

**BARRIERS TO FREE ANTIRETROVIRAL TREATMENT ACCESS  
FOR MARGINALIZED GROUPS IN INDIA:  
POLICY AND PROGRAMMATIC IMPLICATIONS TO ENSURE EQUITY**

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1. Background.....p.1	5. Recommendations.....p.12
2. Methods.....p.2	6. Glossary.....p.14
3. Findings.....p.3	7. References.....p.15
4. Discussion.....p.9	8. Acknowledgements.....p.16

**1. BACKGROUND**

Availability of antiretroviral treatment (ART) has significantly improved the prognosis of people living with HIV (PLHIV) by controlling viral replication, restoring immune system function, extending life, and thus enhancing the quality of life.

In 2004, the government of India began providing free first-line ART in government ART centers. India’s National AIDS Control Organisation (NACO) has explicitly stated that “Under NACP III [third phase of the National AIDS Control Programme], first-line ART drugs will be provided to all those who need it.” (NACO, 2006a – p.114).

NACO estimates that among the 2,376,140 adults living with HIV in India in 2006 about 25% required ART (603,125). In December 2007, twenty percent (118,052) of these adults were receiving free ART from government ART centers (NACO, 2008). Clearly, most persons who require ART are not yet receiving it, and a major challenge for government ART centers is to expand access to free ART.

Marginalized communities – female sex workers (FSWs), injecting drug users (IDUs), and men who have sex with men (MSM) and Hijras (transgender women) – have been recognized by NACO as ‘core high risk groups’ that are worst affected by HIV epidemic in India (NACO, 2006a). NACO maintains that public health facilities need to ensure that ART is provided to PLHIV referred from interventions targeted toward these marginalized communities (NACO, 2006a – p.114). However, there is no information available from NACO on the number or proportion of FSWs, IDUs, and MSM taking ART through its national program (NACO, e-mail communication). Only 128 Hijras/transgender women were receiving ART through the government program at the end of August 2007. In Manipur in 2006, where 49% of reported AIDS cases were categorized as having acquired HIV through injection drug use, fewer than 5% of persons accessing ART from government centers were current IDUs (Sharma et al., 2007).

Positive people networks and community organizations have reported that marginalized groups living with HIV have limited access to free first-line ART from government centers. This has been documented in a series of reports from the International Treatment Preparedness Coalition (ITPC) that recommended creation and implementation of a policy and action plan on equity in ART access for marginalized groups living with HIV (Abraham et al., 2006a, 2006b, 2007a, 2007b; Chakrapani, 2005).

To address inequities in ART access for marginalized groups, it is crucial to identify their different needs and the different constraints they face when trying to access ART (i.e., why some groups are excluded more than others) and to design interventions accordingly (Braveman, 2003; Kalanda et al., 2007). In this policy brief, we summarize findings from a qualitative study that explored barriers faced by marginalized communities - FSWs, IDUs, MSM and Aravanis (local Tamil language term for Hijras/transgender women; see glossary for a complete compilation of terms) - in accessing free ART from government centers. In addition, we discuss key policy and programmatic implications of the study for ensuring equitable access to ART for these groups.

### **Key Terms**

(Based on: Braveman, 2003; Braveman & Gruskin, 2003; Neale et al., 2006)

**Barriers:** Attitudes, ideas, practices, structures or systems that prevent or discourage treatment or service usage.

**Equity:** Social justice or fairness

**Health equity:** Absence of systematic inequalities in health (or in the major social determinants of health) between social groups who have different levels of underlying social advantage/disadvantage – that is, different positions in a social hierarchy.

**Equity in ART access:** Equal opportunity to access ART for all groups of people living with HIV. Absence of systematic inequalities in ART access between social groups who have different levels of underlying social advantage/disadvantage – that is, different positions in a social hierarchy.

## **2. METHODS**

From August 2008 to December 2008, we conducted a qualitative study through 10 non-governmental organizations (NGOs) and community-based organizations (CBOs) working with marginalized communities in Chennai. The study populations included FSWs, IDUs, kothi-identified MSM and Aravanis. We used purposive sampling to recruit the participants for focus groups. Twelve focus groups (n=72 participants), three among each of these four marginalized groups, were conducted. Twelve key informants were interviewed. Key informants were community leaders, directors of NGOs/CBOs, and healthcare providers. Focus group and interview data were explored using framework analysis (Ritchie & Spencer, 1994) to identify categories and derive themes. In accordance with framework analysis, we developed a hierarchical thematic framework and used the framework to classify and organise data according to key themes, concepts and emergent categories. Framework analysis is particularly appropriate for applied qualitative research when a study is oriented towards policy outcomes (Green, 2005). An adapted version of Aday and Andersen's (1974) framework of access to health services was used for analysis.

### ***Characteristics of focus group participants***

FSW participants (n=19) ranged in age from 21 to 48 years (mean = 33 years). Thirty-seven percent (n=7) had completed high school; 42 percent (n=8) were currently married and living with their spouse; and 21 percent (n=4) were on ART. Sex work was reported as the main occupation by all participants.

MSM participants (n=17) ranged in age from 23 to 43 years (mean = 32 years). Twenty-four percent (n=4) had completed higher-secondary education; 53% (n=9) were self-employed; 41% (n=7) were married; 29% (n=5) were on ART; and 47% (n=8) engaged in sex work (part-time).

Aravani participants (n=17) ranged in age from 23 to 46 years (mean = 34 years). Twenty-four percent (n=4) had completed high school; 24% (n=4) were on ART; and 65% (n=11) engaged in sex work.

IDU participants (n=19), ranged in age from 26 to 48 years (mean = 35 years). Thirty-seven percent (n=7) had completed high school; 74% (n=14) were married; 21% (n=4) were on ART; and 32% (n=6) were current users.

### ***National consultation meeting (Nov 26, 2008)***

In an one-day national consultation meeting on November 26, 2008 in New Delhi, a 'pre-final' version of this policy brief was presented to key stakeholders – marginalized community representatives, staffpersons of NGOs and CBOs working with marginalized communities, and officials of NACO. Following the presentation, in three structured group discussions, participants discussed additional barriers to ART access faced by marginalized communities, including specific subgroups, in their region. Participants identified several additional key barriers and made additional recommendations that captured experiences from other parts of India.

