# Suspending Judgement



A report of the training workshop on stigma reduction for health care workers









India Habitat Center New Delhi January 17-19, 2011



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International Center for Research on Women (ICRW) works to advance gender equality and human rights, fight poverty, and promote sustainable economic and social development for all.

We conduct empirical research and promote practical, evidence-based solutions, so that institutions, policies and programs can enable women to control their own lives and participate fully in shaping the future of their societies.

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## **Executive Summary**

#### Introduction

From 17th to 19th January 2011 the National AIDS Coordinating Organization (NACO) and the International Center for Research on Women (ICRW) organized a three day workshop on HIV related stigma reduction for health care workers from different parts of India. The workshop was sponsored and funded by the World Bank and held at the India Habitat Centre, New Delhi.

This workshop was organized to test out an approach and materials for training health care workers about HIV related stigma and Universal Precautions. If successful this approach could be used by NACO to organise a large scale training programme for health care workers – and through this contribute to the reduction of stigma towards people living with HIV in India.

The workshop also built on the efforts of the World Bank to raise awareness on HIV stigma and discrimination through the South Asia Regional Development Marketplace Partnership (2008-09).

The workshop attempted to bring together both public sector and private sector health care providers to develop common strategies for stigma reduction. This was part of NACO's aim of promoting stigma reduction within the public and private sectors.

The workshop was planned and facilitated by a team consisting of Ross Kidd and Vaishali Sharma Mahendra (ICRW consultants) and Enisha Sarin and Ajay Singh (ICRW staff).

The workshop was documented by Jyotsna Lall.

#### **Workshop Structure**

The workshop was organized in two parts:

Part	Days	Topics	Participants
I	1	Introduction to the main issues on HIV stigma – forms, effects, and causes, and an introduction to Universal Precautions	Representatives of the major medical associations (representatives of private sector) + doctors and counselors from public hospitals in which PPTCT operates (36 participants)
П	2–3	Exploring the root causes and effects of stigma and developing strategies to address stigma and strengthen Universal Precautions	Doctors and counselors from public hospitals in which PPTCT operates (22 participants)

#### Workshop Theme – Stigma within the health care Setting

The workshop used the interface of health care and people living with HIV as the focus for the workshop. Stigma has been identified as one of the main barriers<sup>1</sup> to the uptake of HIV prevention and treatment services. For instance, despite strong political support for improved HIV prevention and treatment planning at all levels, there is a nearly 45% attrition rate of pregnant women who test HIV positive in ANC clinics. Stigma experienced by the women, or the fear of stigmatization, may be a critical factor contributing to this high attrition rate.

Research shows that fear of stigma and discrimination makes people less likely to adopt preventive behaviours such as disclosing their status, access care and adhere to drug regimens<sup>2</sup>. Furthermore, a recent analysis of NACO's programme data indicates that more than 50% of HIV infected individuals are not aware of their HIV status. This, in turn, affects the timely access of ART services for those who would test positive<sup>3</sup>. Stigma is a prevalent, but largely unaddressed issue across the spectrum of HIV services, from prevention to testing to treatment. Stigma experienced by HIV positive people is generally manifested on several levels: at the institutional level within the health care system, at the community and family levels, and at the individual level when the HIV positive person blames himself or herself for acquiring the infection, thereby internalizing the stigma. These various sources of stigma must be addressed to increase the efficacy and impact of HIV prevention, treatment, and care.

HIV related stigma has been shown to exist in all health care facilities in India, both public and private. As ART, PMTCT, counselling and testing, and other HIV related programmes become increasingly available, access to these services will depend on the degree to which health workers recognize and respect the rights of all patients to health services in a stigma-free environment.

#### **Workshop Aim and Objectives**

The workshop aims were to:

- Sensitize a group of senior health professionals drawn from both the private and public sectors on stigma related to HIV infected people, and ways of addressing stigma.
- Train a cadre of mid-level health care workers of PPTCT centres attached to public as well as private hospitals on stigma reduction in the context of HIV/AIDS.
- Help health care facilities to develop effective institutional policies around stigma reduction.

The specific objectives of the workshop were to:

- Build a deeper understanding about HIV stigma its forms, effects, and causes and in particular how stigma affects the access of people living with HIV and other marginalized groups to PPTCT, ICT, and ART services.
- Develop increased knowledge about and confidence in dealing with HIV and AIDS and reduced fear and misconceptions about getting HIV through casual contact.
- Address explicitly the issue of Universal Precautions and how UP can support alleviation of fears of transmission that can drive stigma and discrimination.
- Develop a better understanding of and new attitudes of respect and tolerance towards people living with HIV and marginalized groups such as men who have sex with men, sex workers, and drug users.
- Analyze how stigma operates within the PPTCT context and develop practical strategies for uprooting stigma within this context.
- Develop increased commitment to act against stigma within health care settings and develop a code of conduct aimed at creating a safe and friendly hospital environment, one in which health workers and patients feel physically safe and psychologically safe.

#### **Participants**

Two groups of participants attended the workshop:

- 15 senior officials selected from the national medical associations attended the first day of the workshop – invited as champions and advocates for stigma reduction who could take a lead role in building stigma reduction programmes in their respective environments.
- 21 other health workers drawn from the PPTCT programme in public hospitals, and some NGO health workers attended all three days of the workshop. This group included 11 doctors, 3 counsellors, 1 lab assistant, 4 programme managers, and 1 communication advisor.

A list of participants and their organizations is given in **Annex A**.

#### **Workshop Methodology and Training Exercises**

The workshop used a participatory, experience based training methodology, built around small group discussion on stigma related problems drawn from the health work context. This approach was designed to create an open learning climate – one in which participants could share their ideas and experience, bring out their fears (eg about getting HIV in the health setting), re-examine their attitudes towards people living with HIV and marginalized groups, analyze how stigma operates in their own workplace context, and work together to develop strategies to uproot stigma. Health workers will only become aware of their own attitudes and become less judgmental through an active and interactive process – one where they can talk, think and share ideas and feelings with others – rather than through listening passively to lectures. This process helped to build a strong sense of ownership of the problem of stigma and a sense of responsibility for changing it – participants, without any defensiveness, pointed out various forms of stigma in their own health facilities and came up with strategies for creating a stigma free health facility.

The workshop made use of a wide variety of participatory learning tools, including pictures, case studies, participants' own stories, role plays, individual quizzes, rotational brainstorming, and individual reflection as a focus for discussion. The methods kept changing in order to keep the interest level high. To keep everyone awake and energized participants took part in a number of songs and games.





The workshop also made use of direct testimonials given by spokespersons for the PLHIV, MSM, and drug user communities, who know how it feels to be stigmatized. These testimonials had a powerful effect on participants, who admitted they had lots of misconceptions about marginalized groups before this session – and rated this session as the most effective learning session. It gave them an opportunity to relate to people living with HIV, MSM, and drug users as peers rather than the usual context where they are simply patients under their care.

All of the sessions were built around exercises from the Toolkit on HIV related Stigma Reduction in Health Care Settings, a trainer's guide designed by ICRW and international partners (including WHO, UNAIDS, UNDP, and ILO and other international NGOs) to guide health workers in recognizing and challenging HIV related stigma and discrimination in their own health facilities. This toolkit has been recently developed as a standardized training guide for use in pre-service and in-service training of health care workers on a world wide basis. This toolkit builds on Reducing HIV Stigma and Gender Based Violence: A Toolkit for Health Care Providers in India, a toolkit designed and tested by ICRW through a pilot project organized in Andhra Pradesh in 2007.

## **Summary of Major Outputs Existence and Forms of Stigma**

All participants agreed that stigma exists – and is a serious barrier to patient's access to services. They noted that health facilities often start the process of stigma towards people living with HIV: senior health care professionals are often the first to act in a stigmatizing way towards their patients and this behaviour shapes the behaviour and attitudes of other health workers and the community.

Participants identified the following forms of stigma in their own health facilities:

- Keeping HIV positive patients waiting a long time and serving them last, or referring HIV positive patients unnecessarily to other health workers or departments.
- Refusing to provide treatment e.g. doctors refusing to do surgery for patients whose HIV status is unknown, nurses refusing to inject, give drips, or give baths or bed pans to patients suspected to be HIV positive.
- Charging higher amounts (e.g. to women who are HIV positive).
- Separate collection of blood samples from suspected individuals (lab).
- Judgmental and moralizing attitudes among health workers towards patients living with HIV (eg "not being faithful to their partners").
- Talking in front of HIV positive patients about their condition during rounds.
- Marking the case sheets of HIV positive clients to distinguish them from other patients.
- Keeping HIV patients isolated in certain wards when there is no clinical need to do so.
- Forcing patients to be tested for HIV without their consent, without adequate pre- and post- test counselling, and without providing the results of the HIV test to the patient.
- Disclosing the HIV status of clients to other health staff; or to family members or other people without the consent of the clients.
- Revealing the status of HIV positive patients by loudly calling out their names.
- Excessive use of gloves and masks for routine tasks which don't involve the handling of bodily fluids; or wearing gloves only for patients who are suspected to be HIV positive.
- Burning linen used for HIV positive patients after surgery.
- Health workers working with HIV patients are also stigmatized.
- 45.4 % of health care workers avoid contact with patients suspected to be HIV positive.
- 39.7 % PLHIV reported that health care workers reported their HIV status to others.
- 37 % of patients living with HIV reported receiving poor quality care.
- 24 % of women living with HIV reported being denied access to health care services.

UNDP Study 2011

#### **Effects of Stigma on the HIV Epidemic**

Participants identified the following impacts of stigma on the HIV epidemic. They analyzed that stigma or the fear of stigma **stops** people living with HIV and marginalized groups from:

- Accessing health services getting tested for HIV and STIs, getting information on how to avoid HIV transmission and getting condoms and lubricant.
- Openly discussing their sexuality with health workers and providing complete information about their sexual practices – information needed for a proper diagnosis.
- Accessing treatment (antiretroviral therapy or treatment of opportunistic infections) they may delay getting the treatment of drop out after starting treatment.
- HIV positive mothers may avoid going to a health facility for delivery, or drop out of a PMTCT programme for fear of stigma or reprisal from partners.
- **Disclosing their HIV status and getting counselling**, care and support. PLHIV and other marginalized groups, because of stigma, are afraid to tell others about their HIV status.
- As a result, PLHIV may have difficulty protecting their own health and the health of their sexual partners – for example, by insisting on condom use with partners, using clean needles and syringes for drug use, accessing treatment to reduce viral load.

#### **Causes or Drivers of Stigma**

Participants agreed that the main causes of stigma included:

1) Limited recognition of stigma: Health workers do not realize that their attitudes, words, and behaviours are stigmatizing towards people living with HIV or other marginalized groups, and of the resulting negative consequences. Some health workers stigmatize without knowing it.



- 2) Moral judgments and values: Health workers may hold judgmental attitudes towards people living with HIV or other marginalized groups. These attitudes affect the services received by patients and act as barriers to accessing treatment and care.
- 3) Fear of getting HIV through casual contact: Insufficient knowledge among health workers about HIV transmission, can lead to fear about getting HIV through everyday interactions with patients while working in the health facility.
- **4)** Lack of knowledge and resources to implement Standard Precautions on a routine basis forcing health workers to resort to isolating patients suspected to be HIV positive as a form of protection.

#### Moralizing Attitudes – The Need to Suspend Judgement

Participants were remarkably open and admitted to having judgemental attitudes towards people living with HIV and other marginalized groups such as men who have sex with men, transgender people, sex workers, and drug users. This was reflected in moralizing statements such as, "he was unfaithful", "How did she get HIV?" and "Why do MSM practice those behaviours?" Participants did, however, recognize that these moralizing judgements hurt people living with HIV and adversely affected their access to health services. The judgements or the fears of being "found out" and judged discouraged PLHIV and marginalized groups from using health services, or if they did use these services, they often did not reveal their sexuality or drug use to the health worker, and as a result they did not receive appropriate services. Participants concluded that health workers need to *suspend their judgement* — to stop judging people living with HIV and other marginalized groups and treat them with respect and tolerance instead.

Participants admitted that they knew very little about men who have sex with men, transgender people, sex workers, and injecting drug users. For some it was their first time to listen to and learn from representatives of these communities. Normally they meet members of marginalized groups as patients, rather than as resource persons giving them an insight into their lives. The persons who gave the testimonials were patient and answered all their questions, even those which were intrusive or stigmatizing. The gay man, for example, explained that gay people fell in love and wanted long-term, stable relationships like heterosexual people. The HIV positive woman explained that she had faced lots of stigma and discrimination because she was a woman – she was condemned as "being loose" and was kicked out of her house by her in-laws who refused to support her.

Participants said that lack of knowledge about marginalized groups resulted in health workers making assumptions about these groups eg condemning them as "promiscuous" or "mentally sick" or "immoral". They recognized that some of their assumptions were stereotypes – things we say about other people that we know little about. Often we believe these assumptions are facts about other people, when in fact they are false. This belief leads to prejudice, resulting in stigma and discrimination. Because of this lack of knowledge, some health workers may be hostile with patients from marginalized groups, refusing to treat them or using insulting language, asking invasive questions, and breaching their confidentiality. Participants agreed that their lack of knowledge about marginalized groups was the source of stigma – and agreed to learn more about marginalized groups and respect them as human beings.

#### How to interact with patients who are from marginalized groups -**Counselling Skills**

Participants noted that they had very little training on how to interact with marginalized groups, so a role playing session was introduced to develop skills in counseling patients who are gay, sex workers, or people living with HIV. In each of the role play scenarios, the counselor had no advance information on who the patient was and what his/her concerns were - the counsellor's job was to ask questions and listen carefully to find out more about the patient's situation and provide support, without using stigmatizing language.

Through the role playing and debriefing participants learned the following:

- All patients have the right to access counselling services and with the same quality.
- We should accept and respect patients as they are and be non-judgemental.
- We need to make the patient comfortable and put him/her at ease.
- The words we use should be non-threatening, easy to understand, and avoid judgement.
- Treat each patient as an individual and be open to what they need to discuss.
- Listen carefully and respect each patient's issues and explore the context in which they live in order to help frame good decisions.
- Be aware of the difference between giving advice and imposing our own morality eg telling a patient to stop sex work or stop using drugs.



## Fear of Getting HIV in the Health Care Setting and Standard Precautions

Participants agreed that there was a lot of fear among health workers about getting HIV through their work in health facilities. This fear is based on lack of knowledge about how HIV is transmitted, and how HIV is not transmitted. For example some health workers still believe that HIV can be transmitted through casual contact eg through touching a patient who is HIV positive. Because of this fear many health workers insist on knowing who has HIV so they can protect themselves (eg by limiting contact with any patient suspected to be HIV positive). Many health workers feel they have a **right to know** who has HIV, and believe that not knowing who has HIV puts them at risk.

Mechanisms for identifying who has HIV include: sharing information on who has HIV with other health workers, compulsory HIV testing, marking the files of patients living with HIV, etc. These mechanisms are viewed as legitimate ways to protect health workers, but in fact there is no medical justification for these forms of protection. They do not protect the health worker because HIV is not contagious; it is not spread through casual contact. Trying to put patients into two groups – those who are HIV positive and those who are negative – can be counterproductive. It is impossible to tell who is HIV-positive based on appearance. Most blood borne diseases that pose a risk to health workers and patients cannot easily be detected and could be present in the blood of ALL persons, including health workers. Health workers may be more cautious with HIV positive patients and less cautious with HIV negative patients, even though some of the negative patients may be in the window period, when people are at their most infectious or have other blood-borne infections such as hepatitis.

These mechanisms are stigmatizing – they isolate HIV positive patients or those suspected to have HIV, create a climate of fear around them, and cause those with HIV to be stigmatized.

It was generally agreed that **Standard Precautions provide a better, non-stigmatizing method for protecting health workers and their patients from the risk of HIV exposure.** Standard Precautions are based on the assumption that all blood and bodily fluids are potentially infectious, regardless of the patient's known HIV status, and should be applied in all patients, not just those assumed to be HIV positive. Standard Precautions gives health workers more control over ensuring their own safety within the health setting, while ensuring the safety of their patients.

#### **Applying Standard Precautions on a Routine and Consistent Basis**

While it was generally agreed that Standard Precautions provide the best form of protection for health workers, participants noted that more efforts were needed to ensure that Standard Precautions were implemented on a routine and consistent basis in all health facilities. They identified the following constraints on the use of Standard Precautions:

Guidelines on Standard Precautions often don't reach the front line health workers. They
may reach the health facility managers but not get disseminated further.

