









# PATTERN OF RELATIONS AMONG DISCORDANT AND CONCORDANT COUPLES IN THE CONTEXT OF HIV AND AIDS TRANSMISSION

**A Qualitative Study Report** 



Lembaga Kajian dan
Pengembangan Masyarakat

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# A QUALITATIVE STUDY:

# SOCIAL DYNAMICS AMONG DISCORDANT AND CONCORDANT COUPLES IN THE CONTEXT OF HIV AND AIDS TRANSMISSION

IN DKI JAKARTA, PEKANBARU, DENPASAR, AND TIMIKA

**LKPM** 

2009

With great respect and gratitude
To all prostitutes, sex workers,
To all mothers and wives,
To all female drug users,
To all common people willing to defend and advocate for the rights of these people forgotten by
the system
In Indonesia

And thank you to every one that has participated, spent time to open up and express your problems, your fears and anxieties but also your happiness and hopes through this study in Timika, Pekanbaru, Jakarta, and Bali

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## LIST OF TERM

ISTILAH	PENJELASAN
Amome	Amon, the name of the tribe papua
Awig-awig Desa	Regulations village in Bali agreed to by the people in the village
Banjar	Limitations of the village in Bali which refers to the unity of the community, led by a person chosen by the people of this region in agreement
Berate	
bendese	Head of the Village People
Blak-blakan	Talk honestly and open
Brahmana	Highest levels of caste in Bali
Bokap	Father
Bokep	The film depicts scenes related sexual
Bontot	Siblings most small children or young
Bonyok	The state of black-and-blue as a result of physical violence
Burung	Term for penis
Canang	Another name for the offerings that made the equipment as Bali prayer
Comel	Term for people who like to spread open and secret
Damal	Name of tribe in Papua
Dami	Name of tribe in Papua
Desa Adat	unit of community in the Province of Bali which with tradition and manners based Hindu and local customs with specific area and their own property and household management
Desa Dinas	Village management base on Indonesia government system
Female Kotex	Name of the support group of women in Jakarta

Freelance	Sex workers who do not have a pimp or not bound by company
Gerebek	The term for the arrest
Ngewe	Term to initiate sexual
IO	Abbreviation of Opportunistic Infectious Diseases
JAMKESMAS	Health insurance society health insurance from the government
Junkie	Term used to take the drug heroin users
Karaoke	The term for oral sex
KDRT	Violence In households
KDPA	Village AIDS Care Group, Community Bali in a region that groups have a special attention because of the AIDS problem
KDS	peer support group
Keked	The term for the body to feel stiff
KKN	Term used when there is activity bribery to get anything except its own business without the assistance of persons in)
Klien Adat	
Konore	Name of tribe in Papua
Ksatria	Second highest levels of caste in Bali, after the Brahmana
Kulibia	A kind of dowry in Papua, in the form of stone itself be chiseled
Malkon	Malaria Control, funded by the Freeport Company in Tembaga Pura, Timika
Mami	Term for brothel prostitution in the localization
Metadon	Opiate synthetic used in oral
ML	Making Love, sexual conduct
MK	Abreviation of Case Manager
Molor	sleep, Slank language
Moni	Name of tribe in Papua
Nyokap	Mother, Slank language

Neken	an activity in using drug, drug type of amphetamine pill named exctacy
Odalan	Anniversary commemoration ceremony temple, valid in the Bali
On	drunk because the type of drug extacy
Penasun	Drugs needle users, the type of heroin or subutex
Pepe	Another name for vagina
PKM	Community Health Center
Prodia	Name of private clinic laboratory
Rambut lurus	The term used by sex workers in Papua to mention customers who come from areas outside of papua / migrants
Rambut keriting	The term used by sex workers to call customers Papua indigenous people of Papua
Rese	The term for the nature of love affairs took the intervention of others
Sangkep	Rapat dalam bahasa Bali (the term in Bali for the meeting
Service	Serve customers by commercial sex workers
Sepong	The term for Oral Sex
Shabu	another name for drug type of amphetamine
Sudra	lowest level caste in Bali
Teler	another name for drunk, uncontrolled condition after get alcohol or another narcotics
Tempur	A slank for having sex, the literal meaning is to go for a fight
UKM	Abrv: Unit Kegiatan Mahasiswa
	Student activity units – a student organization from campus
YAKEBA	Yayasan kesehatan Bali - is the name of NGO's which is concern on drugs and HIV/ AIDS issues domicile in Bali