### 3. FINDINGS

INDIVIDUAL LEVEL BARRIERS	HEALTHCARE SYSTEM AND PROGRAMMATIC BARRIERS	FAMILY AND SOCIAL BARRIERS
1. Fear of adverse consequences of disclosure of HIV status	1. Negative experiences with healthcare providers	1. Lack of family support
2. Unmet basic needs	2. Lack of comprehensive and adequate counselling	2. Societal and community discrimination
3. Insufficient and incorrect knowledge about ART	3. Unfriendly administrative procedures	
4. Alcohol and drug use	4. Inadequate treatment education in targeted interventions	
5. Psychological barriers	5. Unmet service needs for IDUs living with HIV	

#### A. INDIVIDUAL LEVEL BARRIERS

##### **Fear of adverse consequences of disclosure of HIV status**

The most commonly reported barrier to health care and ART access across all marginalized groups was due to fears of disclosure of their HIV-positive status. When their HIV-positive status is revealed, members of marginalized groups not only face discrimination due to their HIV status; they also face risk of discrimination due to possible disclosure of their sexuality (MSM), injection drug use status (IDUs), or engagement in sex work (FSWs). Adverse consequences include: rejection by spouse (FSWs, MSM), family, and friends; domestic violence (FSWs); loss of support from their own community (all groups); and eviction from home (all groups). For those who engage in sex work (FSWs, and some Hijras/MSM) there is also potential loss of income for subsistence if their HIV-positive status is revealed by their sex work colleagues. To the extent that sex workers feared that taking ART presented risk of disclosure of their HIV status or engagement in sex work, their fear of disclosure translated into fear of initiating ART. Consequently, some postponed initiating ART for as long as possible, until they become symptomatic.

##### **Unmet basic needs**

Most participants were of low socioeconomic status with problems meeting their daily basic needs. Since many Aravanis had been evicted or ran away from their family, they reside in low income areas including slums. Some kothi-identified MSM in sex work are too poor to afford housing and live on the streets. As a result they are victimized by forced sex from ruffians and police. Some IDUs also live on the streets due to lack of family support. As a result of living in poverty, many people from these marginalized groups are primarily concerned about meeting their basic needs – food and shelter – and thus healthcare or initiation of ART become secondary priorities. The widely-held belief among these communities that PLHIV on ART need proper food also leads some to be reluctant to initiate ART, since they are often unable to ensure appropriate nutrition (due to poverty, homelessness).

##### **Insufficient and incorrect knowledge about ART**

Although most participants were found to have adequate knowledge about aspects of HIV, many revealed lack of in-depth knowledge about ART, including benefits and when to initiate therapy (medical eligibility criteria for initiating ART). Some incorrectly believed that cures for HIV exists in alternative and traditional medicines such as homeopathy, Unani (MSM), Siddha (Aravanis), and ‘country medicines’ (FSWs). Participants suggested that most of these erroneous messages or “rumors” are circulated by their own peers. Key informants also stated that lack of knowledge about the benefits of HIV testing and early diagnosis of HIV status indirectly acts as a barrier to ART access for those who are HIV-positive but who do not know their status.

##### **Alcohol and drug use**

Alcohol use was reported as a barrier to accessing ART by all groups. Many societal and family level factors, such as isolation, rejection, labeling (as ‘immoral’, ‘bad in character’), and eviction from home, adversely affect the mental health of MSM, IDUs, and Aravanis, which sometimes

results in alcohol use as a coping mechanism. Key informants reported that some FSWs, especially those who are not with their family, consume alcohol because of the physical stress associated with sex work as well as the stress of 'problem clients' who do not pay money and who force FSWs to have sex with them without condoms (i.e., rape). Sometimes FSWs consume alcohol along with their clients, who promise to pay more money. Health care providers emphasized that patients should not consume alcohol while taking ART in order to ensure ART adherence. But some find it difficult to stop consuming alcohol and doubt their ability to stay abstinent while on ART. For IDUs who also consume alcohol, the challenge is even greater. Key informants reported that the main priority of IDUs living with HIV is obtaining drugs (to avoid painful withdrawal symptoms) and thus they are not concerned about initiating ART. Furthermore, health care providers are not willing to initiate ART for IDUs who are known or assumed to be currently using drugs or consuming alcohol.

### Psychological barriers

Lack of self-efficacy in ART adherence (all groups) and possible relapse into drug/alcohol use (IDUs) prevent some from initiating ART. Some do not initiate ART due to pessimism and fatalistic attitudes that ART helps only to briefly extend life and that premature death will occur whether or not they take ART.

**Table 1. Illustrative quotes for individual level barriers**

<b>Fear of adverse consequences of disclosure of HIV status</b>	
<b>Fear of HIV-positive status being known to family</b>	"We [peers] indirectly tell them [other FSWs] to take ART but they are afraid of what if their family comes to know [about their HIV-positive status] and hesitate to take it. If the family comes to know about that then for sure there will be problems. They are not taking [ART] for these reasons." (A FSW participant)
<b>Loss of income</b>	"While in sex work, if their [HIV-positive] status is revealed, that will reduce the number of clients and their business [income] will be affected. So knowingly they do not take tablets." (An Aravani participant)
<b>Bringing shame to family</b>	"Some kothis think that, 'if we go to hospital, we have to write the names of parents/relatives. If we write like this, everyone will eventually come to know about this'. Then, [society] will look at the entire family in a different way." (A Kothi key informant)
<b>Isolation by the society</b>	"[Some FSWs] think that, 'If other people come to know that we are HIV-positive then they might isolate us from the society' and are reluctant to visit the hospital." (A FSW participant)
<b>Rejection by own peers</b>	"If [they] come to know that I am like this [HIV-positive], my friends [peers] might think about me differently. Then, they will not even refer their clients to me. They won't invite me if there is some function." (A FSW participant)
<b>Unmet basic needs</b>	
<b>Lack of basic amenities and food</b>	"Most of us don't have our basic needs met. We don't have proper shelter. Only slum [people] supports us. In slums, there will not be adequate cleanliness, water facilities will not be fine; food will not be hygienic; mosquito problems..." (An Aravani key informant)
<b>Struggling even for survival</b>	"[Some Kothis would say] 'we are struggling even for our survival; on top of this, what I am going to get by taking ART?'" (A Kothi participant)
<b>Earning money for daily bread is highest priority</b>	"They are living with a hundred rupees per day [that comes] from sex work. When things are like that, only that [money] could be their priority. Only for that [money], they [Kothis in sex work] will give first preference." (A Kothi key informant)
<b>Cannot afford proper food needed to take ART</b>	"If they have to take ART, then they need to have adequate <i>strength</i> [English term]... Since some people don't have [regular access to] food, they are not taking that medicine [ART]. [Some people say], 'If I have to take medicine [ART], then I have to take proper food. It is very difficult for us to get proper food. So, I am not taking that [ART].'" (A FSW key informant)
<b>Food is higher priority</b>	"He is on the streets [homeless IDU]. What will he do if he is given ART? He doesn't have food to eat... For him [getting] food is more important than ART. Also how will ART work if taken without proper food?" (An IDU participant)
<b>Menu offered by counselors is "only for the rich"</b>	"[Only] the rich can take such food [mentioned by counselors]. Can the one on the platform [homeless] drink hot water? Can he take nutritious food such as nuts, dates, and dal? He would just nod his head to the counselor while all these questions keep flashing in his mind. He doesn't get admitted - nor does he get ART. He thinks, 'Oh! There is so much in this [taking ART]. So let me continue doing whatever I am doing now and die when I am going to.'" (An IDU participant)
<b>Insufficient and incorrect knowledge about ART</b>	
<b>Inadequate knowledge about ART</b>	"What many people think is, 'Only when the [CD4] count becomes very low, we have to take ART.' They don't have in-depth knowledge about when to take ART. Don't know where it is available." (A Kothi key informant)  "Someone told me that first-line ART will work only for 2 years. After that there will be some <i>side-effects</i> [English term as mentioned. But it refers to drug resistance in this context]." (A FSW participant)
<b>Belief that alternative or traditional medicine can cure HIV</b>	"In Siddha and Unani [medicines] they [practitioners] say that they cure it [HIV] 100%. They do what the English [allopathy] medicine cannot. So [people] believe this and they go." (A Kothi participant)  "Apart from ART, I have heard about homeopathic medicine... they [Aravanis] said that this homeopathic medicine is better ...and some try it." (An Aravani key informant)

