Doubledecker-identified MSM; Street-based female sex workers; Aravani-identified transwomen; and current/former IDUs who used/use injectable drugs in isolated areas. Nevertheless, participants from these subgroups had numerous insightful and reality-based suggestions that may inform programs and policies to increase acceptability, accessibility and uptake of HIV testing among persons from marginalized communities. Their perspectives are previously lacking in many programs and policies presumably designed to reach these communities as well as many programs that seem to deny their very existence.

## V. RECOMMENDATIONS

### **1. Implement social marketing programs of HIV testing for marginalized groups**

Design and implement innovative mass media and targeted messages in native languages that reach out and appeal to marginalized groups. Such social marketing messages need to 'normalize' and promote HIV testing as socially acceptable behavior leading to supportive social and peer norms on HIV testing.

### **2. Address psychological barriers to HIV testing**

Fear of adverse consequences of positive HIV test results prevents many from undergoing HIV testing. Hence, outreach workers, doctors and counselors should gain competence in eliciting and providing tailored counseling to address the various psychological barriers to undergoing HIV testing and returning to get test results. Health care providers and counselors should specifically address fears that clients may have and also impart hope in the case that they may be found to be HIV-positive.

### **3. Provide education about the various benefits of knowing one's HIV status**

In addition to raising awareness about HIV-related risk behaviors, the various social and medical benefits of early HIV diagnosis need to be stressed in HIV testing mass media campaigns and prevention/counseling messages of outreach workers, counselors and doctors. Knowledge about the benefits and availability of treatment and support services for people living with HIV may facilitate people's decision to have an HIV test.

### **4. Ensure availability of quality HIV counseling and testing services**

Ensure that HIV testing centers are friendly and that health care providers offer competent, non-judgemental, non-discriminatory and quality counseling and testing services to people from various marginalized communities.

### **5. Provide a range of HIV testing options with same-day test results**

Provide a range of HIV testing options, including blood-based rapid HIV antibody screening tests, urine- and saliva-based HIV antibody tests so that people are motivated to undergo testing as they may know their HIV status with same-day test results and benefit from the non-invasive nature of the newer HIV tests.

(Note: If urine- and saliva-based HIV antibody screening tests are introduced, it is necessary to educate the public that these tests *detect antibodies* in urine/saliva but that there is no risk of *transmission* of HIV from saliva or urine.)

### **6. Appoint peer/community counselors in addition to professional counselors**

In addition to professional counselors, in selected VCTCs, appoint trained peer/community counselors to promote HIV testing uptake among marginalized groups.

### **7. Implement programs to reduce stigma and discrimination**

Educational programs should be implemented that target the general public to reduce stigma associated with HIV/AIDS, drug use, and sex work as well as educate them not to discriminate against MSM, Hijras, female sex workers, IDUs, and people living with HIV.

### **8. Pilot test confidential mobile HIV counseling and testing centers**

The use of mobile health vans to reach out to marginalized groups (especially IDUs) and providing confidential HIV antibody screening tests at the outreach sites can promote HIV testing. This strategy should be pilot-tested and adapted according to the local context. People who are tested also have to be linked with other services, such as needle syringe supply

programs, sublingual buprenorphine substitution therapy, and drug-dependence treatment programs.

**9. Establish ‘community-based VCTCs’ run by NGOs/CBOs**

Voluntary HIV counseling and testing centers run by some NGOs/CBOs working with the marginalized groups are recognized as successful models. Funding agencies should support NGOs/CBOs to enable the establishment of these ‘community-based VCTCs’.

**10. Identify missed opportunities and ensure linkages to HIV testing**

Wherever possible, facilities offering services for marginalized groups need to refer people to HIV testing centers or to establish HIV testing centers within their premises. For example, drug dependence treatment centers can either refer recovering IDUs to HIV testing or establish VCTC within their own centers.

## VI. REFERENCES

- Bond, L., Lauby, J., & Batson, H. (2005). HIV testing and the role of individual- and structural-level barriers and facilitators. *AIDS Care. Feb; 17 (2): 125 – 40.*
- Chakrapani, V., Babu, P., Ebenezer, T. (2004). Hijras in sex work face discrimination in the Indian health-care system. *Research for Sex Work. 7: 12-14.*
- Chakrapani, V., Newman, P.A., Mhaprolkar, H., and Kavi, A.R. (2007a). Sexual and Social Networks of men who have sex with men (MSM) and Hijras in India: A qualitative study. The Humsafar Trust, Mumbai, India.
- Chakrapani, V., Newman, P., Shunmugam, M., McLuckie, A. & Melwin, F. (2007b). Structural violence against Kothi-identified men who have sex with men in Chennai, India: A qualitative investigation. *AIDS Educ Prev. 19(4):346–64.*
- Charmaz, K., 2006. Constructing grounded theory: A practical guide through qualitative analysis. London: Sage.
- Downing, M., Knight, K., Reiss, T.H., Vernon, K., Mulia, N., Ferreboeuf, M., Carroll, A., & Vu, C. (2001). Drug users talk about HIV testing: motivating and deterring factors. *AIDS Care. 13(5): 561-77.*
- Ford, K., Wirawan, D.N., Sumantera, G.M., Sawitri, A.A., & Stahre, M. (2004). Voluntary HIV testing, disclosure, and stigma among injection drug users in Bali, Indonesia. *AIDS Educ Prev. 16(6):487– 98.*
- Glaser, B. (1978). Theoretical Sensitivity. Mill Valley, California: Sociology Press.
- Glaser, B.G., & Strauss, A.L. (1967). The Discovery of Grounded Theory: Strategies for Qualitative Research. New York: Aldine de Gruyter.
- Government of Tamil Nadu (2006). Performance Budget. Retrieved February 25, 2008, from [http://www.tn.gov.in/policynotes/archives/policy2006-07/performance\\_budget/pb\\_health.pdf](http://www.tn.gov.in/policynotes/archives/policy2006-07/performance_budget/pb_health.pdf).
- Latkin, C.A., & Knowlton, A.R. (2005). Micro-social structural approaches to HIV prevention: a social ecological perspective. *AIDS Care. 17 Suppl 1:S102-13.*
- Lincoln, Y.S., & Guba, E. (1985). Naturalistic enquiry. Newbury Park, CA: Sage.
- National AIDS Control Organization (2006a). National Behavioural Surveillance Survey (BSS). Men who have Sex with Men (MSM) and Injecting Drug Users (IDUs).
- National AIDS Control Organization (2006b). National Behavioural Surveillance Survey (BSS). Female Sex Workers (FSWs) and their Clients.
- National AIDS Control Organization (2007a). Operational guidelines for Integrated Counseling and Testing Centers. Retrieved February 20, 2008, from <http://www.nacoonline.org/upload/Final%20Publications/Operational%20Guidelines%20for%20Integrated%20Counseling%20and%20Testing%20Centres.pdf>
- National AIDS Control Organization (2007b). NACO News. Vol III; Issue 1. Jan - Mar 2007.
- National AIDS Control Organization (2007c). NACO News. Retrieved March 15, 2008, from <http://www.nacoonline.org/upload/naco%20newsletters/Vol.III%20Issue%203%20-%20Jul.-sep.%202007.pdf> Vol III; Issue 3: July-Sep, 2007. p-13.
- National AIDS Control Organization (2007d). Integrated Counseling and Testing Centers. Retrieved February 15, 2008, from <http://www.nacoonline.org/upload/Documents/ICTCs.pdf>
- Obermeyer C.M., & Osborn, M. (2007). The utilization of testing and counseling for HIV: a review of the social and behavioral evidence. *Am J Public Health. 97(10):1762-74.*