- Some health workers have not received sufficient training on standard precautions.
- Some health workers are lazy or reluctant to follow standard precautions.
- Casual approach e.g. some doctors wear only one glove to conduct a pelvic examination.
- Work overload and time pressure results in health workers not applying standard precautions.
- Non availability and non functioning of equipment especially in government facilities; this includes running water, autoclaving equipment, needle destroyer, shortage of gloves etc.
- High costs involved in getting the materials and equipment for Standard Precautions.
- Management issues some managers are unaware of the procurement process, poor support to obtain supplies.

They made the following suggestions on improving the application of Standard Precautions:

- Providing frequent reminders on the basic message that Standard Precautions should be applied uniformly to all patients, rather than singling out patients assumed to be HIV positive.
- Sensitizing patients and the community on Standard Precautions so that they understand why and how Standard Precautions are practiced – this will help to reduce patients feeling that they are stigmatized (once they understand that SP is practiced uniformly for ALL patients).
- Overcoming the view that Standard Precautions are not practical/feasible or cost effective.



- Allocating sufficient resources for Standard Precautions and effective supply chain management so that protection devices like gloves, masks are always available.
- Providing immunization against Hepatitis B for all health workers, and just doctors.

#### Dr. Bipin Ahmin, an expert on Standard Precautions, added the following recommendations:

- Double gloves should be worn for any surgery over 30 minutes, regardless of the HIV status of the patient.
- There is a code for the disclosure of HIV status to the family and sexual partners of HIV positive patients. Each case has to be evaluated.
- There is also a code for discordant couples. Legally, one cannot inform the partner but can counsel the HIV positive partner to disclose to his/her spouse, except in a divorce case.

#### Post Exposure Prophylaxis (PEP)

The workshop also looked at the issue of Post Exposure Prophylaxis (PEP) and how this issue can lead to health workers being stigmatized. It was agreed that PEP can result in inadvertent disclosure of a health worker's status. If the health worker knows she is HIV negative, she will move quickly to get PEP. If she knows she is HIV positive, she will be less worried about making use of PEP drugs. So this exposes health workers to stigma from colleagues, who may ask -"Why did she not rush for PEP?"

Participants described the following PEP procedures in their health facilities:

- A focal point health professional is appointed to coordinate the PEP service.
- The patient and the exposed health workers are both referred to the counselling centre and their consent taken.
- PEP is not administered without consent.
- On an emergency basis PEP is available without counselling.
- Pre test counseling is not mandatory.
- Separate protocol regarding known and unknown source.
- PEP drugs are stored in different locations of the hospital.
- In case of a pinprick, gloves are removed and immediate washing and rescrub.

Participants also identified the following constraints on the PEP programme:

- Lack of PEP guidelines in some health facilities.
- The new institutes do not have PEP centres as a pre-requisite.
- PEP drugs are often administered without counselling.

- There is a chance of the health worker who takes PEP being stigmatized by other health workers.
- Lack of supply of PEP drugs.
- Delayed reporting of PEP.

Participants agreed on the following strategies to de-stigmatize PEP administration and make it more accessible:

- A designated focal point for PEP who knows how to grade the level of exposure and medicate appropriately.
- Educate all staff on PEP and help them understand that PEP can be potentially stigmatizing.
- Emphasize that WHO has recommended PEP to be safe and effective.
- Encourage all health workers to know their HIV status; if positive, to get access to ARVs.
- Ensure the confidentiality of health workers and patients throughout the PEP process.
- Provide ongoing counselling for those requiring PEP a minimum schedule of counselling.
- A telephone helpline to help health workers get more information on PEP.
- A budget for PEP to ensure that it is available at all facilities.



#### **Strategies for Uprooting Stigma**

It was generally agreed that removing stigma starts at home – that we all need to uproot our own stigmatizing attitudes first before advocating stigma reduction with other people.

In the final session of the workshop and in other sessions participants worked out the following strategies for uprooting stigma within the health care context:

#### **Training**

- Training is needed at all 3 levels tertiary, secondary, and primary.
- Incorporate stigma into the pre-service training curricula for all health workers (doctors, nurses, para-medical, counselors/social workers, etc).
- Include in the stigma training curricula:
  - Upgrading knowledge on HIV transmission, Standard Precautions, and PEP.
  - Re-examining attitudes and encouraging the suspension of judgement.
  - Understanding the concerns, needs, and lives of marginalized groups.
  - Communication skills to interact with different types of marginalized groups in a non-stigmatizing way and without breaching confidentiality.
- Provide in-service training for all health workers SACS to take the lead, but broaden the trainer base so that it is not the exclusive responsibility of SACS.
- Involve people living with HIV and other marginalized groups as stigma reduction trainers.
- Provide codes of conduct for all health workers and all HIV related health programmes.
- Sensitize senior health professionals as models of non-stigmatizing approaches.

#### **Destigmatizing Health Services**

- Ensure equitable access to health services by all patients.
- Agree on codes of conduct or standard operating procedures for all HIV related health services.
- Challenge health workers who refuse to treat HIV positive patients.
- Provide feedback forms and a redressal mechanism for patients and other concerned persons to report denial of services and other forms of discrimination.
- Establish a regular stigma monitoring mechanism in each health facility.
- Promote the consistent use of Standard Precautions with all patients.

#### Counselling, Confidentiality, and HIV Testing

- Counselling:
  - Provide private space for counselling, separate from the blood testing centre.
  - Ensure privacy during counselling.
  - Provide both male and female counselors.
- Confidentiality:
  - Define who needs to know and who does not need to know among health workers.
  - Maintain confidentiality while distributing medicines including PEP for accidental exposure.
- HIV testing:
  - Mainstream HIV testing with the other lab activities.
  - Collect the blood samples from central testing points.
  - HIV status reports should be sealed and addressed to the concerned person.
  - Use a code when referring the patient to the TB program.

#### **Community Awareness**

- Organize media campaigns to raise awareness and change attitudes in the general population.
- Involve local government, work with NGOs, include stigma in the sex education modules in schools.
- Organize home visits in ways that avoid creating suspicion among neighbours.



#### **Individual Action Plans**

As the last activity in the workshop participants recorded their own individual action plans:

- Share what I have learned with other staff members (5).
- Conduct sensitization workshops for other health workers (5).
- Implement a new code of conduct in my own health facility (2).
- Conduct regular meetings on stigma with other health workers.
- Apply what I have learned in the best possible way i.e. de-stigmatize my own practice.
- I will talk about stigma whenever I get the opportunity.
- Incorporate stigma awareness into the training curriculum for health workers.
- Prepare teaching modules on stigma to train health workers.
- Start teaching colleagues by example.
- Become a role model to other staff on how to de-stigmatize our health facility.
- Sensitize other staff to be careful in their non-verbal gestures.
- Ask administrators to open a NACO extension centre in our medical institute.
- Advocate with NACO for more such trainings.

#### **Endnotes**

- 1. Nyblade and Field 2000; Stringer et al. 2003; Turan et al. 2008; Chikonde et al. 2009; Brickley et al. 2008; Sinha et al. 2008; UNICEF et al. 2009; Rahangdale et al. 2010.
- 2. Thomas et al. 2005; Nyblade 2006; Zelaya et al. 2008; Nyblade et al. 2008; Genberg et al. 2009; Visser et al. 2009; Nyblade et al. 2009.
- 3. Sogarwal and Bachani, 2009.

## **Workshop Proceedings**

#### Day 1, Session 1: Inauguration

This three-day workshop was one of the first on the issue of stigma reduction. It was divided into two parts – day one was spent on basic sensitization and the subsequent two days were spent on understanding the issue in greater detail in order to:

A sobering reality is that after more than two decades of the epidemic, stigma and discrimination remain major blocks to effective HIV responses.

- Sensitize a group of senior health professionals drawn from both the private and public sectors on stigma related to HIV infected people, especially HIV positive pregnant women, and ways of addressing stigma.
- Train a cadre of mid-level health care workers of Prevention of Parent to Child Transmission (PPTCT) centres attached to public hospitals on stigma reduction in the context of HIV/AIDS.
- Help health care institutes to develop effective institutional policies around stigma reduction.

The issue and its importance were reflected by the presence of a large number of senior officials from the government and UN agencies working on HIV.



**Dr Mariam Claeson,** World Bank recalled that the last meeting in March 2010 shared the stigma reduction techniques but missed out stigma reduction in health care settings. Stigma is a major barrier to seeking treatment and often leads to treatment that is sought very late or HIV positive patients starting ARV treatment and then dropping out.



The aim is to bring stigma reduction to the forefront. She was of the view that stigma reduction has to begin at the individual level. She said that this workshop was a 'work in process' and not the finished product and urged participants to give their feedback. She also noted that one of the first tasks undertaken by Mr Sayan Chatterjee, Director General and Secretary NACO was stigma reduction.

Ms Aradhana Johri, Joint Secretary, NACO brought home the reality of stigma by quoting recent incidents where a family was burnt alive for being HIV positive or HIV positive students denied hostel accommodation or HIV positive school children thrown out of school. She felt that this workshop was being held not a moment too soon.

She emphasized the need to work on stigma as HIV status carries a large stigma in society with women suffering double stigma.

She highlighted NACO's role in responding to this issue by coming out with a policy on stigma reduction and a draft bill on the Right to Education, Health and Employment is in the pipeline but she also pointed out that brining in new policies is a time consuming process in the government. She was of the opinion that this workshop was a multi stakeholder response to the issue. She felt that some HIV friendly policies had achieved a measure of success through the training of Auxiliary Nurse Midwives and Accredited Social Health Activists, but there was a long way to go.

She noted that the second Red Ribbon Express had been very effective in raising debate and discussion as 8 million people had watched it and 8000 people had been trained on it and politicians had also participated.



She focused on the need to work on stigma reduction in health care settings as she felt that health care workers feared getting infected through contact with HIV positive patients or if Post Exposure Prophylaxis failed. She felt that these concerns indicated a need to adopt standard precautions and a change in attitude. She also felt that in the Indian setting, there was a huge need to engage with the private sector.

Ms Caitlin Wiesen, Country Director, UNDP felt that stigma was the final frontier that needed to be removed. She highlighted India's achievements in terms of coverage and infrastructure. Some of the key successes being:

- 1290 targeted interventions, covering 1.1 million key populations at a higher risk.
- Over 9 million HIV tests carried out in 2009 with 300,000 being among persons of key populations.
- 302,948 adults and 19,613 on ART as on April 2010 with 970 patients on second line ART across the country.

Ms Wiesen also pointed that while there has been a steady decline in new HIV infections, much needs to be done to sustain the achievements and reach the scale to turn the epidemic around. The fact that stigma and discrimination remain major blocks to effective HIV responses was a sobering reality. She noted that stigma operates at both personal and structural levels.

Unfortunately, many social groups associated with HIV – men who have sex with men, sex workers, and injecting drug users – are rejected by society and the infection is seen as a 'just punishment'. They have to face the shock of receiving a HIV positive test result along with the insensitive behavior of some health care workers.

Quite often, we are treated like sex workers rather than women, a distinction that is the heart of the matter. She quoted from the soon to be released UNDP India study on levels of stigma which reported that:

- 45.4 per cent of health care workers avoid people living with HIV.
- 39.7 per cent of PLHIV reported that health care workers reported their status to others.
- 37 per cent reported receiving poor quality care.
- 24 per cent of women living with HIV reported being denied access to health care services.

The other significant statistic is that of the 20 per cent (5.5 million) out of the 27 million pregnant women tested, only a third reached the PPTCT centers – the main cause of the high drop out likely being stigma.

Ms Wiesen pointed out that stigma reduction in clinical settings needed to address not just the attitudes and practices of health care workers but also their needs of information, training and supplies and that no policy or law can alone combat discrimination.

She said that the combined efforts of NACO, civil society and development partners had resulted in improvement of the situation at the ground level but there was a long road ahead in terms of shifting attitudes, norms and behaviour to access health care at the individual, community and societal levels with stigma and discrimination being the last mile – and the last mile is often the hardest.

**Ms Yvonne Cameroni,** UNICEF raised the issue of stigma affecting HIV positive children and of a study where children reported discrimination in health care settings. She also raised the issue of adolescents and the absence of a strategy to address their needs.

**Dr Ravi Verma**, ICRW made a presentation that gave an overview of HIV associated stigma and discrimination. He gave empirical evidence and numbers to commonly known issues that



help decide policy. He also pointed to stigma being a reflection of power dynamics not confined to HIV.

He began with Erving Goffman's definition of stigma as an "attribute that is deeply discrediting (and that reduces the bearer) from a whole and usual person to a tainted, discounted one." He said that stigma was a dynamic process with four steps —

Step 1: Distinguish and label differences.

- Step 2: Associate negative attributes to perceived differences.
- Step 3: Separation of 'us' from 'them'.
- Step 4: Loss of status and discrimination.

He spoke of the causes, consequences and forms of discrimination in general settings and health care settings. He also spoke of the need to address fears and misconceptions, discuss and question the values and beliefs that underlie stigma, and develop possible strategies to challenge stigma. He said that one of the major lessons learnt from ICRW's research is that it was

No one should be turned away from a medical institution without treatment because of his or her HIV status.

easier to make people aware that they are stigmatizing and reduce fear driven stigma than to address and have an impact on 'value-driven stigma'. He advocated a combination of approaches to remove stigma and discrimination and the need to develop practical stigma reduction tools. (For a copy of the detailed presentation, please see Annex 1).

Mr Sayan Chatterjee, DG and Secretary NACO in his key note address agreed that the stigma and discrimination faced by people living with HIV in health care surroundings was a matter of grave concern. He pointed out that the third phase of the National AIDS Control Programme lays a strong emphasis on reducing stigma. He highlighted the role of NACO in working on the issue through sensitization programmes but agreed that it had been limited to a narrow band of service providers. He emphasized the need to scale up this programme and reach out to much larger numbers of health care providers.



He explained that NACO is in the process of developing an integrated strategy for addressing stigma and discrimination that includes addressing stigma at work places and educational settings. He also focused on the sensitization programmes at the community level.

Dr Chatterjee highlighted the recent policy on Greater Involvement of People living with HIV/ AIDS (GIPA) which is to be announced shortly. He also spoke of the social security schemes for people living with HIV such as widow pensions, extra rations, free legal aid and travel concessions. He concluded with the hope that this workshop would give new insights and directions to address stigma and its reduction and that every PLHIV should have access to every health facility be it government or private with dignity.

#### Day 1, Session 2: Expectations, Objectives and Norms: Naming Stigma in health facilities

The objective of this session was for the participants to state their expectations, for the organizers to share the workshop objectives and to develop norms for the workshop. The second part of the session aimed to identify different forms of stigma which occur in health facilities and discuss examples of stigma from their own health facilities

Each participant was asked about his or her expectations of the workshop through a 'buzz group' i.e. each participant turned to his/her neighbour and discussed what they expected to get from the workshop. The expectations that emerged were:

- i. Learn how to convince people to overcome stigma.
- ii. Learn how to remove stigma.
- iii. Introspection as health providers on stigma.
- iv. Be able to 'begin with ourselves'.
- v. Learn from experiences from the field.
- vi. Share personal experiences and challenges.
- vii. Learn how to increase awareness in public at large.
- viii. Learn how to bring in accountability.
- ix. Learn how to measure changes as a result of interventions and learn about instruments that others have used.
- x. Develop a framework that includes people at all levels to reduce stigma and discrimination.
- xi. An in depth understanding of stigma and discrimination.
- xii. How to overcome stigma and discrimination as health care workers providing HIV services.
- xiii. Role of Federation of Obstetrics and Gynecologists Society of India (FOGSI).



- xiv. Some strategy to remove stigma and discrimination in the private sector.
- xv. Good integration between private and public sector.
- xvi. Have a clear idea of deliverables.
- xvii. A road map to go ahead.
- xviii. Identify causes for stigma and discrimination especially in the context of women and children.
- xix. Identify barriers and challenges to HIV care.
- xx. Mechanisms to protect health workers.
- xxi. How to identify key individuals in the community to decrease stigma and discrimination.
- xxii. Consensus on easy to use indicators of stigma to apply widely.
- xxiii. Guidelines to medical council to include communications.
- xxiv. How to overcome personal fears.