	"Some people say that, this [HIV] will be get cured by country medicines. ...Two or three members [FSWs] went to some hospital in [a place in Chennai] thinking that they can be cured." <b>(A FSW key informant)</b>
<b>Wrong messages about ART by peers</b>	"Without consulting a doctor they tell others that 'vision has diminished' and they have itching and things like that. They thus spread a wrong opinion about ART and warn others not to take it." <b>(An IDU participant)</b>
<b>Fear of side-effects</b>	"They are afraid that some <i>side-effects</i> [English term as used] may come. That is a problem." <b>(A FSW key informant)</b>
<b>Alcohol and drug use</b>	
<b>Fear of side-effects if ART is taken with alcohol</b>	"What they [kothis] think is, those who drink alcohol cannot take this tablet [ARTs] and one who takes this tablet should not be consuming alcohol. In case they take ART along with alcohol there will be side-effects... some may feel so... may be due to this [reason] they do not want to take [ART]." <b>(A Kothi participant)</b>  "While taking drinks [alcohol] and medicine [ART] together, it brings side-effects. Yes, just for that [reason], they don't start [taking ART]." <b>(A FSW key informant)</b>
<b>Finding it difficult to stop taking alcohol</b>	"If CD4 [count] is reduced and they [Aravanis] get referred to ART, they cannot stop that habit [alcohol use]. If stopped suddenly, their hands and legs will start shaking [referring to alcohol withdrawal symptoms]...." <b>(An Aravani key informant)</b>
<b>Dilemma in initiating ART if addicted to alcohol</b>	"There are people who are addicted to smoking and alcohol. They are instructed not to consume them when they are on medication. Hence they hesitate and think whether or not to take this medicine." <b>(An IDU participant)</b>
<b>Priority given to drug use</b>	"The reason why they [IDUs] are unaware of HIV is - their main focus is <i>drug</i> . Due to the addiction they don't care about HIV - in spite of the awareness given to them. They [messages] do not reach the person who is under the control of drugs. Drug is the most important thing for him. He [IDU] can take care of him only if he gets rid of them." <b>(A former IDU participant)</b>
<b>Need for recovery from drug addiction</b>	"They [drug users] wouldn't come forward. They would be careless. They mainly need recovery to come out of drug addiction. They can be easily convinced to take ART if they come out of drug addiction." <b>(An IDU key informant)</b>
<b>Psychological barriers</b>	
<b>Fear of life long and regular medication</b>	"[Some say] 'If I initiate ART, I have to take it for life long.' ...they give reasons like this ... and keep postponing taking it...[or] don't go for check-up for CD4 [count]." <b>(An Aravani key informant)</b>  "Some kothis think that they could not regularly take it [ARVs] twice daily. For them, that [taking twice-daily] is a problem." <b>(An MSM participant)</b>  "Apart from that, as it [ART] has to be taken for the entire lifetime, we are afraid that we might not be able to [do so]." <b>(An IDU participant)</b>
<b>Fatalism &amp; Pessimism</b>	"There are a lot of people affected by HIV/AIDS but when we tell the people, some accept while some [people] say like, 'Whatever it is we are going to die anyway: till then let us enjoy and die' and refuse to accept." <b>(A FSW participant)</b>

## B. HEALTHCARE SYSTEM AND PROGRAMMATIC BARRIERS

### Negative experiences with healthcare providers

Although study participants and key informants noted an increasing trend of relatively positive attitudes among government health care providers, several incidents of discrimination in some government ART centers were reported. Having had prior negative experiences or having heard from others about negative experiences in the government health care system act as strong deterrents for some to attend ART centers. Non-verbal cues and facial expressions of support staff were seen as unfriendly and humiliating to many Kothi-identified MSM and Aravanis. Judgmental attitudes, substandard treatment, and even verbal abuse from health care providers were reported, which created significant obstacles to accessing health care or ART.

### Lack of comprehensive and adequate counseling

In general, many participants mentioned that counseling services in the government hospitals have substantially improved over the years. However, some were not satisfied with the quality of counseling services offered in some government ART centers. Some expected more time and thus more details to be given to them. Some expressed concerns about lack of privacy and confidentiality in counseling. Also, some participants - especially from Aravani and IDU communities - expressed the need for peer counselors in addition to professional 'non-community' counselors, as the latter are seen as having insufficient knowledge about them and as lacking sensitivity.

## Unfriendly administrative procedures (enrollment and admission)

To facilitate follow-up of patients on ART, a valid proof of identity/address is required for enrollment in the government ART program. This poses problems for some Aravanis who do not have any valid identity card in their female name. Some Aravanis who have identity and address proof (e.g., ration card) in their male name are asked by the ART centre staff to register only in their male name. While some Aravanis half-heartedly agree with this requirement out of need for free ART, other Aravanis do not accede because it is very humiliating, as they want to be recognized as a woman or transgender woman, a core part of their identity. However, Aravanis who are accompanied at ART centers by staff of CBOs usually do not face this problem because the CBOs take care of follow-up of patients who enroll in the ART program. Similarly, stringent requirement of identity and/or address proof may exclude homeless IDUs and kothis from free ART access.