#### **EXECUTIVE SUMMARY**

Globally more women are being infected with HIV and AIDS. As the epidemic takes on twenty years of age, the number of positive women reaches 40 million. By 2007, the proportion of positive women got to 25%. Even more disconcerting is the epidemic in Tanah Papua whereas it has spread within the general population, and the number of women infected has surpassed their male counterpart. The spreading of the infection in most of the country is attributed to unsterile use of injecting drugs while in Tanah Papua, sexual transmission is the main mode of transmission. Alarmingly the infection has been crosscutting among risk groups: drug users, sex workers because of sexual transmission in addition to more housewives are finding themselves and their children infected.

As support for HIV program is growing, whether locally or from the international community, more studies are being conducted. And yet, most are still taking on a quantitative approach, ignoring the social context, dynamics and interactions affecting women particularly those vulnerable to HIV. Consequently, the inappropriateness of the approach taken by the services, the intake of women in HIV program and services seldom reaches more than 10% of patients/clients/participants.

The study took place in four cities: Jakarta, Pekanbaru [Sumatra], Bali and Timika [Papua]. Each city has different cultural, social, monetary and political settings, which are affecting the position of their women in society and particularly HIV positive women, discordant couples and risk groups including sex workers and injecting drug users. The qualitative approach gives more room for participants to express their situation, problems and allows their voices to be heard in the analysis of this study. The study looks at the different patterns of social relations [relasi] of the women involved in the study, how a positive status, whether theirs or their husbands, and/or children is affected by these relations. The analysis takes on at how the HIV infection has changed the position of women within a discordant relationship in particular decision-makings in sexual relations, their standings in the community and society in general. It provides insights as appropriate approaches by HIV programming, services providers in particular the government and by the community to ensure a more effective, efficient and sustainable HIV response for discordant couples and women in general.

Discordant couples unlike concordant couples are burdened with the perceived discrimination of being positive. It is perceived because most couples are not open about their status or that of their husbands either to their families or their surrounding neighborhood, due to the fear of loosing those social relations. Being positive is a personal value to be known only within the couples. Drug users couples tend to be more open about their status and female drug users have more control over sex. Housewives are more submissive while sex workers tend to hide their profession and their status from their partners if they are not aware of it, or if the partner is aware of their profession, then they both are more indifferent of the risk during sex. Yet, sex workers are totally submissive to their clients and tend to take any acts including violence while having sex with clients. Conflicts, problems are mostly handled within the couple, without much involvement from society and family. It is interesting to note that the infection within the couple, whether it's the

women or the man who's positive, had forged a stronger relation among them that not even the family nor society had intervene despite the influence of those cultural norms. The role of the spouses is important, they need to take a more affirmative position in supporting their wives/partners.

Meanwhile, all groups, sex workers, housewives, drug users are maintaining a cordial relation with their surrounding community. Where you have a strong sense of community, the women are more protected and have stronger bargaining position: sex, social and monetary. Sex workers within brothels are better protected from violent clients, taken cared when sick, and can negotiate condoms than their counterparts working on the streets. Female drug users living in a neighborhood whereas drug use is acknowledged, are protected also from the public pressure particularly police raids. It is the common members of that neighborhood that are ensuring their safety of drug users during the raids. Most participants, especially drug users and sex workers are feeling threatened by the current laws, pushing them into isolation than from common people. And where public services includes HIV programs, housewives, sex workers and drug users have consistent access. Many mentioned limiting themselves to charity based HIV programs from NGOs as it is free and friendly, yet are not aware that the public system that includes Puskesmas [Public primary clinic] is actually able to provide health care accustomed to their needs. The discussion of current HIV programs for women and discordant couples mostly mentions NGO work as information about condom and basic HIV, condom distribution and taking the participants to their clinics.