The expectations of the participants were compared with the stated objectives of the workshop. While there was much overlap between them, there were some new ideas and there would be an effort to incorporate as many of them as possible. The objectives were:

- i. Stigma in the health care context the forms, effects and causes.
- ii. Identification of marginalized groups sex workers, MSM and IDU etc.
- iii. Sharing of Universal and Standard Precautions including Post Exposure Prophylaxis (PEP).
- iv. New attitudes respect and tolerance caring and support.
- v. Strategies for challenging stigma.
- vi. Ownership of the stigma problem and commitment to action.
- vii. New codes of practice to challenge stigma.
- viii. Roll out plan the idea has to grow beyond the 40 odd participants of this workshop.

Next, the norms to be followed during the course of the workshop were decided – again in a participatory manner in an open brainstorming session. The norms decided were:

- i. Participants should be punctual.
- ii. People should speak one by one.
- iii. There should be no murmuring in the background.
- iv. There should be no repetition.
- v. Participants should listen to each other's viewpoint.
- vi. Time management according to schedule.
- vii. The cell phone should be on silent mode.



- viii. Participants should be brief and concise when stating their points.
  - ix. Real life experiences should be shared.
  - x. There should be no discrimination between participants who speak a lot and those who do not.
  - xi. Productive ideas should be highlighted.
- xii. People should be honest and highlight their fears.

Once the modes of working had been decided, the workshop began in earnest. The first activity was naming stigma through pictures. The participants were divided into 10 groups of 3–4 members each. Each group was then asked to choose one picture from a selection of displayed pictures. Each group had to answer the following questions:

- A. What is happening in the picture?
- B. Why is it happening?
- C. Does this happen in your facility? If yes, give examples.

Through this activity, different forms of stigma were identified. (See annex 4.) The participants also shared stories of stigma occurring in their facilities. In addition, this activity raised some questions:

- Does the patient need to know the HIV status of the health care provider?
- Stigma often originates from health care services health workers stigmatize their patients and this behaviour is then followed by the community.
- There was a suggestion that some 'model' centres should be opened where standard precautions would be followed for reduction of stigma.
- How do discordant couples (one positive, the other negative) manage their relationship?

• The requirement of protecting confidentiality raises the whole issue of stigma— if there was no need to maintain confidentiality then there would be no stigma.

One of the facilitators then presented the following synthesis:

- i. Sometimes we treat people badly. We isolate them or reject them e.g. refusing to sit beside someone who is assumed to have HIV; or we gossip about them and call them names. When we isolate or make fun of other people, this is called STIGMA.
- ii. When we stigmatize people, we isolate them, saying they are a danger/threat to us (because we think they might infect us with HIV or we might be negatively affected by their behavior), or we judge them, saying they have broken social norms and should be shamed or condemned.
- iii. Stigma is a belief or attitude. The action resulting from stigma is discrimination or unfair treatment such as PLHIV or other stigmatized groups being refused treatment in a health facility.
- iv. Sometimes health workers make judgments about people without realizing how this will affect them, or the health services they receive. Heavy workloads and stress also affect how we treat our patients.
- v. Stigma is not good. Stigma hurts people. When we stigmatize, it makes people feel bad, lonely, ashamed and rejected. They feel unwanted and lose confidence and as a result, they may take less care in protecting their health (e.g. stop using health facilities and condoms).
- vi. There are different forms of stigma:
  - **ISOLATION AND REJECTION** based on ignorance and fear about HIV transmission or about the behaviours of a marginalized group. The person stigmatized is forced to sit alone, eat alone, live alone.
  - SHAMING AND BLAMING gossip, name calling, insulting, judging. Stigmatized people are "blamed" for assumed "bad behaviour", for breaking social norms.
  - **DISCRIMINATION** (ENACTED STIGMA) unfair treatment such as refusing to operate on HIV positive or marginalized patients, or treating them last, or testing patients without their consent.
  - d. **SELF-STIGMA** – People living with HIV or marginalized groups stigmatize themselves in reaction to stigmatization from society. They accept the blame and rejection of society, and withdraw from social contact or exclude themselves from accessing health and other services out of fear of having their status revealed.
  - STIGMA BY ASSOCIATION People associated with stigmatized groups often face e. stigma themselves. The family of a PLHIV or a person from a key population may be stigmatized because of the stigma faced by their family member – the reputation of the family is affected. Some health workers are stigmatized for working with HIV patients or marginalized groups.
  - f. LAYERED STIGMA – Marginalized groups (MSM, sex workers, injecting drug users) are already stigmatized. When they get HIV they are doubly stigmatized – another

layer of stigma. There are also layers of stigma. People who experience HIV stigma may also be stigmatized on the basis of other stigmatized identities. For example a woman could be stigmatized as a woman, a sex worker, a drug user, a person living with HIV, a woman without children, or as a HIV positive woman who is pregnant. Each layer of stigma magnifies the level of stigma. This makes it even more difficult for them to access health and other services and to get out of their hidden, marginalized existence.

## Day 1, Session 3: Assessing the impact of stigma on access to HIV related services and prevention practices including PEP

The objective of this session was to help participants see how stigma or the fear of being stigmatized affects people living with HIV and other key populations.

For this exercise participants were divided into six groups. Each group was given a case study with questions at the end. Each group had to discuss and answer those questions. (For case studies and questions see annex 5).

The group felt that the impact of stigma was as follows:

- Stigma or the fear of stigma **stops** people living with HIV and key populations from:
  - a) Accessing health services getting tested for HIV and STIs, getting information on how to avoid HIV transmission and getting condoms and lubricant.
  - b) **Openly discussing their sexuality with health workers** and providing complete information about their sexual practices.
  - c) **Accessing treatment** (antiretroviral therapy or treatment of opportunistic infections).
  - d) **Using other services** for example a pregnant woman living with HIV is discouraged from HIV testing and making use of the PMTCT program.
  - e) Disclosing to their partners.
  - f) Protecting their own health and the health of their sexual partners for example, by insisting on condom use with partners, using clean needles and syringes for drug use, accessing treatment to reduce viral load.



- g) Disclosing their HIV status and getting counselling, care and support. PLHIV and other key populations, because of stigma, are afraid to tell others about their HIV status. As a result, they may have difficulty negotiating condom use, accessing services, support, and treatment for HIV, and therefore be at more risk for transmitting HIV to their partners.
- It is the fear of being stigmatized which stops PLHIV and key populations from taking appropriate action to protect their health, and the health of their partners. It is this fear which stops PLHIV and key populations from accessing health services, finding out their own status, and negotiating safe sex/drug use practices with partners. This increases the risk that they will contract HIV, and the risk that they will then pass HIV to their partners.
- If on the other hand, PLHIV and key populations are treated with kindness, support, and care, they will be more likely to access health services and take precautions in their sexual relationships.
- Sometimes when public health professionals try to help, the language that they use is so technical that it backfires and they end up stigmatizing without meaning to.
- There was some discussion on the use of PEP for occupational exposure but the group could not reach a consensus on it.
- There was a rich discussion on vulnerability versus in-built bias. Some participants felt that stigma can only be addressed if the service providers decide not to go into the morality/ immorality of the case but suspend judgement and treat the case as it is and that as health care workers it is important to identify one's own in-built biases. Other participants felt that health care workers are also vulnerable to opinions. There was agreement that while everyone is entitled to have an opinion and as humans we naturally judge other people, we need to suspend our judgements when providing health care. It is the judgements towards PLHIV which hurt – and are counterproductive.

#### Day 1, Session 4: Standard precautions and stigma

The objective of this exercise was to introduce standard precautions so as to avoid stigma and discrimination.

The session began with a small individual exercise called 'Risk Clarification Exercise' (See Annex 4 for details).

This was a set of nine statements that the participants had to agree or disagree with and state why. Each statement and the discussion is given in the following section.

Statement	Discussion
Patients who are HIV positive should be placed in a separate room.	General agreement that this is not needed as HIV not transmitted through casual contact.
The linens of HIV positive patients should be separated from the linens of other patients and washed separately.	There was some disagreement – but the dominant view was that this was not needed as the HIV virus dies with hot water and detergent and exposure to air.
All patients prior to surgery should be given a HIV test.	Some agreement – some felt that this was a good practice but the dominant view was that if standard precautions are followed for all patients then the risk of HIV is minimized. Also there is a window period when the HIV infection would not show up; therefore the test before surgery is meaningless.
You should only use gloves when coming into contact with the blood of HIV positive patients.	Group disagreed – standard precautions should be followed.
Special care should be taken only when cleaning up the blood spills of HIV positive patients.	Group disagreed – standard precautions should be followed.
After giving an injection to HIV positive patients, the needle should be separated and treated differently than needles used with other patients.	Group disagreed – standard precautions should be followed. All needles should be destroyed.
Gloves must be used at all times when touching HIV positive patients.	Group disagreed – standard precautions should be followed.
	When coming into contact with the skin of all patients, a health worker needs to wear gloves only if the patient's or health worker's skin is not intact. There is no need, however, to use gloves when feeding a patient or taking his/her temperature.
Health workers are at greater risk in health care settings of getting hepatitis C than getting HIV.	Group agreed as hepatitis C is 300 times more infectious than HIV.
Health workers should treat the blood of all patients as having the potential of transmitting HIV, HBV and HCV.	The group agreed with this statement.

For the next activity, the group was asked to discuss the following questions in buzz groups i.e. (each participant discussed with their neighbour and then shared in the larger group):

- What are some standard precautions used in your facility?
- What are the barriers to the use of Standard Precautions?

The responses were as follows:

What are some of the standard precautions used in your facility?	What are the barriers to the use of Standard Precautions?
Bed linen washed every 2 days.	Individual attitude/casual approach e.g. some doctors wear only one glove to conduct a pelvic examination.
Hands washed/hand sanitizer used.	Patient load.
Using disposable needles + proper disposal of used syringes.	Tendency to forget to use standard precautions during emergency situations.
Personal protective equipment used.	Non availability and non functioning of equipment, especially in government facilities; this includes running water, autoclaving equipment, needle destroyer, shortage of gloves etc.
Double gloves during surgery.	Reluctance to follow standard precautions.
Proper disposal of sharps.	Ignorance about standard precautions.
Treatment of spills.	Too expensive to follow standard precautions.
Bangle breaker bag used.	Shifting responsibilities – passing the buck!
Color coded bins for waste disposal.	Managerial issues/red tape – doctors unaware of procurement process, poor support to obtain supplies.
Delivery kit used.	Laziness especially in hand washing.
Autoclaving of instruments.	Convenient to disagree to treat HIV patients.
Disinfection of flooring especially in OT.	Some health workers use the same pair of gloves all day long as their form of hygiene, not realizing they may be infecting everyone they come into contact with.

#### The session was summed up with the following observations:

Universal Precautions refers to practices performed to protect health workers from exposure to blood borne micro-organisms. 'Universal' means that these precautions

should be applied universally – with all patients irrespective of whether health workers know their health status or not.

- Standard Precautions has replaced the term 'Universal Precautions'. It is a broader term that includes not only safety for health workers but for patients and visitors as well. It is also a broader term which covers safety from exposure to not only blood and bodily fluids, but also to other health care associated infections.
- Standard Precautions is a system for infection control used to make health facilities safe for health workers and



patients. It involves the use of precautions which are designed to help minimize the risk of HIV exposure by health workers and patients.

- The first principle of Standard Precautions is that health workers apply the precautions to ALL patients, regardless of whether or not they think the patient may be HIV-positive or have any other infectious disease. It is important to emphasize, however, that Standard Precautions deal with all health care associated infections, not just HIV.
- It is safer to act as if every patient is infected, rather than to apply Standard Precautions to some patients and not to others. This is important because it is impossible to tell who is HIV-positive based on appearance. Most blood borne diseases that pose a risk to health workers and patients cannot easily be detected and could be present in the blood of ALL persons, including health workers.
- The second principle is that Standard Precautions are designed to protect both health workers and patients from infection.
- The general topic areas of standard precautions include:
  - Hand hygiene.
  - Using barriers (surgical attire including gloves, masks, etc).
  - Aseptic techniques.
  - Use and disposal of sharps.
  - Instrument processing.
  - Housekeeping and waste disposal.
  - Respiratory hygiene and cough etiquette.

#### Day 1, Session 5: Introduction to Federation of **Obstetricians and Gynecologists Society of India (FOGSI)**

Dr Lakshmi, FOGSI addressed the group and introduced the federation. She said that FOGSI was a large organization with 216 societies and 27,000 members all over the country. They were committed to reducing stigma and actively worked to reduce PPTCT by conducting sensitization workshops for members and running a 24X7X365 helpline for all its members.

They are proposing to conduct one-day sensitization workshops on the issue of HIV transmission, PEP and counseling not just for their members but for any health care workers who need it.

She pointed out the need to engage with the private sector as 60–70 per cent of institutional deliveries take place in the private sector and working with greater awareness will work towards reducing mother to child transmission.

#### Day 2, Session 1: Evaluation Review

At the end of day 1, all participants were given a feedback form and two participant volunteers summarized the learnings.

The feedback was as follows:

#### Likes:

- Very interactive and participatory
- Brought people together on a single platform for discussion
- Dr Ravi Verma's presentation
- · Naming stigma through pictures
- Case discussions were good
- The discussion on universal precautions
- Dr Kidd's inspiring claps!

#### Dislikes:

- None
- Too much cross discussion
- Cultural and personal biases of HCWs not discussed
- Absence of NACO guidelines on universal precautions
- No take home messages
- Most participants reluctant to 'listen' to others

#### **Major Learnings:**

- Sensitization about stigma and the impact of stigma on HIV patient services
- Misconceptions about people regarding stigma
- Medical personnel are a major source of stigma
- Practical approach to stigma reduction
- Discussion through cases and pictures

#### Issues that need further discussion:

- Define tools to identify and manage stigma
- How to deal with discordant couples
- Key population vulnerable or bias?
- Policies for the public and private sector
- NACO guidelines on universal precautions
- Premarital testing
- Confidentiality
- All the topics in the parking lot!

#### Suggestions:

- Conduct a pre workshop awareness level
- Workshop should extend to states and districts
- Two levels of workshops basic (3-5 days) for non doctors and advanced (1 day)for doctors
- Field visits/role plays should be included
- Should include more discussion on gender and psycho social impact on stigma

#### Day 2, Session 2: Learning Review

The learning review was carried out through an exercise called the 'hot potato' where a ball was thrown around and the person who had the ball had to say one thing that they learnt about stigma the previous day. The learnings of day 1 were as follows:

- Stigma begins with senior health care professionals and the others follow.
- Social norms and personal biases guide stigma.
- There is a need to accept every patient.
- There is no need to isolate everybody.
- All participants agreed that stigma exists and that is a huge step forward.
- Stigma itself needs to be evaluated.
- Need to learn more about MSM.
- Stigma leads to higher levels of vertical transmission.
- Need to learn how to convince people that life is still beautiful beyond HIV.
- Greater awareness about marginalized groups.
- Sensitization has to be across the board.
- Linen and syringes of HIV+ve patients do not need separate disposal.

# Day 2, Session 3: Stigma in our own lives: Our own experience of being stigmatized

The objective of this session was to help participants share some of their own personal experiences concerning stigma and identify some of the feelings associated with being stigmatized.

The participants were asked to sit on their own and asked to "Think about a time in your life

when you felt lonely or rejected for being seen to be different from others." It was explained that this does not need to be examples of stigma toward people living with HIV or other marginalized groups; it could be any form of stigmatization for being seen to be different eg being small, poor, or bad at playing cricket. Participants were asked to think about what happened, and how it felt.



Then, they were asked to find someone with whom they felt comfortable and to share their experience with them. Finally, they were invited to share their stories in the large group. In order to facilitate sharing, all the participants sat on the floor in a tight circle to bring in the sense of community and make sharing easier.

This was voluntary; no one should be forced to give his/her story. People shared if they felt comfortable. As the stories were presented, they were asked, "How did you feel? How did this affect your life?" (For examples of the stories, please see Annex 5)

This activity helped the group to understand:

- How it feels to be stigmatized shamed or rejected. It helped put the participants into the shoes of people living with HIV or marginalized groups. It helped them understand how painful it is to be stigmatized.
- That stigma destroys self-esteem. It makes people doubt themselves and their self worth.
- That everybody has felt ostracized or treated like a minority at different times in their lives. And it is okay to feel like that because you are not alone. We have all experienced a sense of social exclusion.
- Some participants felt that stigma made people feel stronger but some felt that it can depress them enough to commit suicide as well.