One ART center in Chennai generally requires that PLHIV initiating ART be admitted for 2 weeks to monitor side-effects, whereas other centers usually do not require admission. Some FSWs reported this admission to be a barrier to initiating ART because they would not be able to explain a two-week admission to their family members, who do not know their HIV-positive status, and because they would not be able to engage in sex work or other work to earn money to feed their family during their hospital stay. Similarly, Aravanis and MSM living with HIV, who often lack family as well as community support, have reservations about being admitted. An additional barrier for Aravanis is that in spite of their preference for admission to a women's ward, lack of uniform guidelines on admission of transgender patients results in some getting admitted to a male ward even if they are in woman's attire and have undergone emasculation. Some key informants and participants, however, felt that it is important that, wherever possible, ART centers admit PLHIV for a week or two to monitor side-effects.

**Table 2. Illustrative quotes for Healthcare system and programmatic barriers**

<b>Negative experiences with healthcare providers</b>	
<b>Non-verbal behaviors that hurt</b>	"Even while entering inside [the government clinic]... lower rung staff such as Aayah [woman helper] and ward boys will laugh [negatively] at us. We don't know how we appear to them. According to us, we look good." (An Aravani participant)
<b>Queries that hurt</b>	"While going to give blood for testing in [ART center], [lab staff asks] 'Are you using condom or not? Are you getting money? Will there be any wounds in his [client] organ.' They are not supposed to ask these types of questions." (A FSW key informant)
<b>Keeping the distance – literally</b>	"While counseling... their [counselor] chair would be in front [near the table in-between the two] and ours at the back [away from the table]. If we try to move it to front [near the table], they would say, 'It's ok. You stay there.' I would sit a little away [from the table] and answer. They are afraid that it would spread to them. They have the fear. But they know how it spreads. They won't sit comfortably and talk to us." (An IDU key informant)
<b>Lack of comprehensive and adequate counseling</b>	
<b>Inadequate information in counseling</b>	"Some people [counselor] would say only, 'your CD4 [CD4 count] is low. Get the health tonic.' They [counselors] are very slack and do not explain things in detail." (A FSW participant)  "Only 10 or 15 minutes would be allotted if fifty [PLHIV] are there for ART. They [counselors] don't see whether the message reaches him or not." (An IDU participant)
<b>Lack of privacy and confidentiality</b>	"They have learnt how to give counseling but they don't practice it properly. [Counseling] has to be given one-to-one in a separate room. There is nothing like that." (A FSW key informant)  "They don't even have a door [in the counseling room]; there is only one screen. People come and go. People peep in to check whether the talk [counseling session] is over or not. I can't ask any details. She [counselor] also does not have time. Many are waiting...There is no privacy." (An MSM key informant)
<b>Need for peer counselor</b>	"It would be good and useful if a rehabilitated ex-drug user is appointed as counselor in [government hospitals]. Only a former drug addict can clearly understand a 'drug addict' and others cannot." (An IDU participant)  "It would be nice if Aravanis are there to give counseling for us...because, they will have in mind that these people belong to my own community – we have to take care of them. Thus, the job [services] will be good. Everyone will benefit." (An Aravani key informant)
<b>Unfriendly administrative procedures</b>	
<b>Lack of transgender-friendly registration and admission guidelines</b>	"There are lots of things that need to be changed. There is a separate queue for men and women. Those men and women see Aravanis as an object to mock at." (An Aravani key informant)  "Some hospitals put us in male wards and some in female wards. Until recently, in [name of the hospital] we were asked to put on a male dress and admitted to a male ward even if we are Nirvan [emasculated] and in Chatla [in woman's attire]." (An Aravani participant)
<b>Practical problems in getting admitted for two-week observation period</b>	"If I have to be started on ART, I need to get admitted in the hospital for 15 days. How can I do this when I have four children? My in-laws will question me about my health. I cannot say that my CD4 is low to them and leave my four kids and come [to hospital]. They don't know that I am involved in this [sex] work and I am [HIV-] positive." (A FSW participant)

<b>Need for proof of address and identity for enrollment</b>	<p>"When [patients] go for ART, they [service providers] ask for proof of address. They will ask either to bring a ration card or voter identity card. Until now, Aravanis have not been recognized as Aravanis [means no legal recognition of being an Aravani] ..." (An Aravani key informant)</p> <p>"When they are infected by HIV and their CD4 level comes down, they are compelled to take ART. When they are put under ART, it gives rise to many obstacles. Mainly, they are asked for ration card, address proof, photo, etc. He [IDU] had already been sent away by the family for taking drugs. Then how could he get all those things?" (A key informant who is a service provider to IDUs)</p>
<b>Difficulties faced by Aravanis who migrate often</b>	<p>"[Some] Aravanis are never attached to a place. They keep shifting homes often. There are also some Aravanis who will stay in Chennai away from their native homes. They will be on ART here [in Chennai] and when they go to [their] native home to stay there [for some months], getting ART [from the nearest ART centre] is a big problem. They cannot change the record details to get it in a different place. We have to get a letter from the doctor [in Chennai]. In this way there are so many procedures to be followed." (An Aravani participant)</p>
<b>Inadequate treatment education in targeted interventions</b>	
<b>Lack of ART education during outreach</b>	<p>"Both in NGOs and CBOs, focus is only on how to protect oneself from getting HIV. Outreach worker is not saying what [to do] after one gets HIV ... [They] distribute condoms, give jelly [water-based lubricants], [and talk about] how to do safe sex ... [But] No clear information on ART is given [by outreach workers]. [NGOs] need to train them. Will they [outreach workers] always have to tell only about STD and HIV [in the field]? They can also tell about ART." (An MSM key informant)</p>
<b>Lack of ART education during site counseling</b>	<p>"[In NGOs] if they become HIV positive, counseling will be given like this – 'Take this food. Take healthy food. We have to increase CD4 count' and so on. Even in NGOs, it is rare for them to talk about 'there are first-line and second-line in it [ART].' Only 20% tells that... They talk about ART only after seeing CD4 count. Before that, no one talks about ART." (An Aravani participant)</p>
<b>Need to train outreach staff</b>	<p>"Even though they [outreach workers and peer educators] have knowledge up to the level of saying 'Take ART when your CD4 becomes low,' they still require some more classes [training]." (A FSW key informant)</p>
<b>Need to educate all (irrespective of HIV status and CD4 count)</b>	<p>"They [outreach staff] won't talk about ART... Only when it is less than 200 they talk about ART..... Reveal everything about it [taking ART] - like the obstacles you would have while you take ART, the way in which you should take it, its merits and demerits. But they should tell this to everyone. I may be [HIV] negative today but maybe I become [HIV] positive tomorrow. I need to know. And I can tell other people." (An IDU key informant)</p>
<b>Need for media campaigns</b>	<p>"Since there is no one who does not listen to FM [radio], it shall be announced in FM that these are places [ART centers] where treatment [for HIV] is given." (A FSW key informant)</p> <p>"[MSM who are not covered by NGOs/CBOs] don't have a chance to know about ART. [HIV programs] can use media to tell about [ART] that, 'if people [who get infected with HIV] take ART, they can live for a long period.'" (An MSM key informant)</p>
<b>Unmet service needs for IDUs living with HIV</b>	
<b>Lack of effective linkages</b>	<p>"It is a policy issue. If NACO and MSJE [Ministry of Social Justice and Empowerment] sit together and develop some kind of formal referral and coordination mechanisms then it would be easier. Currently we are referring people to other centers [needle syringe projects, OST projects, and detox/de-addiction and rehabilitation centers] by word of mouth or phone calls because we have friends at those centers." (An IDU key informant)</p>
<b>Lack of screening for hepatitis viruses</b>	<p>"But basically no test is taken. Mainly, the drug addicts would have a virus called hepatitis B which causes jaundice. No test is done for that." (An IDU participant)</p>