Sumartojo, E. (2000). Structural factors in HIV prevention: concepts, examples, and implications for research. *AIDS. 14 Suppl 1: S3 - 10.*

Tamil Nadu State AIDS Control Society (TNSACS). State project implementation plan [based on NACP-3]. 2007.

Woodford, M.R., Newman, P.A., Kakinami, L., and Chakrapani, V. (2008). To Be Tested or Not? HIV Testing Behaviors among Men Who Have Sex with Men (MSM) in Chennai, India: Implications for Prevention Programming. Society for Social Work and Research. Research That Matters (January 17 - 20, 2008).

## VII. GLOSSARY

### ***Hijras / Aravanis***

Hijras are biological/anatomical males who reject their 'masculine' identity in due course of time to identify either as women, or "not-men", or "in-between man and woman", or "neither man nor woman". Thus they can be considered to come under the international umbrella term 'transgender (male-to-female) people'. Hijras in Tamil Nadu are called as 'Aravanis'.

*(Adapted from the research report: Chakrapani, V., Newman, P.A., Mhaprolkar, H., and Kavi, A.R., Sexual and Social Networks of men who have sex with men (MSM) and Hijras in India: A qualitative study. The Humsafar Trust, Mumbai, India. April 2007.)*

### ***Integrated Counselling and testing Center (ICTC)***

An integrated counselling and testing centre is a place where a person is counselled and tested for HIV, on his own free will or as advised by a medical provider.

The main functions of an ICTC include:

- Early detection of HIV.
- Provision of basic information on modes of transmission and prevention of HIV/AIDS for promoting behavioural change and reducing vulnerability.
- Link people with other HIV prevention, care and treatment services.

*(Adapted from: 'Operational Guidelines for Integrated Counselling and Testing Centres'. NACO, 2007)*

### ***Injecting Drug User (IDU)***

In this report, a broad definition of 'IDUs' has been used to cover people who have injected experimentally or continue to inject occasionally up to and including heavily dependent drug users who may inject several times each day. IDUs may inject legal or illegal drugs, stimulants (such as amphetamines and cocaine), depressants (such as heroin and benzodiazepines) or other drugs such as steroids. They may inject intramuscularly (into the muscle) or intravenously (into the vein).

*(Adapted from the definitions of the WHO and UNODC:  
<http://www.cdc.gov/outreach/who/Glossary.pdf>; [http://www.unodc.org/pdf/report\\_2000-11-30\\_1.pdf](http://www.unodc.org/pdf/report_2000-11-30_1.pdf))*

### ***Men who have Sex with Men (MSM)***

This term is used to denote all men who have sex with other men, regardless of their sexual identity or sexual orientation. This is because a man may have sex with other men but still considers himself to be a heterosexual or may not have any particular sexual identity at all. This, basically an epidemiological term, coined by public health experts, focuses exclusively on sexual behaviour for the purpose of HIV/STD prevention.

*(Adapted from the research report: Chakrapani, V., Newman, P.A., Mhaprolkar, H., and Kavi, A.R., Sexual and Social Networks of men who have sex with men (MSM) and Hijras in India: A qualitative study. The Humsafar Trust, Mumbai, India. April 2007.)*

### ***Sex Worker***

The term 'sex worker' is intended to be non-judgmental, focusing on the conditions under which sexual services are sold. Alternate formulations are: 'women/men/people who sell sex'. Clients of sex workers may then also be called 'men/women/people who buy sex'. The term 'commercial sex worker' is no longer used, primarily because it is considered to be saying something twice over in different words (i.e. a tautology).

*(Adapted from: UNAIDS Terminology Guidelines, 2007.  
[http://data.unaids.org/pub/Manual/2007/20070328\\_unaids\\_terminology\\_guide\\_en.pdf](http://data.unaids.org/pub/Manual/2007/20070328_unaids_terminology_guide_en.pdf))*