# Day 2, Session 4: Naming stigma in our health facilities

The objective of this activity was to enable participants to identify forms of stigma in different PPTCT related programmes.

This was accomplished through rotational brainstorming. The larger group was divided into five smaller groups. Each group was asked to list down the stigma observed in their health facilities in different locations – Laboratory, Operation theatre/surgery, TB programme, HIV testing and counselling and Wards.



#### The forms of stigma listed were as follows:

Laboratory	Operation Theatre	TB Programme	HIV testing/ counselling	Wards
Separate collection of blood samples from suspected individuals	Refusing surgery to HIV + or without HIV status report	The DOTS centre caters only to TB and HIV suspects	Testing done in isolation, clients feel stigmatised	Isolation in wards
Wearing gloves only for suspected individuals	Overuse of barriers like gloves/masks/ special kits	TB patients delay coming to DOTS centre because they assume it is only for HIV	Self stigma as the patient enters the HIV room	Labelling as +ve on case sheets
'Designated' technicians for testing	Made to wait – HIV patients always treated at the end	Breach of confidentiality	Language/ terminology used during counselling often stigmatises	Protecting self with over use of gloves and generating excess waste in low risk settings
Eagerness to disclose status before counselling	Referring HIV patients to other facilities	Post cards sent to defaulters' homes	People waiting outside the room are looked at with suspicion	Talking in front of patients about their condition during rounds
HCWs working with HIV patients also stigmatised	Burning linen used for HIV patients after surgery		Testing without consent	ART dispensed without confidentiality
Reports handed out by loudly calling out a name	Refusal to assist in surgery		No privacy during post test counselling	Nurses refusing to inject/give drip to +ve cases
			Judgemental attitude towards the high risk group	Hesitation in cleaning spills
			Discussing case histories with others	Create panic in other patients by giving out wrong messages
			Giving NVP tablet during counselling	

# Day 2, Session 5: Fears of HIV Transmission in Health Facilities and Stigma

The objective of this session was to identify which health care activities are high risk (of getting HIV) and which are low/no risk, explain which low/no risk activities commonly done in health facilities are stigmatizing to patients and explain how universal precautions can help to ensure health worker safety in the health setting.

The methodology was a discussion using pictures depicting fears of getting HIV in the health care context to classify low risk and high-risk activities.

Participants were asked to classify activities as high risk and low risk and a discussion on the risk factors associated with it.

High Risk	Low/No Risk	
Giving an injection	Taking a patient's temperature	
Taking blood from a patient	Taking a patient's blood pressure	
Delivering a baby	Feeding the patient	
Stitching a wound	Bathing a patient	

The formula of QQR i.e. Quantity, Quality and Route of Transmission decide whether an activity is low risk or high risk. (See handout on QQR in Annex 9)

It was emphasized that health workers fear of getting HIV in health facilities is based on lack of understanding on HIV transmission and how HIV is transmitted and how HIV is not transmitted.

There was also a discussion on how these routine activities might be perceived as being stigmatizing by HIV positive patients, for example:

- Wearing gloves and masks when not needed i.e. performing low risk activities with protection.
- Marking case sheets with symbols to identify the HIV status.

There was also a discussion on the need to protect health care providers from infection and on what they could do to protect themselves. Participants had the following ideas on how to introduce Standard Precautions:

- Some participants felt that the application of Standard Precautions is often not practical/ feasible/cost effective.
- Easy availability of PEP.
- Supply chain management so that protection devices like gloves and masks are always available.
- Confidentiality of patients.
- Communication this included sensitization of patients, community and workers to ensure that they are aware and do not single out people.
- A common code of conduct.
- Hepatitis B vaccination for every health care worker and not just doctors.
- Sharing experiences between staff members during training or meetings.



There was much discussion on who should know the HIV status of the patient among health workers. There was also discussion on stigmatizing without meaning to do so – in the case of health workers encouraging 'top feeding' of a baby of an HIV +ve mother in ward of mothers who are discouraged to top feed.

#### The major learnings from the session include:

- Some health workers insist that it is their right to be told who is HIV positive so they can protect themselves against HIV. They claim that not knowing who has HIV puts them at risk. They identify who have HIV by isolating HIV patients in separate rooms, or marking HIV patients' files, or simply telling other health workers. Or they use double gloves when they are with patients whom they assume are HIV positive. These practices are wrong they stigmatize PLHIV and create a climate of fear around them and they do not decrease the risk of HIV transmission in the health facility.
- There is no medical justification for the above practices they do not protect the health worker because HIV is not contagious, it is not spread through casual contact. Trying to put patients into two groups those who are HIV positive and those who are negative can be counter-productive. Health workers may be more cautious with HIV positive patients and less cautious with HIV negative patients, even though some of the negative patients may be in the window period, when people are at their most infectious or have other blood-borne infections such as hepatitis.
- Standard Precautions provides a better, non-stigmatizing method for protecting health workers and their patients. Standard Precautions are based on the assumption that all

blood and bodily fluids are potentially infectious, regardless of their known HIV status, and should be applied in all patients. Standard Precautions gives health workers more control over ensuring their own safety within the health setting, while ensuring the safety of their patients.

- We often assume that we as health workers are the ones who are getting infection, but in some cases we may be the ones who are passing the infection. So Standard Precautions protects both health workers and patients – and health workers should realise that they can potentially pass on infection to patients.
- Everyone in a health facility is at potential risk of contracting HIV nurses, doctors, nonclinical health workers, patients, and visitors are all at risk in different ways. For example, medical staff are at risk during clinical procedures, while members of the cleaning staff are at risk of infection while cleaning instruments or disposing of waste.
- Knowing how HIV is actually transmitted is an important first step in preventing HIV infection in the health facility. It is equally important to learn how HIV is NOT transmitted so that health workers know how to properly protect themselves and others.
- Practicing correct precautionary measures and explaining why these precautionary measures are taken are two good ways to ensure that people in the health facility are adequately protected and patients feel less stigmatized by the necessary precautions.
- Infection in the health facility may occur through contact with blood or other body fluids, which may occur through broken skin, injuries with contaminated needles and/or sharp instruments, transfusion of infected blood or blood products, splashing of contaminated body fluid into the mucous membranes, or the use of contaminated razors.
- There is no evidence of transmission through other modes. Transmission does not occur through:
  - casual social contact such as talking, hugging, or sitting next to someone with HIV.
  - feeding patients or taking their temperature with a thermometer.

# Day 2, Session 6: PEP and stigma

The session began with the reflection that as occupational exposure is any situation, which exposes or puts a health worker at risk of either infection or injury and therefore a health worker who is exposed to blood and bodily fluids on the job is entitled to certain forms of support.

The group was divided into pairs and asked –

- How is PEP applied in your health facilities?
- What are some strengths or weaknesses?

How is PEP applied in your health facility?	What are the strengths and weaknesses of the process?
There is a focal point for applying PEP.	The group could not identify any strengths in the process.
Patient and exposed person both are referred to the counseling centre and their consent taken.	<ul> <li>The weaknesses were:</li> <li>The new institutes do not have PEP centers as a pre requisite.</li> </ul>
PEP not begun without consent.	<ul> <li>PEP begun without counseling.</li> <li>There is a chance of stigmatization by other</li> </ul>
On an emergency basis PEP is available without counseling.	HCW after PEP.   Availability of PEP may cause the staff to further discriminate against HIV+ve.
Pre test counseling is not mandatory.	<ul> <li>Lack of supply of PEP drugs.</li> <li>Delayed reporting of PEP.</li> </ul>
Separate protocol regarding known and unknown source.	Lack of guidelines.

Following this, the group was divided into five smaller groups and each group was given a separate case study to discuss and answer the following questions (see annex 6 for case studies):

- How can we ensure that HIV stigma, or fear of stigma, does not prevent health workers from accessing PEP when it is needed?
- What recommendations can we make to ensure that PEP is more accessible?

All case studies focused on issues related to PEP.

#### The participants felt that:

- Ensuring confidentiality is maintained would help in accessing PEP.
- PEP can result in inadvertent disclosure of a health worker's status. If the health worker knows she is HIV negative, she will move quickly to get PEP. If she knows she is HIV positive, she will be less worried about getting PEP. So this exposes health workers to stigma from their colleagues. Colleagues will ask "Why did she not rush for PEP?" Because of this stigma issue, it is difficult for colleagues to counsel the health worker.
- Educate all staff on PEP and emphasize that WHO has recommended PEP to be safe and effective.
- Encourage all health workers to know their HIV status; if positive, to get access to ARVs.
- A telephone helpline.
- A budget for PEP to ensure that it is available at all facilities.
- Awareness and sensitization for HCW/orientation for stigma reduction/working towards change in attitude.
- A manual on how to conduct a sensitization exercise.

- Psycho social counselling.
- Ongoing regular counselling/need for follow up counseling a minimum schedule of counseling.
- Peer counseling.
- A designated custodian for PEP someone who knows how to grade the level of exposure and medicate accordingly.
- HIV friendly hospitals.
- Addition of stigma to the curriculum of health care workers (doctors, nurses and para medics).

# Day 2, Session 7: Analyzing Stigma in Health Settings and **Finding Solutions**

This activity drew from the earlier activity where the groups had listed the forms of stigma in different parts of the health facility i.e. the laboratory, the operating room, the surgery, TB/ DOTS Centre and at the HIV testing and counseling centre.

To analyze stigma in health settings, the larger group was divided into five smaller groups. Each group was given a topic related to stigma for which they had to write the forms the stigma took the possible causes and effects and propose solutions.

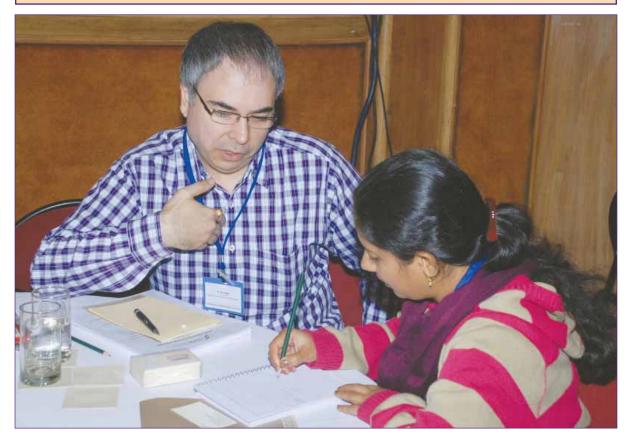
#### The topics were:

- 1. The Health Care Worker breaking the confidentiality of the HIV+ clients.
- 2. The Health Care Worker refusing to provide services to HIV+ clients.
- 3. The Health Care Worker stigmatizing women living with HIV+ and who get pregnant.
- 4. The Health Care Worker stigmatizing marginalized groups.
- 5. The Health Care Worker stigmatizing the poor.



Group A: HCW breaking the confidentiality of the HIV+ clients			
Forms	Causes		
<ul> <li>Casual gossip among colleagues about HIV+ patients</li> <li>Hesitation of HCW when approaching the HIV+ patients</li> <li>Information shared among health workers during change of duty</li> <li>Stating HIV+ status on patient information sheet without using any code words</li> </ul>	<ul> <li>Confidentiality breached due to the 'novelty value' of HIV patient</li> <li>Ignorance of HCW about the confidentiality guidelines</li> <li>Fear of HIV</li> <li>Lack of knowledge, information, training and sensitivity</li> <li>The need to protect themselves and their colleagues</li> </ul>		
Effects	Solutions		
<ul> <li>Patient gets disturbed and depressed and even gets suicidal</li> <li>Patient is lost to follow up and medical services</li> <li>Patient feels isolated and withdraws from friends and family</li> <li>Patient is unable to function well in his/her job, profession i.e. becomes dysfunctional</li> <li>The disease progresses in the absence of treatment</li> <li>Patient will seek alternative methods – quacks, faith healers, friends etc</li> </ul>	<ul> <li>Conduct sensitization programs so that all HCWs have a basic knowledge of HIV/AIDS</li> <li>Keep a special code to identify HIV+ patients so that the confidentiality is maintained</li> <li>Impart communication skills to HCWs so that they do not accidently breach confidentiality</li> <li>Attitudes in society need to change – awareness raising campaigns through mass media</li> <li>Work towards treating HIV and AIDS like any other disease</li> </ul>		

The matter of using a code to identify HIV and other high risk patients was discussed; the group was divided on the issue with some feeling that some HCWs had the right to know the status while others feeling that this knowledge was desirable in order to treat the patient better. One participant mentioned that during statistical analysis every disease had been given a code therefore there was no harm in using the code.



Group B: HCW refusing to provide services to HIV+ clients		
Forms	Causes	
<ul> <li>Refusing to give intra muscular and intra venous injections</li> <li>Not giving a bath or bed pans directly to the patients</li> <li>Refusing to collect blood samples</li> <li>Refusing to conduct surgeries or deliveries</li> <li>Delaying treatment and surgeries</li> <li>Referring to other levels/departments</li> </ul>	<ul> <li>Low awareness among HCW about transmission routes of HIV</li> <li>Socio cultural prejudices about HIV+</li> <li>Fear of infection</li> <li>Low awareness of universal/standard precaution and post exposure prophylaxis</li> <li>Lack of HIV vaccine</li> <li>No cure for HIV infections</li> </ul>	
Effects	Solutions	
<ul> <li>Promoting self and community stigmatization</li> <li>Becomes a barrier to health seeking behavior</li> <li>Reduces the quality of care</li> <li>Increases ostracization by public and community</li> <li>The psychological impact is increased – results in a tendency for suicide</li> <li>Delayed treatment leading to poor outcomes</li> <li>Ultimately leads to preventable mortality and morbidity</li> </ul>	<ul> <li>Short Term Solutions</li> <li>Involvement of senior HCWs (doctors and matrons) in providing services to HIV infected</li> <li>Feedback forms for the patients to report refusal of treatment in every hospital</li> <li>Orientation and advertisement of availability, place, person for PEP</li> </ul>	

Group C: HCW stigmatizing women living with HIV+ who get pregnant			
Forms	Causes		
<ul> <li>Lack of proper counseling</li> <li>Judgmental behavior through body language and other behavior</li> <li>Verbal and non verbal stigmatization</li> <li>Isolating the woman in a separate ward</li> <li>Calling out the name while handing over the report</li> <li>Writing the diagnosis in the case sheet</li> <li>Delay in giving treatment</li> <li>Delay in surgery or delivery</li> <li>Charging higher amounts</li> <li>Avoiding giving an injection or IV drip</li> <li>Lack of proper care in AN/IN/PN</li> <li>Blaming woman for getting pregnant</li> <li>Advising abortion or sterilization</li> </ul>	<ul> <li>Lack of awareness and sensitization of the HCW</li> <li>Lack of hospital policies</li> <li>Lack of coordination between the health care providers</li> <li>Lack of standard precautions</li> <li>Lack of supply chain management</li> <li>Lack of awareness in society regarding HIV</li> </ul>		
Effects	Solutions		
<ul> <li>Psychological distress to the woman – may lead to suicide</li> <li>Risk of increased transmission to the child</li> <li>Increase of maternal and infant mortality</li> <li>Lack of support from family and society</li> <li>The attitude of the HCW reinforces negative images/behavior for society</li> </ul>	<ul> <li>An ongoing sensitization program</li> <li>Training, specifically on PPTCT</li> <li>Inclusion of the topic of stigma in the curriculum of health care providers i.e. doctors and nurses</li> <li>Change in policies</li> <li>Constant supply in materials</li> <li>Follow universal precautions</li> <li>Do not isolate HIV+ patients in the ward</li> <li>Use some codes to identify HIV patients in the case sheet</li> <li>Uniform costs and services</li> <li>Regular meeting among staff</li> <li>National policies</li> <li>Most importantly – political commitment</li> </ul>		