### **Inadequate treatment education in targeted interventions (TIs)**

Key informants expressed the view that TIs among FSWs, IDUs, MSM, and Aravanis focus on providing HIV prevention education and condoms, with relatively little attention given to providing ART-related information. Aravani participants complained that even counselors in NGOs give little information about ART. Often, counselors seem to provide ART-related information only at the point at which medical eligibility criteria are met, rather than providing education to help PLHIV prepare for this future likelihood. Participants from all groups complained that outreach workers – almost all of whom are from their own communities – do not provide detailed information about treatment. Key informants suggested that this is the result of inadequate knowledge of ART among outreach workers themselves, who lack in-depth training on ART and treatment-related issues. They also suggested that treatment education should be given to all who report high-risk behaviors irrespective of their HIV status and that general mass media campaigns on ART should be initiated to reach everyone in order to cover those who may not be reached through TIs.

### **Unmet service needs for IDUs living with HIV**

In spite of the benefits of opioid substitution treatment (OST) to help IDUs living with HIV to become 'stabilized' and eventually drug abstinent, relatively few IDUs are on OST. Only two OST projects - one supported by NACO and another by United Nations Office on Drugs and Crime (UNODC) – exist in Chennai. Key informants stressed the need for establishing and strengthening linkages among the needle/syringe programs, OST programs, and detoxification/de-addiction and rehabilitation centers to create a continuum of services. Participants and key informants reported that IDUs were not routinely screened for hepatitis B and C viruses (HBV/HCV) before starting ART; lack of diagnostic kits and interrupted supply of kits were cited as the reasons.

## C. FAMILY AND SOCIAL BARRIERS

### Lack of family support

Most participants reported lack of family support for people from these marginalized communities. Many Aravanis are evicted from their home or run away from their family during their childhood because of nonacceptance of what their families perceive as gender inappropriate behavior. Hence, many live alone or together in communities in low income areas such as slums. Although many MSM live with their parents or spouse, they too lack family support because they usually do not disclose their sexuality or HIV-positive status. FSWs who are 'housewives' engaging in sex work ('home-based' or 'secret' sex workers) are in a similar situation. They usually hide their profession from their spouse and children even though they engage in sex work to meet their family members' needs. Some IDUs are rejected by their family for being drug users and thus are homeless.

### Societal and community discrimination

Members of marginalized communities living with HIV face double or triple stigma and discrimination due to their HIV-positive and marginalized status (sex work, sexuality, drug use). In addition to societal stigma, they also face discrimination even within their own communities. Often they are isolated and rejected by peers. For example, some sex workers, including Kothis and Aravanis, might disclose to their male clients the HIV-status of their HIV-infected colleagues to reduce the competition in sex work and to reduce the prospects of acquiring HIV through a common client. Fear of discrimination also prevents many PLHIV from marginalized groups from joining 'mainstream' PLHIV networks. Thus they are unable to access the services available through these PLHIV support networks. Even those who do join mainstream PLHIV networks often do not disclose their marginalized group status.

**Table 3. Illustrative quotes for family and social barriers**

<b>Lack of family support</b>	
<b>Need for family support</b>	"[Aravanis] need love from someone. Aravanis need support. Someone should encourage me when I think – 'Why should I take ART?' Only once, a counselor can tell like this - 'Take food on time, only then you will be fine.' Even for me, if my family supports me, I will be more healthy. This is my opinion." (An Aravani key informant)
<b>Lack of acceptance of sexuality in family</b>	"My parents were looking for an alliance for me. Hence I wanted to know whether I have HIV – since I had sex with several men...It was a shock that I was found to be [HIV-] positive. My parents eventually came to know that I have HIV as well as how I got it. They told me they would take care of me even if I am HIV-positive – but they had one condition – that I should not tell others how I got it...Even now my relations with my parents and brothers are strained...No dignity. But life goes on." (An MSM participant)
<b>Nondisclosure of HIV status to family</b>	"Since my [family] is not aware of my activities [sex work] and I have this [HIV], taking this medicine will be a big problem for me." (A FSW participant)
<b>Overburdened with household work</b>	"I have to do all the housework to send my children [to school] and husband [to work]. By the time, it would become around 10-10.30 [am] and then once back in the evening I need to work until late night. Where will I find time to take the medicine?" (A FSW participant)
<b>Disowned by family</b>	"The main hindrance among the drug addicts to taking ART is that most of them are rejected and sent away by their family." (An IDU participant)
<b>Fear of bringing shame to family</b>	"He thinks that he will earn a bad name for the family, and the society would view the family differently as he is infected by HIV. Due to this fear / stigma...he comes out of the family.... This is the basic reason." (An IDU participant)
<b>Societal and community discrimination</b>	
<b>Isolation, rejection and labeling</b>	<p>"The entire locality has isolated her [a FSW living with HIV]. She is not even able to get a job of carrying sand [daily-wage labor]. Wherever she goes, the father-in-law comes and tells about her [positive status]. When this is the situation taking ART is a big problem." (A FSW participant)</p> <p>"If [they] come to know that I am like this [HIV-positive], my friends [peers] might think about me differently. Then, they will not even refer their clients to me. They don't invite me if there is some function." (A FSW participant)</p> <p>"No one is encouraging them [HIV-positive Aravanis] to take medicines properly or counseling them to take care of their life. There is no adequate awareness and sensitization within our community. If there are ten Aravanis living together in a place and if one is found to have HIV then the other nine Aravanis will discriminate against her. No one takes care." (An Aravani key informant)</p>

### Additional key barriers identified in the national consultation meeting

In the national consultation meeting with key stakeholders on November 26, 2008, participants reported that especially in Northeast India, which is a hilly region, PLHIV faced problems with transportation to ART centres because of travel costs and long travel times. They also reported that IDUs living with HIV within prison settings find it difficult to initiated or to continue ART.