The study found three patterns of social relations: intimate that is a relation within the couple only; domestic which is the relation that includes the direct surroundings including family, cultural structure, neighborhood; and public which involves the public system [government-citizen]. These are the three relations in which the participants are involved. These are the social relations, which should be considered when designing a program for women involved in a discordant relationship.

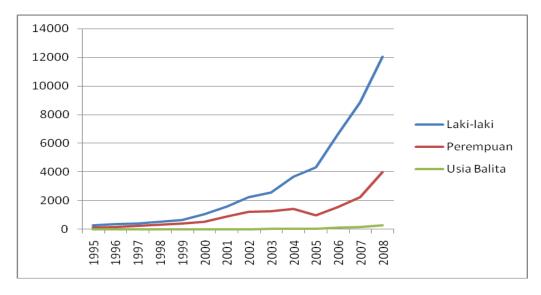
Thus far, most program dominantly carried by NGOs are focusing on the intimate relation. They tend to focus on the act of having sex [via condom distribution, ABC principles, etc] and don't educate the couples, particularly these women to face their surroundings whether it's the family system or cultural structure [community leaders, religious systems, etc], let alone to be able to demand their rights as civilians: right to health care, equal opportunities, political rights and so on. The aspect of empowerment should be highlighted in all efforts and as these women have shown, organizing groups: whether it's sex workers, drug users or housewives is an effective approach to build an enabling environment for these vulnerable women. As their position in society becomes stronger, they would also have a stronger bargaining position as living couples and as women in general.

#### 1. HIV AND AIDS IN INDONESIA – A GROWING FEMINIZED EPIDEMIC

The latest estimates of most at risk population pulished by the Ministry of Health [MOH] for 2006 indicated that there is a range of 177,200-265,000 of female sex workers [FSW] and 2,435,000-3,813,000 clients, 190,460-247,800 drug users [IDU]<sup>1</sup>. The report also shows that there is a proportion of 10% of women among the IDU population<sup>2</sup>.

The government-MOH and NAC and epidemiologist have projected future AIDS cases using Asian Epidemic Model, that by the year 2010 there is a increasing tendency becoming 400.000 with a quarter of death, and by the year 2015, an increase into 1,000,000 cases with 35% of death cases. In the same year, there will be 38,500 babies born of HIV positive women.

The number of found cases rises by the year whether among men and women togther with more children under the age of five found with an HIV infection [refer to picture 1; Increase HIV and AIDS cases aggregated by sex and under the age of five]. This growing number of infected women and children is an alarming sign of how the quality of the countries future generation is in jeopardy. Monthly reports from several PHC in DKI Jakarta, whereas every month they are admitting babies already at 3-5 AIDS stadium, and most were not recovered eventhough referred to the closest hospital<sup>3</sup>.



Picture 1. Increase HIV and AIDS cases aggregated by sex and children under the age of five

Most of Indonesia is experiencing a concentrated epidemic, driven by the use of injecting drugs from the 1990s until today whereas 50% of AIDS cases are injecting drug users. Although the

<sup>&</sup>lt;sup>1</sup> Departemen Kesehatan, Estimasi Nasional Populasi rawan Tertular HIV/AIDS, 2006

<sup>&</sup>lt;sup>2</sup> ibid

<sup>&</sup>lt;sup>3</sup> Dinas Kesehatan-DKI Jakarta, Kompilasi Laporan Kasus Layanan HIV di Puskesmas DKI Jakarta, 2007 – 2008.

number of female drug users is stil small compared to their male counterparts [the 2006 estimates shows that there is a proportion of 10% of women among the IDU population), but a study supported by AusAID and IHPCP together with several local NGOs and Drug User Networks described that female drug users's problem are more complex than what male drug users are facing, such as their vulnerability to sexual and physical violence by drug dealers, sexual partners, or police officers. Female drug users tend to be more secretive and exclusive and rarely express their existence and aspiration to society, because of local customs, traditional values particulaly related the image of a woman<sup>4</sup>. Therefore female drug users rarely seek treatment and access healthcare or any drug treatments.

The 2007 IBBS indicated that there is a about 6 % – 16% direct female sex workers [DFSW] and 2% - 9% indirect female sex workers infected [IFSW] with HIV. Among DFSW in Tanah Papua and Bali, HIV prevalence is highst while among IFSW in Batam an Jakarta.<sup>5</sup>. Most FSW got infected in their first 6 months of working<sup>6</sup>. These facts show that female sex workers get infected in the early stage of them entering the sex industry and shows how vulnerable to the HIV infection, therefore medical, social and other services should be provided immediately.