Group D: HCW stigmatizing marginalized groups  The group identified the marginal groups as:  • Male and female sex workers  • IDU  • LGBT  • Street children  • Truck drivers  • Tribals	<ul> <li>Migrant labor</li> <li>STI clinic attendants</li> <li>Professional blood donors</li> <li>Alcohol and other substance users</li> <li>People with criminal history, jail inmates</li> </ul>
Forms	Causes
<ul> <li>Maintaining physical distance i.e. not touching</li> <li>Labeling, verbal abuse</li> <li>Refusal and/or delay in services</li> <li>Non verbal discrimination</li> <li>Unnecessary referrals</li> <li>Unwanted irrelevant questions</li> <li>Derogatory remarks</li> <li>Incomplete treatment</li> <li>Asking for money or favors for services (sex, drugs)</li> <li>Violation of rights</li> </ul>	<ul> <li>Personal beliefs</li> <li>Attitudes shaped by morals, value systems and social norms</li> <li>Belief and misconception about marginal groups</li> <li>Cultural and religious values</li> <li>Media propagating negative stereotypes</li> <li>Half baked concepts and knowledge</li> <li>Rigid mind sets i.e. unwilling to accept change</li> <li>Poor political commitment i.e. lack of policies, guidelines, trainings, stigma reduction workshops</li> </ul>
Effects	Solutions
<ul> <li>Anger</li> <li>Anxiety</li> <li>Low self esteem</li> <li>Depression leading to suicide</li> <li>Poor health seeking behavior</li> <li>Poor utilization of services</li> <li>Non adherence</li> <li>Seeking inappropriate/unsafe treatment (from quacks)</li> <li>Encourage more of high risk behavior leading to greater spread and higher prevalence</li> <li>Isolation</li> <li>Financial loss and impoverishment</li> <li>Discrimination towards others in the family</li> <li>Unwanted and unplanned pregnancies</li> <li>Increased health expenditures and budgets</li> </ul>	<ul> <li>More stigma reduction workshops for increased sensitization</li> <li>Advocacy for leaders</li> <li>Develop/agree on codes of conduct or standard operating procedures</li> <li>Develop wider understanding of marginalized groups and ensuring equitable access to services</li> <li>Training of HCWs</li> <li>Redressal mechanism for denial of services and discrimination</li> <li>Economic development in the country to reduce migration</li> <li>Encourage voluntary blood donation</li> <li>Availability of free condoms in jails</li> <li>Availability of free needles and syringes</li> <li>Spread of needle exchange programmes</li> </ul>

Group E: HCW stigmatizing the poor		
Forms	Causes	
<ul> <li>Patients not heard</li> <li>Not treated with respect</li> <li>Disregard and understanding of their problem</li> <li>Being judgmental</li> <li>Having pre conceived notions</li> <li>Underestimating their capability to understand their disease</li> <li>Postponing their surgeries</li> <li>Referral – passing the buck</li> </ul>	<ul> <li>Our (HCWs) attitude</li> <li>Pre conceived ideas of this class</li> <li>Lack of funds</li> </ul>	
Effects	Solutions	
<ul> <li>Absence of proper diagnosis, leading to an increase of morbidity and mortality</li> <li>Discourages the patient from coming back to the doctor for treatment</li> <li>Progress and spread of disease</li> <li>Postponement of surgery leads to morbidity and sometimes mortality</li> <li>Bad reputation of the institute/hospital</li> </ul>	<ul> <li>Change of attitude</li> <li>Awareness and sensitization of HCWs regarding the health problems of the poor</li> <li>Sensitization of doctors</li> </ul>	

The analysis of stigma on health care settings concluded with summarizing the causes of stigma as follows:

- The three main causes or drivers of HIV related stigma are: a) lack of awareness that they are stigmatizing; b) inadequate knowledge on HIV transmission and fear of getting HIV through casual contact; and c) judgemental attitudes.
- Judgemental attitudes towards other key populations bring up issues of:
  - gender (e.g. the common perception that "men who have sex with men and transgender people are not real men").
  - culture (e.g. the perception that "homosexuality, sex work, or use of drugs is 'abnormal', breaking social norms").
  - religion (e.g. the perception that "same sex relationships, sex work, and use of drugs is immoral, against the teachings of our faith").
- Health workers alone cannot solve many of the root causes of stigma. However, general awareness of the root causes will help health workers better understand the needs and concerns of PLHIV and marginalized groups, so they can provide better services.
- Stigma leads to low uptake of health services by PLHIV. Reducing stigma is key to increasing the uptake of HIV prevention and services, improving HIV disclosure, and improving patient follow-up to treatment, care, and support services.

# Day 2, Session 8: The blame game

The objective of this session was to help participants identify labels used to stigmatize people living with HIV and other marginalized groups and recognize that these words HURT.

This was done through rotational brainstorming. There were six flip charts stuck all over the room with the following labels:

- MSM
- Sex Worker
- Drug User
- Women
- Street Children
- PLHIV

The larger group was divided into six smaller groups and they went around the room to the flipchart stations and wrote 'what people have to say' about each group. Each group went to all the flipchart stations and was given two minutes per chart.



At the end, the group formed a circle on the floor and one person read out each list, starting with the phrase 'We are .... (sex workers, MSM, etc) and people call us ...'.

The names used for each were as follows:

Group	What 'people' have to say about them	
MSM	Deviant, unnatural, abnormal, <i>mamu, gay, koti, panti, chakka</i> , pervert, burden on society, shame on family, asshole, homo, bobby, gigolo, 50-50.	
Sex Worker	Prostitute, call girl, item girl, sinner, bar-bela, available, veshya, randi, devdasi, chinai, dhandhewali, mujerewali, bitch, spreaders of HIV, husband stealer, family breaker, deserve to be raped, dirty, will do anything.	
Drug User	Burden, uncultured, thief, danger, all are HIV+ve, irresponsible, less than human, violent, risk for desires, moral-less, womanizer, unproductive, psychic, addicts, criminal, sinful, hippy, nashedi, charasi.	
Women	Maal, mast cheez, patakha, emotional, ornament, housewife, sexy, unpredictable, beauty without brains, unreliable, better halves, goddess, beauty with brains, intellectual duffer, sex object, my woman is a woman the others are a sex project, chastity is a requirement of women, private property.	
Street Children	Dirty, lazy, need sympathy and care, sadak chaap, lafange, thieves, criminals, should be sent to other states, scoundrels, beggar, pick pockets, drug users, bastard.	
PLHIV	Immoral, deserve what they got, bad boys, dirty, <i>bechaara</i> , sinner, burden on society, should be castrated (male), prostitutes, should be expelled from society, do not deserve to be alive	

Following this exercise, after all the lists had been read out, the group was asked the following questions:

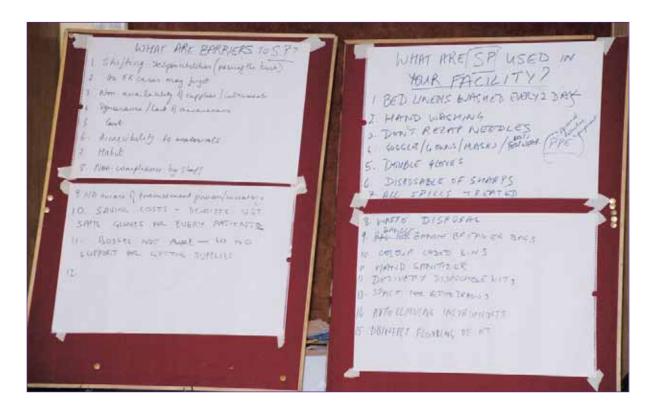
- How would you feel if you were called these names?
- How would you feel if your sister or brother were called these names?

There was some amount of laughter as the names were read but while it was commented upon, its meaning was not explored. It could have been an indicator of stigma or a sense of discomfort or nervousness.

The group felt that such labels would have made them feel guilty, depressed, angry, violent, hurt, demoralized and make them lose confidence.

The session was summed up with the following observations:

- We are socialized or conditioned to judge other people. We judge people based on assumptions about their sexual and other behaviour.
- Sex is a taboo it is regarded as something shameful that we should not talk about. So we often shame and blame people whose sexual behaviour is different from ours.
- People living with HIV, MSM, and sex workers are all labelled sexually immoral. In the exercise they were called "sex crazy", "irresponsible", and "AIDS carriers". These judgements are based on sexual morality.
- People who use drugs are also judged with insulting words "dirty," "dangerous," "HIV carriers".



- Key populations are already stigmatized even if they are not HIV positive. They are stigmatized partly because are disadvantaged and lack the power to resist these labels or challenge the stigma.
- All of these labels show that when we stigmatize, we stop dealing with people as human beings. Using mocking or belittling words gives us a feeling of power and superiority over them and we forget people's humanity.
- Stigmatizing words are very strong and insulting they have tremendous power to hurt, to humiliate, to destroy people's self-esteem. When we "shame and blame" people for their characteristics or behaviour, it is like stabbing them with a knife it hurts!
- So how should we treat people living with HIV and other key populations? We should give them: a) respect and affection; b) support and encouragement; and c) space, place, and recognition. If we treat them well, they will keep their self-esteem and feel empowered and take charge of their lives, accessing health services and taking care of their sexual health.

# Day 2, Session 9: Exploring out attitude towards marginalized groups

The objective of the session was to help people explore their attitudes and values about PLHIV and other key populations and recognize how their own attitudes regarding PLHIV and other key populations might impact on their work as health workers.



This was done through a voting of whether people agreed or disagreed with a set of statements followed by a short discussion on the issue. (Please see annex 7 for the details of statements).

For some of the statements where the majority decision was one that promoted stigma, there was a discussion/sometimes clarification and a revote. This was especially true of statements like, 'health workers have a right to know which of their patients are HIV+ve.' Or 'health workers have a duty to inform the spouse and family of a person who is HIV+ve.' These statements were hotly debated with some participants saying that in case of high risk HCWs needed to know the HIV status. The subtle difference between 'needing to know' and 'desirable to know to provide better health care' similarly on whether on not the spouse and family should be informed, some doctors felt that in order to stem transmission, the spouse needed to be informed. Some doctors quoted the Partner Notification Act wherein a doctor is duty-bound to disclose to the spouse that his/her spouse is suffering from syphilis and they felt that HIV should be treated like syphilis. The group finally agreed that for the duration of the treatment, it would be better to suspend judgement and counsel HIV+ve persons to voluntarily disclose their status to their spouses.

Some statements led to a discussion between 'high risk behaviour' (cautionary) and 'bad behaviour' (judgemental) e.g. having multiple concurrent partners is high risk behaviour and not bad behaviour.

Interestingly, all agreed that HIV+ve HCWs should be allowed to practice as preventing them would be discriminatory!

For some statements like 'sex workers love money and are lazy to work. They could easily get other jobs' or 'sex workers should be allowed to marry and continue their work as sex workers'; some participants found it difficult to agree or disagree and chose not to respond.

On whether or not needle and syringe programmes would increase drug use and drug users, there was agreement till the time the group was informed that research had shown that decriminalizing the activity decreases drug use and therefore HIV transmission.

The exercise was summed up with the following observations:

- Some of the statements are *stereotypes*, negative things we say and believe about people living with HIV and other high risk groups. Often we believe these misconceptions are facts about other people, when in fact they are false. This belief or assumption leads to stigma and discrimination.
- We are socialised to judge other people based on assumptions about their behaviour. PLHIV, MSM, transgender people, sex workers, people who use drugs, prisoners, and migrants are regarded as breaking social norms – so some people think that they deserve to be condemned and punished.
- It is not incorrect to have moral values but "judging" is wrong. We have no right to judge others – and the judging ends up hurting people.



- Whether we agree with someone or not, we don't have a right to judge or belittle them. We should *treat them as human beings* who deserve our respect and empathy. To stigmatize is to wipe out their humanity and treat them as having no value.
- There is a need for awareness that our opinions have effects on other people. Some of these opinions are very judgemental towards PLHIV and other high risk groups. As a result they may feel hurt, humiliated and depressed, and this affects their access to health services and how they protect their sexual health.
- As health workers we have a professional obligation to remain objective and non-judgemental with patients and to avoid letting our personal beliefs and attitudes become barriers to providing compassionate and high quality care to patients.



## Day 3, Session 1: Evaluation

At the end of day 2 also, all the participants had been given a feedback form and two participant volunteers had summarized the learnings.

#### Likes:

- · Voices our own stigma
- Group discussion on issues of MSM, sex workers, street children
- Active participation by all
- The games
- Constant changing of places and positions
- Discussions from the points written by the participants
- · People sticking to lunch and tea

#### Dislikes:

- A number of things left in the parking lot
- Overlapping discussion
- Tea and Coffee

#### **Major Learnings:**

- Even health care workers can be judgmental and moralistic
- The words used for naming sex workers, MSM, street children
- Interactive session for health care workers

#### Issues that need further discussion:

- NACO guidelines
- PLHIV
- MSM
- · We need tools to come to a decision

#### **Suggestions:**

- Such workshops should be conducted in all states and hospitals
- Interactive session should be documented in electronic media

# Day 3, Session 2: Learning Review

As on day 2, this was also conducted through the hot potato exercise. The learnings and likings of day 2 were as follows:

- The sessions were interactive and not a monologue.
- People who knew more about stigma and discrimination became the starting point for discussion.
- Sharing experiences of stigma makes you humble and makes you realize the importance of other people.
- Everyone has faced stigma one time or the other.
- The patient is more important than the route of transmission.

- Need to remove stigma from self rather than others.
- Learnt the importance of listening.
- The workshop would have been better if the conclusion had been crisper. Missed a take home message.
- People listen to feedback 'murmurings' in the room decreased after feedback of day 1.
- Liked the atmosphere where I could air my views which were different from others.
- Issues in parking lot need to be discussed still confused about standard precautions and universal precautions.
- Learnt that one does not need to compromise one's values but also that there is no need to impose those values on others.

# Day 3, Session 3: Panel Discussion

The objective of this session was to explain some of the basic facts and issues affecting key populations and describe how stigma and discrimination in health facilities affects key populations. This was through a panel of three resource people who were invited to tell their own story – a brief description of their lives, including their experience of stigma and responding to a series of questions which had been brainstormed the day before.

There were three panellists; a MSM, an HIV+ve woman (whose child was also +ve) and a young woman who had been a drug user and was trying to give up the habit.

The young man spoke of the time when he found out he was different from the other boys of his school and how he managed to find a place for himself and of his decision to give up his career as a banker and work with a community based organisation working on issues of MSM. He was very open and answered the participants' questions with a candour that really facilitated the groups learning. He also spoke of the stigma he faced and continues to face in health care facilities, including being asked not to use the lift. He told the group that being gay was not a choice for him that he was born that way. He spoke of his feelings of being isolated and lonely but felt he was fortunate as he had sought help from a professional counsellor who helped him gain confidence and it was this that helped him work as a counsellor for other young men.

There was curiosity in the group about homosexuality and bisexuality and this was discussed in some detail. Also discussed was true homosexuality and situational homosexuality such as the one seen in jails and in the army. Some participants asked about multiple partner relationships among MSM to which the resource person responded that men also wanted stable relationships but the atmosphere was not conducive to long term relationships between men.

The HIV+ve woman spoke of finding out first her husband being HIV+ve, who died shortly after being diagnosed and then finding out her own positive status but the worst she felt was finding out her 9 year old son's positive status. She spoke of the discrimination she suffered from her



in-laws who broke ties with her, the discrimination she and her son face from her brother's family even though they provide moral support and she stays with them and the discrimination in the health care facilities. She felt that an HIV+ve woman's character was always questioned or her husband's character was assumed to be 'loose'. She feels that the need to look after her son gave her strength to move ahead and the support of the +ve peoples network that helped her gain financial independence.

The third resource person spoke of how she got into addiction starting with soft drugs, alcohol and then to hard drugs. She spoke of the support she received from the rehabilitation home where she is currently staying. Meanwhile, she tested HIV+ve but she still has not told her

father though her mother knows her status. She fears stigma and therefore has not disclosed her status.

Each of the stories brought different issues that need to be addressed even though there were some commonalities.

What was clear was that while stigma is being recognized as an issue, there was still a lot of stigma present everywhere in society including health care facilities. The brunt of this stigma is borne by certain key groups or high risk groups.

All the stories brought out the need to work with adolescents to raise awareness on issues of understanding one's own sexual reality and the need for safe practices.



The HIV+ve woman's story brought to light the gender dimension of this epidemic. Typically, women face loss of support, denial of property rights and the stigma remains the same in health care settings.