## 4. DISCUSSION

People from marginalized communities in Chennai—MSM, sex workers, transgender women and IDUs—who are living with HIV face a variety of barriers to accessing ART. In spite of the theoretical availability of free first-line ART from government ART centers for ‘all those who need [ART]’ (NACO, 2006a), PLHIV face barriers to ART access on individual/psychological, institutional, programmatic, and social levels.

Although the findings have been presented as analytically distinct, in reality there is considerable interaction among the various levels of barriers – sometimes more obvious than others. For example, it is understandable that actual or perceived discrimination by health care providers may deter people from accessing health facilities. Discrimination by health care providers in turn is fostered by societal ignorance, prejudice and misconceptions about marginalized groups. Given the lack of understanding of marginalized groups and discrimination in health care settings, blaming individuals for not accessing ART and for not disclosing their sexuality (MSM), drug use, or engagement in sex work is both wrong and counterproductive. Individuals may be responding in reasonable ways to protect themselves from stigma and discrimination. Similarly, the individual-level barrier of fear of adverse consequences of disclosure of HIV status, a predominant theme that emerged across all marginalized groups, is strongly related to the social barriers of stigma and discrimination faced by PLHIV and marginalized groups in Indian society. Thus, it is crucial to focus on the various contextual factors that prevent individuals from initiating ART.

At the individual level, barriers include fatalism, fear of side-effects, and inadequate and incorrect knowledge about ART. Fatalism may be explained by the lack of a cure for HIV, internalized stigma and resultant lack of self-esteem among members of marginalized groups because of widespread societal stigma and discrimination. Fatalistic attitudes, together with lack of psychosocial support and unmet survival needs, may result in not giving priority to one’s health or to initiating ART. While most MSM, FSWs, and IDUs in Chennai may have adequate knowledge about some aspects of HIV (APAC, 2007; NACO, 2006c & 2006d) the current study indicated that they have limited knowledge about ART and treatment-related issues. Lack of adequate knowledge about ART was also found in a multi-state study conducted among marginalized groups living with HIV (Chakrapani et al., 2007a). Systemic steps that could be taken to improve knowledge about ART include: incorporating information about ART into targeted interventions among marginalized groups, which currently focus on HIV prevention education and condom promotion and distribution, but not ART (WHO, 2003); training outreach workers on treatment issues; improvement of infrastructure and staffing levels at government centers to allow adequate time and privacy for counseling; training of health care providers to counter stigma and discrimination related to HIV/AIDS, same-sex sexuality, transgender people and drug use; and government mass media campaigns on ART availability. Another systemic step could be flexibility around the two-week hospital admission for PLHIV who are initiating ART.

Lack of adequate knowledge about ART may also help to explain excessive fear of ART side-effects, which, along with skepticism about allopathic medicine, may motivate some to seek alternative and traditional medicines in place of ART. There is a common belief among wide segments of the Indian patient population that alternative medicines with virtually no side-effects can be effective or even cure chronic diseases that are not cured by allopathic medicine (Chandrashekhara et al., 2002; Gogtay et al., 2002; Mehrotra et al., 2004). Thus, education about ART should include accurate and unbiased information about what alternative medicines can and cannot do. Recently, the Indian government announced a ban on advertisements that offer potential cures for HIV infection (The Hindu, 2008).

Some FSWs, IDUs and Aravanis are reluctant to initiate ART because they exist in contexts in which it is particularly challenging to stop consuming alcohol, which is highly recommended at government ART centers for those taking ART. This points to the need for treatment of alcohol dependence among these groups that addresses what may be population-specific challenges.

Staff and healthcare providers at government ART centers share with the broader society negative attitudes toward marginalized groups and conceptions about sexual morality and drug use that could lead to inadequate care. Entrenched attitudes about sexuality and sex work are difficult to modify. Criminal laws against adult consensual same-sex sexual behaviors (Section 377 of the Indian Penal Code) and laws that punish sex workers and drug users often lead people, including healthcare providers, to have prejudices and negative attitudes toward these communities and even to justify discrimination (Chakrapani et al., 2007b). Lack of understanding of transgender people could also account for the lack of transgender-friendly procedures in healthcare settings. The core issue of legal recognition of the gender identity status of transgender women needs to be addressed because the hospital registration and admission procedures that are insensitive or humiliating to transgender women discourage them from initiating ART. While the current training programs for healthcare providers and staff do include sections on stigma and discrimination, the adequacy of these modules has been recently questioned (Pinagapani & Shanmugam, 2008). For example, there are practically no interactions with marginalized groups or people living with HIV during these training programs, which are central components of reducing negative attitudes.

Changing the negative attitudes of the general public in relation to sexuality and marginalized groups also will be challenging. To start, as recommended by UNAIDS (2007), public education campaigns to counter HIV/AIDS stigma and discrimination and to promote acceptance of PLHIV, including those from marginalized groups, need to be implemented.

Proper training for healthcare providers and staff is important, but not sufficient – the Indian healthcare system is faced with a crisis of ever increasing patient volume that has a strong tendency to overwhelm the available human resources and infrastructure (Satpathy & Venkatesh, 2006). Thus, policymakers should ensure that trained human resources and infrastructure are appropriately proportionate to the client load in the public health systems in general and the government ART centers in particular.