Meanwhile Tanah Papua posesses a different epidemiological pattern, whereas the epidemic has moved on from a concetrated level to a generalized epidemic driven by sexual transmission. In 2006, MOH estimated that among 8.000 - 14.000 people the prevalence reached more than 1% in the districts of Mimika and Merauke<sup>7</sup>. There is around 10 - 15% male adolescents aged of 15 - 24 yo already sexually active and 50% before marriage. Pre-marital sex among female adolescents aged of 15 - 19 yo is also high, 6% in Merauke, 90% in the high lands of Jayawijaya, 30% in Biak and 20% in Jayapura<sup>8</sup>.

<sup>&</sup>lt;sup>4</sup> IHPCP, "Perempuan-perempuan diLingkar Napza; studi kualitatif di 8 kota besar di Indonesia": presentasi dalam lokakarya penelitian oleh KPAN. 2007.

<sup>&</sup>lt;sup>5</sup> Departemen Kesehatan RI, "STBP Pada Kelompok Beresiko Tinggi di Indonesia: Fact Sheet. 2007.

<sup>6</sup> ibid

<sup>&</sup>lt;sup>7</sup> Departemen Kesehatan RI, "Laporan Triwulan Kasus HIV/AIDS. 2009.

<sup>&</sup>lt;sup>8</sup> Komisi Penanggulangan AIDS nasional, 2006; Laporan UNGASS 2004 - 2005

These are strong indication of a feminized epidemic across the country but also in particular in Papua as can be seen on **Table 1**; Number of HIV and AIDS cases in Papua Province.

**Tabel 1: Number of HIV and AIDS cases in Papua Province** 

Sex	HIV	AIDS	Total	Situasi diatas menunjukkan bahwa saat ini sedang terjadi penularan
Male	1107	1203	2310	dikalangan Perempuan secara umum. Kerawanan perempuan yang
Female	1221	963	2184	meningkat akan tertular HIV/AIDS, memungkinkan terjadinya
Unkown	47	7	54	penurunan kualitas generasi penerus bangsa. Apabila situasi ini tidak
Total	2375	2173	4548	dicegah secara cepat dan dengan metode yang

tepat maka dampak penularan akan semakin berakibat buruk. Studi ini menggambarkan situasi perempuan secara umum terkait aspek sosial, budaya, dan medis. Aspek-aspek tersebut diperhitungkan karena persoalan perempuan tidak dapat dipandang secara sempit hanya pada salah satu sisi saja.

#### 2. RESEARCH METHODOLOGY

The study took place in four cities: DKI Jakarta, Pekanbaru, Denpasar, dan Timika. All four cities were selected based on its experience in responding to the AIDS epidemic which each being dominated by different modes of transmission. DKI Jakarta and Bali have higher cases of HIV and

AIDS from injecting drug users [IDU] while Pekanbaru and Timika's epidemic are fueled by transmission from sex.

The research involved networks of vulnerable groups [networks of drug users and sex workers] in each citie. These networks supported the research by recruiting participants and preparing all the interviews. Data gathering from focus groups discussions and indepth interviews were carried on from February till Mei 2009

Each city had three groups of women which were a combination of: (1) Injecting drug

Denpasar Sal

users (2) Female sex workers, (3) Housewives. Each group discussion had 8-10 participants based on the criteria described in **table 2**.

Indeph interviews verified information gathered in the group discussions, and inquired further information to better capture the social, political, economical and the AIDS response in each city.