The major learnings of the panel discussion with resource people were as follows:

- Some people know little about key populations, so out of ignorance they judge them unfairly or isolate/reject them out of fear.
- When we know little about others, we often make assumptions or accept stereotypes about them. We attribute characteristics to a group and everyone belonging to that group. We assume that all members of the group have the same characteristics, e.g. that all men who have sex with men are promiscuous, all sex workers love sex etc.
- These assumptions are stereotypes, things we say about other people that we know little about. Often we believe these assumptions are facts about other people, when in fact they are false. This belief leads to prejudice, which can result in stigma and discrimination.
- Each of these groups is unique and includes people with diverse knowledge, attitudes, and practices. We often think we know more about these groups than we actually do, or generalize when we should not. We still have a lot to learn!
- By learning more about key populations, we will begin to overcome some of our doubts or prejudice about key populations and be less fearful or condemning towards them.
- We need to understand and respect key populations as human beings. Men who have sex with men, transgender people, sex workers, people who use drugs, migrants, and prisoners are as fully human as anyone else and entitled to be treated in the same way.

The participants were extremely appreciative of this session. The panel discussion opened participants' eyes to the lives of people living with HIV, gay men, and drug users, and challenged the prejudices and stigmatizing attitudes within the group. (Before the panel one participant, thought it was acceptable to ask a PLHIV "how they got HIV", not seeing this as a stigmatizing question, and another asked about MSM – "Why do they do this behaviour?"). Some participants said that they learnt the most from the panel discussion.

# Day 3, Session 4: Counselling Techniques

The objective of this session was to describe counselling situations that challenge their value judgements, to demonstrate how to use counselling skills to counsel patients from different backgrounds and to explain how their own value judgements could impact on their counselling sessions.

The methodology used was to identify situations that make participants uncomfortable when counselling patients. Some of the situations that came up were:

- How to counsel a gay person?
- How to counsel a teenage girl who is pregnant?

- How do I maintain confidentiality?
- How do I deal with the stigma associated around condom demonstration?
- How do I deal with a discordant couple?
- How do I counsel an HIV+ve couple who wants a second child?

The participants were then divided into groups of three. Each group had one patient, one counselor and one observer. Each group was given three situations so that each participant took turns in playing each of the three roles. The patient and the observer were given the situation and the counselor had to find out the patient's situation without stigmatizing. The observer had to focus on the roles the counselor was performing. (For counseling situations, please see annex 8)

Between each change, the activity was processed through the following questions:

- How did it go?
- Did the counsellor make any value judgements? And
- What have we learnt from this?
- How might our own value judgments interfere with the counselling process?
- What can we do if we find that our own judgments or inexperience are affecting the service we offer to a particular patient?

The session was summed up with the following learnings:

- We need to make the patient comfortable and put him/her at ease.
- The language used should be non-threatening and easy to understand. It is important to remember that there is deep rooted morality associated with language. A bias exists in most of us that some words are not used in public by a certain class of people. It is important to use language in a straightforward way and communicate clearly.
- We need to be aware of the difference between giving advice or the skills to be able to deal with the situation at hand.
- We need to be aware of how our values and judgements can impact on our counselling practice.
- We need to accept and respect patients as they are since this is one of the cornerstones of counselling.
- Treat each patient as an individual and be open to what they need to discuss. We need to respect each patient's issues and explore the context in which they live in order to help frame good decisions.
- All patients have a right to access our counselling service and with the same quality.
- Remember the key counselling principles we need to accept everyone and be nonjudgemental.



# Day 3, Session 5: Developing a code of conduct

This was the final 'working session' of the stigma reduction workshop. The objective was to develop a code of conduct to reduce stigma and reduction in health care settings. In order to do this, the group was divided into five sub groups. Each group was assigned one of the following five topics:

- a. Access to HIV Services
- b. Counselling and Testing
- c. Confidentiality (including disclosure)
- d. Standard Precautions
- e. Training on HIV and AIDS

Each group was asked to come up with a set of suggestions and recommendations on their assigned topic. This was not compiled as a separate document but the group decided that this should be shared with NACO.

The output of the group was as follows:

Торіс		Suggested solutions	
Access to HIV Services  The services listed were: PPTCT STR/RTI (ICTC) ART Centre TB HIV clinic PEP Pediatric ART center Drop in center	The barriers to accessing these services are seen as:  Self stigma Perceived additional stigma Attitude of HCW Societal norms Cost Low awareness of HIV Geographical distance No linkage with health care system No linkages among the mentioned services	Suggested solutions:  Awareness programs in all types of media  Sensitization programs for HCW for changing attitudes  Involvement of peer educators  Sex education in schools  Increase in ICTC centers which should be linked  Linkages with the health care system  Helpline  Signage in local language  Directions  Support service to those reluctant to access services  Code of conduct for each kind of service mentioned  Create 'stigma free hospitals' that are monitored and reported	
Counseling and testing	<ul> <li>Proper space for counseling with audio visual privacy, separate from blood collection centre.</li> <li>Proper training for health care workers i.e. training that includes         <ul> <li>microskill building to deal with different groups of clients</li> <li>a revised training curriculum</li> <li>counseling should be considered as a team approach rather than a one to one process and</li> <li>a continuous evaluation process should take place in hospitals among HIV service providers for better counseling and redressal of issues of stigma.</li> </ul> </li> <li>Both male and female counselors should be available</li> <li>Integration with other health services</li> <li>All HCW to be trained in counseling</li> <li>Adapt and practice standard safety precautions</li> <li>HIV testing mainstreamed with general lab technicians</li> </ul>		
Standard precautions			

### • Est

Training on

**HIV/AIDS** 

- Budgetary allocations
- · Involvement of policy makers
- Establish/revive/strengthen IC Committee
- Frequent reminder on safe practices like hand washing at hand washing stations
- Training is needed at all 3 levels tertiary, secondary, and primary
- National Policy Change (NACO) incorporate stigma in existing training curriculum in medical colleges, nursing, para medical, psychology, social work
- Guidelines for doctors, nurses, students and other health care workers with hands on role modelling
- SACS training in ALL local societies
- Training to be complemented with media to raise awareness in general population
- Community involve the local government, work with NGOS, include stigma in the sex education modules in schools
- · Certified courses on stigma
- Therapist/psychiatrist group therapy
- During ANC, a blood sample is drawn twice once for general testing and once for HIV, this can be a single window operation
- Involving 'expert patients' PLHIV and other key populations as trainers
- Broaden the trainer base not the exclusive responsibility of SACS

# Day 3, Session 6: Addressing issues in the parking lot

Dr Bipin K Amin, Professor of Medicine and Head of Medical Unit, Civil Hospital and BJ Medical College, Ahmadabad, Training Faculty, WHO and NACO answered the questions that were placed in the parking lot.

- Double Gloves Wearing double gloves definitely reduces transmission of infection. It
  is advised that double gloves be worn for *any* surgery that is likely to last for more than
  30 minutes, regardless of the HIV status of the patient. The correct protocol is to wear
  the larger glove inside and the correct sized one outside.
- Disclosure of HIV status to patients' family and sexual partners there is uniform code that exists for this and each case has to be evaluated. It seems important to do so during a hospital to hospital transfer.
- Discordant couple In this case too, there is no uniform code. Legally, one cannot inform but can counsel to disclose to wife/sexual partner/s except in a divorce case.
- Provision of PEP to others outside the health system currently there are no guidelines for non occupational exposure. A victim of criminal rape maybe however be given a basic dose before sending for tests.
- Does a doctor have the right to demand HIV status before surgery? This was answered with another question – 'does the patient have the right to demand the HIV status of the doctor?'

# Workshop Evaluation and Recommendations

#### **Final Evaluation**

The final session was an overall evaluation of the workshop. Each participant was given a feedback form to fill. Section 1 of the evaluation form sought assessment on each of the workshop activities on a five point scale, section 2 asked the participant to assess their own participation in the programme, section 3 asked them to list their major learnings from the workshop, section 4 asked them to rate the workshop as a whole, section 5 asked them to write what they liked about the workshop, section 6 asked them to write what they disliked about the workshop and in the last section they were asked what they would do to reduce stigma in their own facilities upon return. The overall feedback was that the participants learnt a lot about stigma and thoroughly enjoyed the three days of training.

The details of the evaluation are placed in Annex 12.

# Strengths

- The workshop validated the importance of stigma reduction within the health care setting. It was generally recognized that there is a need for a systematic process to uproot stigma and discrimination in the health care setting and help health workers learn and adopt new, non-stigmatizing practices and a more consistent use of Standard Precautions. This will help to achieve the broader objective of encouraging more people living with HIV and marginalized groups to access health care services.
- The workshop underlined the need for stigma reduction training which uses a participatory approach – one which moves beyond a purely intellectual look at stigma and allows health workers to name the problems of stigma in their own health setting, overcome their fears about getting HIV in the workplace, and work out their own new, non-stigmatizing forms of practice. Changing attitudes on stigma cannot be achieved



through lectures where participants are spoon-fed and treated as a passive audience for messages delivered by their trainers.

- The most effective sessions were the **panel of personal stories** told by marginalized groups; and **participants' own stories about being stigmatized**. Both sessions dealt with feelings and talked from the heart, not just the head. The testimonials opened participants' eyes to the lives of PLHIV, gay men, and drug users, and challenged the stigmatizing attitudes within the group. The stigma reflection session helped participants think about their own experiences of being stigmatized a first step towards building empathy to others who are stigmatized.
- Participants admitted to having judgemental attitudes towards PLHIV and other marginalized groups. For some it was their first time to listen to and learn from PLHIV and gay men talking about their lives. Participants began to see that their moralizing judgements hurt people living with HIV and adversely affected their access to health services. Participants concluded that health workers need to suspend their judgement to stop judging people living with HIV and other marginalized groups and instead treat them with respect and tolerance.
- The workshop demonstrated the **need for guidelines or codes of conduct** as part of the behaviour change process. There was a big demand for this from participants and NACO should develop a national code of conduct for stigma free health facilities as a complement to the training and the basis for monitoring.
- The sessions on Standard/Universal Precautions and PEP were well received and it
  was generally accepted that Standard Precautions and PEP should be an integral part of
  training on stigma. There is also a need to update and disseminate guidelines on Standard
  Precautions.

#### Weaknesses

Inviting a mixed group of health work professionals was a good idea, but there was **insufficient** balance within this **group** – 16 doctors, 4 counsellors, 1 lab technician, and no nurses. (All the nurses



turned down the invitation.) Having less doctors and more nurses would have improved the workshop dynamics. The doctors dominated discussions and asserted their status within the workshop. Future workshops should use mixed groups (eg health workers within a single hospital), and cadre specific groups (eg workshop for nurses), depending on the context.

- Lots of Don'ts, not enough do's. The workshop did not allocate enough time to answer participants' questions and provide clear, "take home" messages at the end of each exercise. Using participatory approaches is the right approach to change attitudes, but there is also a need to be clear and prescriptive at the end of sessions.
- Our participatory process did create some openness in the group and helped to facilitate initial changes in attitudes, but the stigmatizing attitudes are firmly entrenched three days may not be enough for some of the doctors (still loaded with class, caste and gender prejudice)

# **Key Learnings**

- It was generally recognized that stigma is a serious barrier to efforts to address the HIV epidemic; it prevents individuals from getting tested and treated and practising prevention. Stigma by health workers compromises their provision of quality care, and discourages people living with HIV from accessing prevention, treatment, and care services. There is an urgent need to address the issue of stigma and discrimination in the health care setting.
- Participants agreed that there was lots of fear among health workers about getting HIV through their work in health facilities. This fear is based on lack of knowledge about how HIV is transmitted. Some health workers still believe that HIV can be transmitted through casual contact with an HIV positive patient and insist on knowing who has HIV so they can protect themselves. Many health workers feel they have a right to know who has HIV, and believe that not knowing who has HIV puts them at risk. Health workers' view that they have a right to know who has HIV was noted in the opening speech by Aradhana Johri (IAS Joint Secretary) and became a useful conceptual starting point ie the idea that health workers don't have a right to know who has HIV.

#### Recommendations

Evidence from programmes in different parts of India indicate that stigma reduction in health care settings can produce powerful changes in reducing stigmatizing attitudes and discriminatory practices. Stigma reduction in health care settings is "ready" for scale, with a reasonable evidence base and tested training materials. The government should act to reduce stigma in health care services as a top priority, support stigma reduction training for all health care workers, and integrate stigma reduction into all prevention, care and treatment efforts.

There is a need to design and implement a national strategy to reduce stigma and discrimination within health care facilities. The strategy should include:

- A training programme to orient different cadres of health workers on how stigma operates within the health care setting and help them develop new codes of practice.
- Development of policy and guidance frameworks on care and treatment services to people living with HIV and other marginalized populations eg codes of conduct for a stigma free health facility – to be uniformly applied across all health facilities.
- The provision of feedback forms and a redressal mechanism for patients and other concerned persons to report denial of services and other forms of discrimination.
- Monitoring the implementation of new codes of practice and advising management on how to strengthen stigma reduction within each health facility.
- Promoting the systematic and consistent use of Standard Precautions in all health facilities.

The stigma reduction training programme should have the following features:

- It should be designed for a broad range of health workers (doctors, nurses, pharmacists, lab technicians, counsellors, paraprofessionals, community health workers, etc), administrators, supervisors and managers, and other staff working in health care facilities.
- It should address both pre-service and in-service training contexts. Pre-service training will mean that stigma training modules are included within the curricula for medical, nursing, and other health worker training schools.
- The stigma training curriculum should include:
  - Getting participants to name and own stigma as a problem within their own health care setting and analyzing effects and causes.
  - Creating a personal understanding of how it feels to be stigmatized.
  - Upgrading knowledge of HIV transmission and skills in practizing Universal/Standard Precautions and PEP (a way of overcoming fear related stigma).
  - Exploring the concerns, needs, and rights of different marginalized groups (e.g. MSM, transgender people, sex workers, injecting drug users, etc).

- Challenging moralizing attitudes and values which underpin stigma and learning to suspend judgement.
- Communication skills to interact with different types of marginalized groups in a respectful and non-stigmatizing way and without breaching confidentiality.
- Developing strategies and skills to challenge stigma, and codes of practice on how to treat patients in a caring, non-stigmatizing way.

More attention needs to be given to stigma reduction among marginalized populations such as MSM, transgender persons, sex workers, and injecting drug users. These groups face multiple and intersecting sources of stigma, including self-stigma, which blocks their health care seeking.

Their needs and rights should be included in the stigma reduction curriculum, and they need to be given a major role in planning and delivering the training since they have an inside understanding of how stigma operates. The aim of using this GIPA approach would be to provide opportunities for health workers to interact with PLHIV and stigmatized groups beyond the boundaries of the client/health worker relationship.

The stigma reduction strategy should also include empowerment training for people living with HIV and other marginalized groups to enable them to better cope with stigma and stand up for their rights when they experience stigma and discrimination in health care and other settings.

There is a need for a standardized toolkit for training health workers on stigma and universal precautions, based on the existing toolkits already developed in India and internationally (ICRW India toolkit, inter-agency health workers toolkit, Population Council toolkit, and others). This toolkit could be developed through a toolkit development workshop, bringing together a group of training and material production specialists drawn from relevant agencies to:

- a. Review and revise exercises in the existing toolkits.
- b. Develop new exercises as needed.

The new toolkit will provide a standardized training resource, but at the same time it should allow for a certain amount of flexibility needed for different contexts, target groups, and training arrangements. Trainers in different institutions will select the modules suited to their target group and context to make their own training programme. The modules, however, should be divided into those which are seen as 'core' (recommended for all groups) and those which are 'optional' (selected on the basis of the context). It is expected that the core modules will be delivered to all trainees; the optional modules will be used, depending on the scale of the epidemic and the specific issues in each context.

The training should take into account the **different levels of education and experience** within the target group, which may include highly educated health care cadres such as doctors and nurses and other health staff, paraprofessionals or other functionaries who may have little or no education. Given the large gap in education and familiarity with HIV issues, there may need to be optional training activities for specific groups. For example paraprofessionals, security

guards, and other functionaries may need more time and material on basic HIV transmission in order to overcome fears.

In the short term stigma training may need to be delivered as separate, stand alone courses focused on stigma reduction, but in the long term stigma training should be **integrated** into other forms of HIV training, so it is seen as integral and critical. The aim would be to "mainstream" stigma – to make it a regular part of all training activities for health care workers.

Training events should lead to practical action. The aim is to get health workers to meet with their peers, discuss stigma issues, and work together to bring about stigma reduction. Working with others makes it possible for people to learn together about stigma, develop common ideas about what needs to be done, set group or community norms for new attitudes and behaviour, support each other in working for change, and monitor the results of change (with the involvement of PLHIV and marginalised populations).

Stigma training should be **long enough** (a minimum of 2 days and ideally longer) to be able to make a breakthrough in changing attitudes.