Specific issues for IDUs include reluctance among physicians to initiate ART for IDUs and lack of proper screening, diagnosis, and treatment for HBV/HCV co-infections. Physicians hesitate to start ART for IDUs because they question whether IDUs – former or current – would adhere to ART. While abstinence from drugs should not be mandatory for initiating ART in IDUs (WHO, 2005 & 2008), it is also important that current IDUs be linked to OST and to other drug-dependence treatment programs. NACO's national guidelines on ART management clearly state that screening for HBV and HCV infections for IDUs is 'mandatory' (NACO, 2007b). However, in reality, there is a lack of screening tests for HBV/HCV for PLHIV including IDUs, and lack of free or affordable treatment for HCV-positive people in government hospitals. These factors discourage IDUs from initiating ART since they believe initiating ART could impair their health if their liver is already damaged by HBV and/or HCV. Thus, it is crucial that screening for HBV/HCV co-infections for all PLHIV be conducted and that affordable/free treatment for HCV and HBV infections to be provided for PLHIV.

There are few other studies that focus specifically on barriers to ART access among marginalized groups. However, one study showed that FSWs living with HIV in Mumbai faced discrimination from health care providers, were evicted from brothels once their HIV-positive status was known, and faced delays in being referred to government hospitals for treatment when they were in custody in remand homes (Gaikwad, 2007), which tends to corroborate some of the barriers reported in the current study.

A series of policy reports on ART access in India noted that marginalized groups face barriers in accessing free ART from government hospitals and recommended the need for an action plan to ensure equitable access to ART (Abraham et al., 2006a, 2006b, 2007a, 2007b; Chakrapani, 2005). In Mumbai, the NGO Medecins Sans Frontieres (MSF) has started providing ART to those patients who have been excluded from the government ART program, which further supports results from the present study. MSF states: "Most of MSF's patients come from marginalized groups such as transgender women (Hijras), men who have sex with men, commercial sex workers, migrant

workers and those living in poverty...Some 500 patients should be receiving ARV treatment through our program in 2007.” (MSF, undated)

WHO states that there is a need “to monitor the coverage [ART] of marginalized populations, such as intravenous drug users and sex workers” (WHO, 2004) and recommends collecting disaggregated data from treatment sites on the number of people being treated from various segments of the population, including those from marginalized groups. However, at the time of publication of this report, NACO was not collecting these data, which is needed to determine whether members of marginalized groups have equitable access to ART from government centers. This is in spite of ‘equity,’ including commitment to monitor equity by relevant indicators, being a guiding principle of the third phase of National AIDS Control Programme, (NACO, 2006a, p.6)

WHO also states that specialized interventions are necessary to meet the specific needs of members of marginalized groups living with HIV. For FSWs, MSM, and IDUs, these interventions should address legal status, social isolation, police abuse, and discrimination in health services (WHO, 2004), which recognizes both shared and population-specific barriers to treatment.

This study had some 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 ART access. All study participants were recruited through NGOs/CBOs that work with marginalized communities. Association of the study participants with NGOs/CBOs could have led to a relatively high degree of knowledge about HIV and the benefits of initiating ART, and higher levels of ART access and utilization. Thus, others from these communities may report even greater barriers to ART access. Additionally, because the clientele of the NGOs/CBOs are from a lower socioeconomic background and educational status, one cannot transfer the findings to marginalized people from higher socioeconomic or educational backgrounds.

A related limitation is that we may not have captured all the diversity in the barriers to ART initiation 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-identified MSM. We were unable to recruit gay- or bisexual-identified MSM. Similarly, FSWs who are reached by NGOs/CBOs and who participated in the focus groups were predominantly ‘home-based’ (or ‘secret’) sex workers, many of whom live with their husband and children. Thus the barriers faced by other subgroups of female sex workers (such as ‘brothel-based’ sex workers) could not be identified. In summary, this study has mainly captured the experiences of specific subgroups of marginalized communities: kothi-identified MSM; street-based FSWs; Aravani-identified transwomen; and current/former IDUs who used/use injectable drugs in isolated areas. Future studies need to include other subgroups of these marginalized communities in other localities to help determine specific solutions for removing context-specific barriers.

In conclusion, barriers at several levels (individual, social and healthcare system levels) are faced by marginalized groups in accessing free ART at government centers. In order to be effective, policies and programs should be designed and implemented to address barriers to ART access at all these levels. This will help NACO meet its commitment to ensure availability of ART to “all those who need it.”

## 5. RECOMMENDATIONS

### 1. Address stigma and discrimination faced by people from marginalized communities and PLHIV

- **Implement programs to reduce stigma and discrimination:** Implement educational and sensitization programs for the general public to reduce stigma associated with HIV/AIDS, drug use, sex work, same-sex sexuality, and transgenderism, and also educate them to accept and not to discriminate against PLHIV, FSWs, IDUs, MSM and transwomen. Similarly, create a supportive environment for PLHIV among marginalized communities by promoting acceptance of PLHIV and supportive peer norms through targeted interventions and advocacy by community leaders.
- **Implement anti-discriminatory policies in healthcare settings:** Anti-discriminatory policies should be introduced and implemented in healthcare settings to ensure non-discriminatory and quality care for marginalized communities and PLHIV.
- **Pass the HIV/AIDS bill into law:** Introducing and enforcing laws/regulations that safeguard the rights of PLHIV and marginalized groups is a crucial step towards eliminating discrimination. Thus, there is a need to pass the national HIV/AIDS bill into law since it articulates specific measures to address stigma and discrimination faced by PLHIV / marginalized groups and to protect their rights.
- **Address legal barriers to effective treatment for marginalized groups:** Review laws that criminalize consensual sex between adult males, sex work, and injecting drug use, and take steps to remove direct or indirect barriers posed by these laws to marginalized groups in accessing HIV prevention and treatment services.

### 2. Address psychological and other individual level barriers to ART initiation

- **Provide training to healthcare providers to address individual level barriers:** Psychological barriers such as lack of self-efficacy in drug adherence, fear of side-effects and fatalism prevent some from initiating ART. Hence outreach workers, counselors, and doctors should be trained to be competent in eliciting and providing tailored counseling to address the various psychological barriers to initiating ART.
- **Create linkages with other services:** PLHIV who are dependent on alcohol and/or drug use need to be linked with drug dependence treatment and harm reduction services (needle/syringe programs, OST, residential rehabilitation, etc.) that are tailored to the various challenges among different marginalized communities.
- **Link PLHIV who currently inject drugs into OST programs:** Current IDUs living with HIV have difficulty accessing ART because their priority is on drug use (due to severity of withdrawal symptoms) and because physicians hesitate to initiate ART for IDUs. It is therefore crucial that current IDUs be linked with OST programs to help them attain a stable lifestyle and to assist them in adhering to ART. Also, it is important to educate physicians not to deny ART based on the drug use status (past or current) of PLHIV.