Tabel 2. Participants criteria for FGD

Criteria	Female Drug Users	Female Sex Workers	Housewife				
Number of	10 people each city	10 people each city	10 people each				
participants			city				
Sex	Female						
HIV status of	Had or has sexual partner	Had or has sexual partner	Is or was married				
partners	[married or not]	[married or not]					
Occupation,	Used drugs in the past one	Sex worker for at least 1 year					
daily activities	year						
HIV Status	Has been test for HIV and know of their status [herself and of her partner]. Basically						
	partners are discordant and concordant. If the participant is positive, then the						
partner is negative and visa versa.							
Age	Between 18 – 40 year						

Recruited participants voluntarily partook in this study with all of their identities and recorded data kept confidential. Prior to gathering data, instruments were field tested with a trial group of female IDUs in Jakarta. Later on, the instruments were appropriately updated to ensure that they better capture the reality of these women. Each research team would have their interviews and discussions transcribed, categorized and reported. In addition to interviews, a small survey was distributed to each participants with data including demography, health, income, HIV status and attitudes upon knowing their status. Eighty two questionnaires were gathered and analyzed for this study.

The following **tabel 3.** are aspects and issues discussed in this study.

Tabel 3. Issues and aspects discussed in questionnaires

Issues and aspects	Description of basic findings
Patter of relation between man	System of sexual relations with partners, partners perception
and women	towards their professions or behaviors, conflict resolution,
	interaction with partners
Social construct	Participation in societal activities, roles in society, appreciation
	and aknowledgement from society, rules and regulation or
	policies that are binding the participants
Control over financial	Decision making concerning finances and management,
resources	involvement in financial management
Avaibiliy of services for women	Access to services (easy, cheap, accommodating working hours),
	Preparedness of health providers (providers attitude, facilitites,
	complain response)
Programs for women	How programs are accommodating to the needs of women [IDU,
	workers, sex workers, housevives]

#### 3. FINDINGS

#### 3.1. PARTICIPANTS CHARATERISTICS

Participation of each city varied as each has different cultural, social and economic/financial condition. Hence participants gathered had different characteristic..

The following **table 4**. discusses the number of participants participating in the study.

**Tabel 4. Number of participants** 

City	Female drug	Female sex workers	House wife	Indepth interview
	users	WOIKEIS	wite	
DKI Jakarta	9	6	10	
Denpasar	9	10	11	1 person (Head of AIDS CommissionK Bali)
Pekanbaru		4	6	1 person (Peer support group lancang kuning)
Timika		10	7	2 persons
				(leader of traditional village and Secretary of
				AIDS Commission Timika)
TOTAL	18	30 persons	34	4 persons
	persons		persons	

Most participants are aged between 30 - 34 years old, while sex workers are younger ranging from 19 - 24 years old. The highest level education noted is high school, while for sex workers most are

elementary school [SD] graduates. Meanwhile housewives had a relation with their partners for around 20 years, while female sex workers for 8 years and sex workers for 2 years. Female sex workers involved in this study had the highest rate of HIV positive status [70%], female drug users 60% and 47% of housewives were positive HIV.

Most participants are Molsems (75.6%), originating from Java (25.6%), and most were in their current relation for more than a year (54%). Some participants are sex workers (31.7%), housewives (26.8%) and workers  $\{12.2\%$ ). The questionnaire also asked the occupation their partners, and most worked in the private sector (34.1%), entreperneur (22.7%) and workers  $\{17.7\%$ ).

The average income of participants ranged from Rp. 500.000 – Rp. 1.000.000 permonth (29.3%). What is interesting to note is that most of the participants are spending more than what they earned. Their expenses included: parents, debts or helping a family member [extended family].

#### 3.2. Sexual Relational Pattern

#### Decision making in sexual intercourse

Housewives are the most inhibited when it comes to making decision related to sexual relations with their partners. The decisions include: style, time and frequency of having sex. Religious doctrines and the perception that under any circumstance wives have the obligation to serve their husbands, forces housewives to give in to their partners without any self-consideration.

- " ... I do it because it is my obligation as a wife. Even if I am sick and I am not in the mood for it, or just physically am not feeling well, maybe it's the religious doctrine that not to serve your husband is a sin. At the end sexual intercourse becomes an obligated service to our husbands under any circumstance."...(A, Denpasar, IRT)
- " ...I often fake orgasme for my husband so that he feels happy, meanwhile in truth...well it's all pretending ..." (X, Denpasar, IRT)
- "...sometimes I get tired from taking care of our children, the house, so I sometimes look for excuses to avoid having sex, but if I can't avoid it anymore, I would just pretend to enjoy it so that it's all quickly over..." (B, Pekanbaru, IRT)
- "...but if my husbands wants it while I don't, there's nothing I can do, it my duty as a wife. I have to fulfill my obligation...(W, Timika, IRT)

Differently female sex workers feel that it is more important to provide better services to their clients than with their partners or husbands. Meanwhile, when with their husbands or partners, sex workers whom partners are not aware of their profession, they would pretend to be inexperience during intercourse so that the partners never find out of their profession.