There are advantages to be gained in **training mixed groups of health cadres** (e.g. doctors, nurses, health auxiliaries, etc attending the same workshop). Workshops using this approach, however, need to be skilfully facilitated in order to ensure a balance in participation (i.e. to make sure the higher educated cadres do not dominate).

Stigma reduction training should be combined with advocacy and policy development to create PLHIV friendly health facilities and the provision of supplies and protective equipment to enable health staff to carry out their duties with minimum risk of occupational exposure.

There is a need for more resources committed to identifying and training facilitators for stigma reduction training; capacity strengthening within organizations involved in HIV prevention, care and treatment; and a serious effort to involve networks and organisations of people living with HIV as partners in the training.

There is a need for UPDATED national guidelines on UP, PEP, and stigma reduction toolkits.

# **Looking Ahead...**

The participants, now back to their respective settings and work, continue to share about the effects of this workshop, the benefit they've had and ways in which they have been able to use the workshop experience to their advantage in their work setting.

Dr. Sree T. Sucharitha, MD, Sr. Medical Manager, SAATHII shares from Chennai, "We conducted an experience sharing meeting with our PPP (Public Private Partnership) site doctors yesterday at Vijayawada which was attended by 29 doctors, 3 staff nurses, 10 program staff from our PPP team. I took a session on 'dealing with stigma in health care settings' and we could interact with the doctors regarding stigma related issues and we all pledged our commitment and support to promote stigma-free, patient-friendly environments for them to access services."

# Annexures

# **Annex 1. List of Participants and Facilitators**

#### Dr. Sushil Munjal

LRS institute of chest and TB, New Delhi

#### 2 Dr. Manika Aggarwal

Present Address: Department of Community Medicine North Eastern Indira Gandhi Regional Institute of Health and Medical Sciences, Shillong

#### Dr. B. Venkateswara Rao

Programme Officer, Guntur General Hospital (PPTCT) OBG Dept.

#### 4 Dr. Husnoddin Shaikh

A.A. Hospital Malegaon Ali Akbar Hospital MMC Malegaon, Nasik

#### 5 Dr. Kshama Kedar

IGMC Nagpur ICTC-II Associate Professor Gynecology department Government medical college&Hospital, Nagpur

#### 6 Dr. Chingling (Associate Professor – PPTCT)

TNMC, Mumbai

#### 7 Dr. B.K. Rath (Paed.)

ICTC-II, Nawarangapur, D.H.H., Nawarangpur

#### 8 Dr. Abhijit Bhattacharya

Central Hospital, Eastern Coalfield Ltd. ICTC Unit, Central Hospital, ECL Burdwan

#### 9 Dr. Biswajith Chakarathy

Professor & Nodal officer for PPTCT Section Raj Muthaiya Medical College, Annamalai Nagar, Chidambaram

#### 10 Dr. Swami

ASHA Kirana Charitable Trust, Medical Manager, Mysore

#### 11 Dr. Neerja Jindal

Prof & Head, Microbiology Deptt.(Incharge ICTC) G.G.S. MEdical College, Faridkot

#### 12 Mr Devashish Dutta

HIV/AIDS Manager New Delhi

#### 13 Ms. Prachi Garg

National Aids Control Organisation

#### 14 Ms. Premalatha GR, Program Manager

Bapuji Child Health Institute, Davanagere

#### 15 Dr. Sre Sucharitha, Medical Manager

SAATHII-Andhra Pradesh PPP Program

#### 16 Ms. Vikas Kurne, Program Coordinator

SAATHII-Maharashtra PPP program

#### 17 Chitra L. Kanth. Gender- Female

Project Co-ordinator, ASHA Foundation

#### 18 Mr. P. Naga Babu

Lab Technician, PPTCT Unit, Kakinada

#### 19 Mr. Shashikant Patil

Counsellor Seth G. S. Medical College & K.E.M. Hospital Dept. of Microbiology, Mumbai

#### 20 Mr. Gouranga Mandol

Central Hospital, Eastern Coalfield Limited

#### 21 Ms. Shivali Nagesh Barge

Modern Clinic, Pune

#### 22 Dr. Alok Vashishtha, M.D., F.I.H.M. (USA)

Consultant in HIV/AIDS Medicine Centre for Infectious Diseases (CID)

#### 23 Dr Sonali Vashishtha

Centre for Infectious Diseases (CID)

#### 24 Dr. Shubhra Raina

Assistant Director (STD)
Delhi State AIDS Control Society

#### 25 Dr. Suneela Garg

Maulana Azad Medical College Professor, Community Medicine, MAMC, New Delhi

#### 26 Dr. Laxmi Shrikhande

Indian Association of Gynecological Endoscopists Shrikhande Laser & Endoscopy Centre, Nagpur

#### 27 Dr. Riddhi Shukla, M.D, DGO

Consultant Gynaecoligst Aarogyam Speciality Hospital, Ahmedabad

#### 28 Anandi Yuvraj

Regional Coordinator ICW

#### 29 Dr. Roy Wadia

Executive Director, Heroes Project, Godrej Research Centre

#### 30 Ms. Mondira Jaisimha

Senior Advocacy Director, Heroes Project

#### 31 Mr. Nagendra Varada

**Director of Communications and Programs** Heroes Project

#### 32 Ms. Akhila Shivdas

**Executive Director** Centre for Advocacy and Research, New Delhi

#### 33 Dr. Sarita Aggrawal

National Chairperson HIV Committee FOGSY Professor and Head Obstetrics & Gynecology Institute of Medical Science, Bilaspur

#### 34 Mr Devashish Dutta

HIV/AIDS Manager UNICEF, New Delhi

#### 35 Ms. Neha Chauhan

UNAIDS, New Delhi

#### 36 Dr. Ravi Verma

Regional Director, Asia International Center for Research on Women (ICRW), New Delhi

#### 37 Dr. Enisha Sarin

Portfolio Director, Gender and HIV International Center for Research on Women (ICRW), New Delhi

#### 38 Mr. Ajay K Singh

**Technical Specialist** International Center for Research on Women (ICRW), New Delhi

#### 39 Ms. Molamma Mathew

Administrative Assitant International Center for Research on Women (ICRW), New Delhi

#### 40 Ms. Vaishali Sharma Mahendra

Independernt Consultant, New Delhi

#### 41 Mr. Ross Kid

Independent Consultant, Botswana

#### 42 Ms. Jyotsna Lall

Independent Consultant, New Delhi

# **Annex 2. Workshop Programme**

	Day 1 (17 January)	Day 2 (18 January)	Day 3 (19 January)
09:00 - 11:00	Opening Speeches	Evaluation & Learning Review	Evaluation & Learning Review
11.00	Overview presentation on Stigma (Dr. Ravi Verma)	Stigma in Our Lives: Our Experiences of Being Stigmatised	Learning from Marginalised Groups (Panel Presentation)
	Self-Introductions, Expectations, Objectives, and Workshop Norms	Naming Stigma in Specific Health Care Contexts	
11:00 – 11:15	TEA/COFFEE BREAK	TEA/COFFEE BREAK	TEA/COFFEE BREAK
11:15 – 01:00	Naming Stigma in Health Facilities through Pictures	Fears of HIV Transmission in Health Facilities	Counselling Skills for Working with People living with HIV and Marginalised Groups
		Post Exposure Prophylaxis	
01:00 - 02:00	LUNCH	LUNCH	LUNCH
02:00 - 03:30	Assessing the Impact of Stigma on Access to HIV related services and PEP (Case Studies)	Analysing Stigma in the Health Setting and Finding Solutions	Writing a Code of Conduct for a Stigma Free Health Facility
03:30 - 03:45	TEA/COFFEE BREAK	TEA/COFFEE BREAK	TEA/COFFEE BREAK
03:45 - 05:30	Universal/Standard Precautions & Stigma	The Blame Game; Stigma towards Marginalised Groups	Report back – groups report on their proposed codes of conduct
	Daily Evaluation	Exploring our Attitudes towards Marginalised Groups	Closing speeches and award of certificates
		Daily Evaluation + Homework	

### Annex 3. Overview presentation on HIV Stigma by Dr. Ravi Verma

#### What Is Stigma?

"An attribute that is deeply discrediting [and that reduces the bearer] ... from a whole and usual person to a tainted, discounted one."

"Disqualification from full social acceptance." (Goffman 1963)

- Societal phenomenon
- Contextual (social, cultural, political & economic forces)
- Form of social control
- Turns "difference" into inequity (gender, age, sexual orientation, class, race or ethnicity)
- Devaluation to create superiority
- Social exclusion of individuals or groups (Parker & Aggelton 2002)

#### **Dynamic Process with four steps**

- Distinguish & label differences
- Associate negative attributes to perceived differences
- Separation of 'us' from 'them'
- Status loss & discrimination (Link and Phelan 2001)

Response to fear, risk or threat (Gilmore and Somerville 1994)

#### Discrimination

Unfair and unjust treatment of an individual based on the basis of the:

- real or perceived status or attribute (e.g. medical condition)
- belonging, or being perceived to belong, to a particular group (UNAIDS)

#### **Stigma & Medical Conditions**

Disease stigma is greatest when:

- Not well understood
- Perceived as contagious (physical, social) and a threat
- Associated with perceived 'deviant' behavior
- Viewed as the responsibility of the individual
- Condition is severe, degenerative, or disfiguring
- Undesirable and unaesthetic death

(Alonzo and Reynolds, 1995; Cogan and Herek 1998; De Bruyn 1999)

#### Why Stigma & Discrimination?

- Fueling spread of HIV
- Barrier to effective HIV prevention, care, treatment, mitigation programs 26% to 53% of vertical transmissions may be attributed to stigma (Watts et al, 2010)
- Reduces quality of life and life chances
- Causes pain and suffering
- Human rights violation

#### Consequences of stigma in any setting

- Physical and social isolation
- Abandonment by spouse & family
- Gossip & Verbal Abuse
- Loss of livelihood
- Loss of housing
- Rejection by peers
- Loss of reputation
- Violence

#### Forms of Stigma – Health Care Setting

- Denial of treatment
- Neglect
- Differential Treatment
  - Visible separation/isolation (separate wards)
  - Marking (e.g. charts, by clothing)
  - Gloves (e.g. double, only when treating HIV+ person)
- Testing & disclosure without consent often to family members
- Verbal Abuse/Gossip

# Consequences of stigma in health settings

- Prevention
  - **Testing**
  - Disclosure
  - **Risk Recognition**
- Care and support
- Health Care
  - Access: Treatment Seeking & Adherence
  - Delivery/Quality of Care

#### **Raise Awareness**

- Foster understanding and motivation for stigma reduction by:
  - Creating recognition of stigma
  - The benefits of reducing it
  - Safe space to reflect and gain skills for change

### Address fears & misconceptions

- Address fears and misconceptions about casual transmission of HIV
- How it is and is not transmitted.
- In-depth information
- Interactively
- Listen, learn & respond to specific fears related to daily living context

### Discuss and Challenge the 'Taboo'

- Provide safe spaces to discuss, reflect, understand and question:
  - The values and beliefs that underlie stigma and discrimination
  - Where they come from
  - · What they do
  - Separating the person from the behavior
  - Gender, inequity, sexuality, violence, drug use

### **Employ a Range and Combination of Approaches**

- Participatory & interactive education
- Strengthening organizations of People Living with HIV and other vulnerable groups
- Contact strategies
- Mass Education
- Institutional reform
- Policy dialogue
- Legal & policy reform and enforcement
- Provision of services, including treatment

### **Operate at Multiple Levels**

- Individual
- Family
- Community
- Organizational/institutional
- Government/legal
- National, State, District, Community

### **Address the Multiple Layers of Stigma**

- Vulnerable groups experience stigma related to multiple sources:
- Drug use, sexuality, gender, sex work, HIV, violence

### **Key Lessons Learned**

- Awareness building & reducing fear driven stigma 'easier' than moving value-driven stigma
- Fear of 'blood' harder to shift than 'casual' contact
- Participatory methods & process work
- Sensitization & training for all implementers
- Community ownership key
- Combination approaches
- Ongoing activities

#### **To Action**

- Development of practical stigma-reduction tools:
  - Understanding and Challenging HIV-stigma: Toolkit for Action
  - Reducing HIV Stigma and Gender-Based Violence: A Toolkit for Health Care Providers in India

# Annex 4. Naming Stigma Through Pictures (Group Analysis)

Picture	Comments – what and why
Picture of man outside health care facility	<ul> <li>Man has discovered his positive status, confused, whatever counsellor has told has not registered</li> <li>Low awareness and limitations of first counselling session</li> </ul>
Picture of nurse wearing gloves to take the temperature	<ul><li>Nurse discriminating; too many barriers</li><li>Low awareness about HIV, attitude</li></ul>
Man with confusion	<ul><li>Man discovers he is +ve and has lots of questions</li><li>Self stigma</li></ul>
Nurse shrinking away from boy with anal problem	<ul><li>Nurse's discomfort at an anal problem</li><li>Moving away due to stigma and discrimination</li></ul>
Man with X ray	<ul><li>Man sitting away from others</li><li>Probably discriminated, breach of confidentiality</li></ul>
Flamboyantly dressed woman being denied entry	<ul><li>Discrimination</li><li>Probably because of stereotypes</li></ul>
Woman crying in one corner and two people talking about her	<ul><li>Woman crying</li><li>Possibly being spoken about with stigma</li></ul>
Picture of doctor and nurse with patient in the background	<ul><li>Nurse wearing gloves and advising doctor</li><li>Stigma and discrimination by health care worker</li></ul>
Nurse wearing 2 pairs of gloves	<ul><li>Over protection</li><li>Stigma and discrimination by health care worker</li></ul>
Everyone turning away from patient	Isolation     Social stigma

# Annex 5. Case Studies on the Impacts of Stigma

### Case Study A: Effects of stigma on men who have sex with men

Krishna started to have sex with men when he was a teenager, and managed to hide this from his family. He knew that being a man who has sex with men was natural for him, but he was worried his family would find out and make his life miserable. Other friends had been "discovered" by their parents and their lives had become hell and he wanted to avoid this.

When he grew older he lived in the same town as his family, but lived on his own. His family suspected he might be gay, but they didn't bother him until he was 30, when they started to pressure him to get married. He agreed to the marriage to get them off his back.

Soon after getting married, he found out that one of his previous male partners had tested HIV-positive, so he started to worry about his own status. What would people think if he was HIV-positive? Would they find out that he has sex with men? How would he be treated?

He went to the health facility to take a HIV test, but the counselor made him feel very uncomfortable. He asked lots of questions about Krishna's sex life. When Krishna mentioned having had sex with men, the counselor said, "No, you are not one of those! You seem different!" Krishna left the health facility without taking the test and told himself he would never go back.

He was so worried that his wife would find out about his male partner that he just continued to have sex with her without using condoms.

#### **Discuss:**

- a) What happened in the story? Why is Krishna behaving the way he is?
- b) How does stigma affect disclosure to his partners and his use of health services?

# Case Study B: Effects of stigma on people living with HIV

Raju was a migrant labourer. He worked for 10 years in the capital city, returning three times a year to his village to see his wife Lakshmi and two sons. While he was away his wife gave birth to a girl and another boy. After a while Raju started to suffer from a constant fever. He went to a clinic where he tested HIV positive. When Raju's employer discovered he was HIV-positive, he was fired. Raju found it difficult to get other work, so he returned to his village. When he arrived home, he told no one. He didn't want to face any more shame. Lakshmi asked him what was wrong, but he kept silent. He survived for one more year before dying. During this year one of his sons started to get sick, too. After he died, Lakshmi went for a HIV test and learned that she was HIV-positive.

#### **Discuss:**

- a) What happened in the story? Why did Raju not tell his wife?
- b) What are the consequences of Raju not disclosing his HIV status?

### Case Study C: Effects of stigma on people who use drugs

Manoj finished university and started his own business, selling computer equipment. He also got married. After the birth of his first son he decided to expand his business. He travelled around the country to get customers, and in the evenings he spent a lot of time in bars. In one bar he met a sex worker, called Lakshmi. He fell in love with Lakshmi and began to see her on a regular basis and they stopped using condoms. Lakshmi introduced him to drugs, saying it would make sex more enjoyable – and he agreed. After a while he became addicted. He used drugs by injection, sharing needles with Lakshmi and two other sex workers.