### 3. Provide treatment education to marginalized groups, including those living with HIV

- **Provide ART education through multiple avenues:** Provide and reinforce treatment messages to FSWs, IDUs, MSM and Aravanis in different forms and through different providers (peers, outreach workers, doctors, and counselors).
- **Educate all members of marginalized groups about ART (irrespective of HIV status and CD4 count):** Treatment messages should not be restricted only to those who are known to be HIV positive. Giving ART-related treatment messages to all (irrespective of their HIV status) helps diffusion of this information among the community and avoids labeling people who receive treatment messages from outreach workers as being HIV infected. Additionally, these ART messages should address commonly held misconceptions such as cure of HIV by alternative medicines and unfounded fear of ART side-effects, which may be more effectively addressed as part of a longer term process both before and when ART is actually prescribed.
- **Implement awareness campaigns on ART and its availability:** Publicize accurate information about ART and its availability in selected government hospitals through mass media and innovative communication campaigns that appeal to and reach out to marginalized groups, especially those living with HIV. These campaigns might need to go hand-in-hand with HIV testing campaigns.
- **Strengthen the capacity of PLHIV networks and marginalized groups:** Capacity of the PLHIV networks and CBOs working with marginalized groups needs to be strengthened to provide

treatment education and outreach to PLHIV from marginalized communities. Sensitization and training about the needs and issues of marginalized groups living with HIV are necessary for both mainstream PLHIV networks and CBOs working with marginalized communities.

#### **4. Ensure availability of quality counseling and treatment services**

- **Relax requirements regarding address/identity proof:** Lack of appropriate proof of identity or address should not limit needy PLHIV from receiving ART. Consider alternative arrangements such as recommendation letters from NGOs or positive people networks.
- **Be flexible in the two-week hospital admission requirement:** Be flexible and pragmatic in the implementation of the two-week admission requirement (in some ART centers) for initiating ART to prevent that requirement from being a barrier for some PLHIV from marginalized communities.
- **Ensure people-friendly environment and quality services:** Ensure that ART centers are friendly and healthcare providers (especially counselors and doctors) offer competent, non-judgmental, non-discriminatory and quality counseling and treatment services to people from marginalized communities living with HIV.
- **Develop transgender-friendly guidelines:** Consult with Aravani/transgender communities and develop guidelines for sensitively dealing with the gender identity-related issues faced by Aravanis/transgender women: name and gender of enrolment and ward admission (women's or separate ward).
- **Develop 'standards of care':** Develop 'standards of care' for ART initiation, management, and monitoring for marginalized groups living with HIV, and ensure that healthcare settings adhere to these standards of care.
- **Ensure screening of all PLHIV for HBV/HCV:** Ensure that standard clinical guidelines are followed in screening people living with HIV (especially former or active IDUs) for HBV/HCV before starting ART as well as soon after an HIV-seropositive diagnosis.
- **Support treatment of HBV/HCV co-infected PLHIV:** Develop mechanisms to support treatment for HBV and HCV infections in IDUs (including those living with HIV).
- **Appoint trained peer counselors:** In addition to professional counselors, in selected ART centers, appoint trained peer/community counselors to promote ART uptake among marginalized groups.
- **Provide 'smart cards' for easy access to ART:** Quicken the process of providing 'smart cards' for PLHIV to ensure uninterrupted and easy access to ART from any government ART centre.

#### **5. Establish better coordination mechanisms at the policy level**

- Establish and strengthen coordination mechanisms among relevant ministries – especially between NACO – under the Ministry of Health and Family Welfare (MoHFW), Ministry of Social Justice and Empowerment (MSJE), and the Law and Home Ministries. At the state level, linkages need to be built among the State AIDS Control Society (SACS), and the State Departments of Health and Social Welfare.

#### **6. Develop and implement a national policy and action plan to ensure equity in ART access for marginalized groups**

- Ensuring equity in ART access for marginalized groups should be clearly articulated in the policy statements and annual action plans of NACO. The national action plan to ensure equity should address:
  - Setting targets for marginalized groups living with HIV to be reached through the national ART program based on local epidemiology;
  - Monitoring ART inequity: collecting disaggregated data according to marginalized group status in ART centers and HIV testing centers, and quantifying inequity information by comparing ART access among different groups of PLHIV; and
  - Implementing steps toward eliminating inequities.
- PLHIV networks and marginalized groups should be actively involved at all levels to make effective use of their experience and expertise in monitoring and review of scale-up of ART programs to ensure equitable access to ART for marginalized groups.

## 6. 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 the state of Tamil Nadu are called 'Aravanis.'

### **Injecting Drug Users (IDUs)**

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).

### **Kothis**

Kothis are a heterogeneous group. 'Kothis' can be described as males who show varying degrees of 'femininity' (which may be situational) and who are involved mainly, if not only, in receptive anal/oral sex with men. Some proportion of Kothis have bisexual behaviour and many may also get married to a woman. A significant proportion of Hijra-identified persons also identify themselves as 'Kothis'. In this report, the term 'Kothi-identified MSM' is used to denote feminine males who self-identify themselves as 'Kothis' but not as Hijras.

### **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 behavior for the purpose of HIV/STD prevention.

### **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).

### **Transgender person**

A term used to describe those who transgress social gender norms; often used as an umbrella term to mean those who defy rigid, binary gender constructions, and who express or present a breaking and/or blurring of culturally prevalent/stereotypical gender roles. Transgender people usually live full or part time in the gender role opposite to the one in which they were born. In contemporary usage, "transgender" has become an umbrella term that is used to describe a wide range of identities and experiences, including but not limited to: pre-operative, post-operative and non-operative transsexual people; male and female cross-dressers (sometimes referred to as "transvestites," "drag queens," or "drag kings"); intersexed individuals; and men and women, regardless of sexual orientation, whose appearance or characteristics are perceived to be gender atypical. (A male-to-female transgender person is referred to as '*transgender woman*' and a female-to-male transgender person is referred to as '*transgender man*.')

### **Transsexual person**

Individual whose gender identity is that of the opposite gender (sex). There are male-to-female and female-to-male transsexuals. A transsexual may or may not have had sex reassignment surgery and thus could be 'pre-operative' transsexual, 'post-operative' transsexual or 'non-operative' transsexual. (A male-to-female transsexual person is referred to as '*transsexual woman*' and a female-to-male transsexual person is referred to as '*transsexual man*.')

### **Definitions are adapted from:**

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WHO and UNODC websites: <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)

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