One day Manoj started to have a lot of pain when urinating. He went to a clinic to get tested for a STI. The doctor gave him a funny look, asked if he was using drugs, and told him he was ruining his life with drugs. Manoj got very upset and left the clinic. He bought some penicillin from a friend and treated himself.

Manoj's life started to fall apart. Some of his patients suspected he was using drugs and they stopped doing business with him. His wife suspected he was using drugs and she refused to sleep with him.

When Manoj saw Lakshmi again, he told her about the STI. Lakshmi said they should be more careful but Manoj said he didn't need to use condoms with her. They continued to have sex without condoms and to use drugs together.

Manoj's friend told him to check his HIV status. Manoj took the HIV test and found out he was positive. Manoj was shocked and confused and didn't know how he would tell Lakshmi and his wife. He became very depressed and worried about what he would do next.

#### **Discuss:**

- a) What happened in the story? Why is Manoj behaving the way he is?
- b) How does stigma affect his use of injecting drugs, use of condoms, and use of health services?
- c) How does stigma result in the continuing spread of HIV?

# **Annex 6. Risk Clarification Exercise (Individual Exercise)**

Please tick (x) in the appropriate column your response to the following statements

Code: 1 = Agree 2 = Disagree 3 = Not sure

Statement	1	2	3
1. Patients who are HIV positive should be placed in a separate room.			
2. The linens of HIV positive patients should be separated from the lines of other patients and washed separately.			
3. All patients prior to surgery should be given a HIV test.			
4. You should only use gloves when coming into contact with the blood of HIV positive patients.			
5. Special care should be taken only when cleaning up the blood spills of HIV positive patients.			
6. After giving an injection to HIV positive patients, the needle should be separated and treated differently than needles used with other patients.			
7. Gloves must be used at all times when touching HIV positive patients.			
8. Health workers are at greater risk in health care settings of getting Hepatitis C than getting HIV.			
9. Health workers should treat the blood of all patients as having the potential of transmitting HIV, HBV and HCV			

# Annex 7. Stories of Being Stigmatised: Participants' **Own Stories**

### Story 1

I am a doctor. I married and shifted to a new town. I was working with an NGO that had a hospital that catered to HIV positive patients. I found out that I could not rent a house the moment I mentioned the name of the hospital where I was working as everyone assumed that I too must be HIV positive. I lied and managed to rent a house. A few months later my wife conceived and unfortunately had an abortion. The gynaecologist on learning where I worked refused to touch my wife and referred her elsewhere. Finally, my friend's wife who was a gynaecologist treated her and more importantly consoled her.

### Story 2

My parents originally came from China four generations ago. I have oriental looks and everywhere I go, people ask me intrusive questions about what I eat and people keep shouting 'chini' when they see me. It used to hurt me but not anymore.

# Story 3

I was born in a small village. My father was an alcoholic and therefore the entire village discriminated against us and pointed fingers at us. All of us grew up with the stigma of being children of an alcoholic father. This led to a distancing from my father. He committed suicide. A few years later I discovered that I was HIV positive. But having grown up with stigma all my life, it did not matter any more.

# Story 4

I had started working in an NGO when I was studying. One day I got an opportunity to attend a conference and I went. On my return I was asked to leave my job as I was told I had attended the conference without permission and therefore misrepresented my organisation. I begged them to reconsider but it did not work. Now I am determined to succeed and 'show those people' who treated me so callously.

# Annex 8. Case Studies on Post Exposure Prophylaxis (PEP)

## Case Study A: Radha

Radha is a 42 year old midwife working in the ante-natal clinic at a hospital. Radha tested herself for HIV two years ago when her husband died. She tested positive. She has not told anyone at work. One day Radha is taking a blood sample from a young mother when she splashes some blood on her face and in her eyes. She goes to wash it immediately but her colleague sees her and starts panicking. She tells Radha that she must report the incident to the Sister in Charge and go for PEP. Radha is worried that her HIV status will now be exposed.

#### **Discuss**

What are the issues facing Radha in this situation?

What advice would you offer to Radha?

Are there guidelines or policies that would help someone in Radha's situation?

### Case Study B: Manju

Manju is a student nurse in the third year of her studies. She is single but has been dating for the last year. Although Manju loves nursing, she fears that she might get HIV from her work with the clients in the wards. She hates taking blood or giving injections. Manju has read all about PEP and tests herself for HIV every three months, in case she has been exposed.

#### **Discuss**

What are the issues facing Manju in this situation?

Would you advise health workers to test themselves regularly for HIV?

Are there guidelines or policies that would help someone in Manju's situation?

# Case Study C: Raju

Raju is a male nurse on the surgical ward. He is happily married with two children. Last week he was involved in a procedure, which resulted in possible exposure to HIV transmission, and Raju was advised to go for PEP. When he was tested for HIV before going for PEP, he tested positive. Raju has not been to work since then, and is feeling angry and confused.

#### Discuss

What are the issues facing Raju in this situation?

What assistance do you think Raju needs?

Are there guidelines or policies that would help someone in Raju's situation?

### Case Study D: Meeta

Meeta is a 38 year old married woman who works as a nurse in a large hospital. One day as she was trying to inject a client, she accidentally pricked herself. Meeta did not inform any of her colleagues at work, but as soon as she got home, she cleaned her wound with alcohol. Meeta knows about PFP but does not want to access it.

#### Discuss

What are the issues facing Meeta in this situation?

Should Meeta be offered PEP – if so, why?

Are there guidelines or policies that would help someone in Meeta's situation?

### **Case Study E: Sunita**

Sunita is a 30 year old woman who was raped one night while returning home. The next morning she went to see an NGO for advice. The NGO staff took her immediately to a hospital to get PEP. When they reached the hospital, the nurse sent them to the medical officer in charge, saying that they only had a limited supply of ARV drugs. When they approach the medical officer in charge, he says he is not sure what the PEP policy is and sends them back to the department.

#### Discuss

What are the issues facing Sunita?

Should Sunita be offered PEP?

Are there guidelines or policies that health workers should follow in this situation?

What might be the barriers in offering Sunita PEP?

# Annex 9. QQR – Quantity, Quality, and Route of **Transmission**

### What is QQR?

For HIV transmission to take place, the quality of the virus must be strong, a large quantity must be present, and there must be a route of transmission.

## Quality

For transmission to take place, the *quality* if the virus must be strong. HIV does not live on the surface of the skin - it lives inside the body. HIV cannot survive outside the human body – it starts to die as soon as it is exposed to air. If it is exposed to heat (eg if someone bleeds into a cooking pot), it will die. The only place the virus can survive outside the body is in a vacuum (like a syringe) where it is not exposed to air.

### Quantity

For transmission to take place, there must be enough quantity of the virus in body fluids to pose any risk. HIV is found in large quantities in blood, semen and vaginal fluids and breast milk – so in these fluids there is a risk of transmission. HIV is found in small amounts in saliva, vomit, feces and urine, and not at all in sweat or tears – so in all of these cases there is no risk of transmission, unless blood is present. Thus cleaning or bathing a patient is also quite safe, provided all wounds are covered. .It is easiest to transmit HIV when someone tests negative because it is during the "window period," that someone has the highest quantity of virus. Once infected, it can take someone up to 3 months to test positive for HIV.

#### **Route of Transmission**

For HIV transmission to take place, the virus must get inside your bloodstream. Our body is a closed system. Healthy skin is an excellent barrier against HIV. HIV cannot pass through unbroken skin or even broken skin very easily. If you cut yourself, the blood flows outwards, away from the bloodstream. If you touch someone else's cut, blood will not swim into your bloodstream!

Common sense and everyday hygiene mean that many concerns that people worry about would not really happen in everyday life. For example you wouldn't share a toothbrush if it was covered in blood; you would wash if you cut yourself; you would wear gloves or cover your hands if you are cleaning up someone's diarrhea.

These three conditions – Quantity, Quality, and Route of Entry (QQR) - help to explain why HIV cannot be transmitted by such activities as

- Touching the skin or sweat of a person living with HIV
- Changing the clothes of or serving food to a person living with HIV
- Taking the blood pressure of a person living with HIV
- Shaking hands with someone living with HIV
- Hugging someone with HIV

#### Other Factors that Increase the Risk of Sexual Transmission

- Viral load of infected person. Higher viral load increases risk of HIV transmission. The highest viral loads occur at the initial stage of HIV infection (before an individual even tests positive for HIV) and the final stages of AIDS.
- Having multiple partners. If you have sex with multiple people regularly and do not use condoms with all partners, HIV can pass quickly through your sexual network. Remember, a viral load (quantity) is highest right after infection. So, if you got infected last week and have unprotected sex with someone else today, you will most likely pass on the virus. This is during the window period, before you even test positive.
- **Presence of cuts or wounds.** Wounds or cuts on either partner increase the chance of HIV entering the bloodstream.
- Presence of other sexually transmitted infections (STIs). STIs cause sores or broken skin, making it easier for infected blood to get through the skin into the bloodstream.
- Having sex during the menstruation period or when a woman is bleeding.
- Not using a water-based or silicone-based lubricant during anal sex. Lack of lubricant could cause additional tearing to the rectum and even lead the condom to break.

#### THE HIV TRANSMISSION EQUATION

**Human host with HIV** – someone has to carry the virus in order to infect someone else

Body fluid that carries large amount of HIV – blood, semen, vaginal fluid, breastmilk

Opening into the bloodstream – needle holes, mucous membranes such as the vagina, rectum, urethral opening of the penis and foreskin, esophagus, eyes, cuts/tears in the vagina, anus, penis or mouth

Activity that can move these fluids between people – unprotected sex (anal, oral, or vaginal), sharing injection needles, breastfeeding, blood transfusion

= POSSIBILITY OF HIV INFECTION

### Annex 10. Statements for Value Clarification Exercise

- 1. Health workers have a right to know which of their patients are HIV-positive.
- 2. HIV positive patients should be treated at a separate facility, rather than in the same facility as other patients.
- 3. Health workers have a duty to inform the spouse and family of a person who is HIV-positive.
- 4. Women living with HIV should not be allowed to have babies.
- 5. People who get HIV through sex deserve it because of their bad behaviour.
- 6. A health worker who is living with HIV should not be allowed to treat patients.
- 7. Being MSM is a mental illness so MSM should be given treatment for their mental illness.
- 8. Sex workers love money and are lazy to work. They could easily get other jobs.
- 9. Sex workers should be allowed to get married and continue their work as sex workers.
- 10. Needle and syringe programmes (NSPs), which provide sterile needles and syringes to people who use drug, will result in more drug use and more drug users.

# **Annex 11. Case Scenarios: Counselling Exercise**

- 1. You are a man and have been with your male partner for 2 years. Two days ago he told you that he had fallen in love with someone else and was leaving you. He also said that you should get checked for HIV. You are feeling very sad and start crying in the counselling session.
- 2. You sell sex as a way of surviving and really enjoy meeting different people and earning money. There is some sexual practices e.g. anal sex that you want to ask the counsellor about to see if there is a risk of HIV and to get some advice about – but you are not sure how they will react.
- 3. You have been given a positive result for HIV and are feeling very angry. All you can talk about to the counsellor is how it is all your wife's fault and you will make sure she is 'punished' when you get home.

### **Annex 12. Final Evaluation**

### Section 1: Assessment of activities

# Workshop Activities	VP	Р	Α	G	Ε
1. Opening Speeches	0	0	3	9	7
2. Naming Stigma Through Pictures	0	0	2	6	11
3. Effects of Stigma on Access to Health Services (Case Studies)	0	0	1	9	9
4. Universal Precautions	0	1	2	10	6
5. Our Own Experience of Being Stigmatised (Individual Reflection)	0	0	1	6	12
6. Naming Stigma in Surgery, Lab, Ward, Counselling Room, etc	0	0	2	11	6
7. Fear of HIV and Improving our Knowledge on HIV Transmission	0	0	1	9	9
8. PEP and Stigma	0	0	2	10	7
9. Forms, Effects, Causes, & Solutions to Stigma in Health Setting	0	0	2	7	10
10. Blame Game – Stigmatising Words to PLHIV, MSM, Drug Users		0	1	9	9
11. Exploring Our Attitudes towards PLHIV, MSM, Drug Users, etc		0	1	7	10
12. Panel Discussion on Marginalised Groups		0	0	5	14
13. Counselling Skills – Paired Role Playing		0	0	9	10
14. Final Session – Writing Code of Conduct for Health Facilities	0	0	1	7	11
15. Energizers – Claps, Games and Songs	0	0	0	0	19

VP = Very Poor. P = Poor. A = Average. G = Good. E = Excellent

# Section 2: How did you feel about your own participation and interaction in the workshop?

Excellent (3). Great (3). Very good (3). Amazing (2). Very interactive workshop (2). Helped to build up my confidence. I will never forget this workshop in my life. Gained lot of extra knowledge. Good teamwork. Good interaction with other health workers – and made some new friends. I felt encouraged to air my opinions, even if others did not agree. Everyone's participation was excellent. Workshop encouraged me to contribute more than the best of my abilities.

# Section 3: What were the most important learnings for you from this workshop?

- Getting a deeper understanding on stigma (5)
- Universal precautions and PEP (3)
- New training methods so that learning is more interactive and not boring (3)
- The best strategies for reducing stigma (2)
- Learning how PLHIV, MSM, and drug users feel from the panel presentation (2)
- The importance of changing our attitudes in order to reduce stigma
- Starting to re-examine long held stigmatizing attitudes and beginning to change them
- Forms, effects, and causes of HIV stigma and solutions to reduce stigma
- How stigma discourages PLHIV and other marginalized groups from using health services
- Stigma reduction will bring down transmission rates in the populations
- Unintentional breach of confidentiality in health facilities
- The exact guidelines to be used in reducing stigma
- How to motivate health workers
- How to interact with female sex workers
- The need to stop stigmatizing PLHIV, MSM, drug users, sex workers
- Gay men natural, inborn, physiological phenomenon
- Learning the views of health workers from other parts of the country
- Learning the skills to conduct stigma training in my own health facility
- Importance of passing on this new understanding to other health workers
- The importance of participatory methods to reduce stigma
- Learning to be humble and help move the tables and chairs from Ross

# **Section 4: Rating on Workshop**

	Very Poor	Poor	Average	Good	Excellent
Overall Workshop	0	0	1	6	12
Facilitators	0	0	0	4	15
Workshop Methods	0	0	0	5	14
Food/Logistics	0	0	1	8	10

#### Extra Comments on the above

- Energizers were great. Good work keep it up! (2).
- We need power point slides, case studies, pictures, and other training materials to replicate this training in our own area (2). Conduct the same training in all districts with SACS support.
- Organize more workshops on stigma for other health workers.
- Morning break needs to be improved.
- The service in our hotel was very poor.

### Section 5: Likes about the Workshop

- Highly participatory (6) everything was great (2) Bravo! No boring lectures very interactive. Claps, songs and games. Dr. Ross' method of keeping everyone actively involved in all activities.
- Variety of methods to learn about stigma pictures, our own stories, case studies, role plays.
- Learning about how stigma feels from the personal stories of MSM, PLHIV, and drug users - helped to change our attitudes. Role plays and sharing of personal stories on stigma.
- Team of facilitators. Thanks to ICRW for organizing this workshop.

# **Section 6: Dislikes about Workshop**

- Nothing (13).
- No expert opinion as final authority/take home message.
- Workshop was too short we needed 5 days to cover everything, without having to
- You should have involved all SACS people so they can fund stigma workshops in all hospitals.

- Liked the panel presentation need for more inputs from marginalized groups.
- Very good coordination except remark on "Indian" counsellors and doctors.
- Parking lot. Some participants talked too long. Some irrelevant talk. Food

# Section 7: What will you do to promote stigma reduction when you return to your own health facility?

- Share what I have learned with other staff members (5).
- Conduct sensitization workshops for other health workers (4).
- Implement a new code of conduct in my own health facility (2).
- Conduct regular meetings on stigma with other health workers.
- Train those in my setting a) health workers b) beneficiaries (infected and noninfected).
- To apply what I have learned in the best possible way i.e. to de-stigmatize my own practice.
- I will talk about stigma whenever I get the opportunity.
- Incorporate stigma awareness into the training curriculum for health workers.
- Prepare teaching modules on stigma to train health workers.
- Start teaching colleagues by example.
- Become a role model to other staff on how to destigmatize our health facility.
- Sensitizing other staff to be careful in their non-verbal gestures.
- Asking administrators to open a NACO extension centre in our medical institute.
- Advocate with NACO for more such trainings.