"... with clients we have to give them our best so that they would return to us ..." (X, Pekanbaru, PSK)

- "...style, position and other things all depend to the client, I just go along. If he's satisfied, then I would get more money ..." (Y, Jakarta, PSK)
- "... later my husband would become suspicious, how come I am able to provide such good service, he would get an idea of my profession. It's better to be quiet about it. Whatever my husband wants, he will get it ..." (A, DKI Jakarta, PSK)

On the other hand, female drug users are more at ease in deciding how to have sex with their partners. Usually, sexual activities are decided together with their partners

"...if my boyfriend doesn't want to do it my way, I can just leave him, find another men. Especially since we're not married yet ..." (C, Denpasar, Penasun)

"...my partner also inject such as I, so we seldom have sex, if we do, if any of us doesn't want to have sex, then it won't happen ..." (D, Denpasar, Penasun)

In sexual relations that are based on economic motives, women tend to put themselves at a lower bargaining position to their clients, in order to ensure their satisfaction, being afraid not to be in demand anymore, or not to get future clients. Some sex workers participants admitted being physically abused by their clients, yet still they would not refuse that violent client when asked to serve him again.

- "...he pulled out my hair, bit my butt, slapped my face. If not because of the money, I would not have taken the violence. The next day, he asked for me again, and was even more violent. He tied my hands behind, and just paid my just Rp.1.3 million for all that..."(F, Jakarta, PSK)
- "...I actually don't like it, but they [clients] pay, and because they are the ones paying, we just go along with whatever style they want..." (Z, Denpasar, PSK)
- "...with my boyfriend I am more at ease to say what I want in sex, I can communicate or have discussion about it..." (Z, Denpasar, PSK)

#### 3.3. Relational Pattern And Responding To HIV

#### Relational pattern within couples and Disclosure of HIV status

Women having partners with similar social backgrounds tend to be more open about their HIV status. For sex workers whom partners are aware of their profession, it becomes easier to reveal their HIV status, especially if the partners was/is also a client. But revealing the HIV status is almost impossible or it becomes very confidential to clients [whom are not partners/boyfriend], due to financial motives. Sex workers whom partners are not aware of their profession, they tend to keep their status to themselves fearing being abandoned or divorced.

"...indeed, I do think about my status, but I'm afraid that if I do memang kepikiran juga soal status, tapi mau kasih tau nanti kabur lagi dia..." (B, WPS, Denpasar)

"...Idon't feel ready to be open about my status with my partner, I am afraid he will not accept me, and will want to break up..."(R, WPS, Denpasar)

"...my husband works at night, so we both know the risks...." (M, WPS, Denpasar)

Female drug users whom partners are drug users too or with partners that are aware of their drug use tend to be more open about their HIV status, also to their peers. There is feeling of solidarity among drug users, where they would inform each other of their status and encourage each other to have themselves tested.

"...since we are both using drugs, we don't care about getting infected, anyway we are also having sex..."(A, Penasun, Denpasar)

"...I haven't told him about my status, he's a white collar worker and is not exposed to these issues..." (V, Penasun, Denpasar)

On the other hand, most housewives were tested for HIV after their spouses and children were indicated to be positive and usually that is following being gravely ill. They believe that there were infected by their spouses as they are not having other risk behaviors. Most of these housewives, as they became aware of their status and of their husbands and children, they tend to keep it secret, making it a matter between her and her husband. The couple would keep it from their family or in laws.

"...I was in Bogor [West Java] at that time, when my husband became very ill. He was hospitalized and three months later he died. That's when my doctor asked me to be tested, and it turned out I was positive..." (B, IRT, Timika)

#### Relational Pattern With The Extended Family And Openess Concerning HIV Status

Relational pattern with the extendef family in this study refers to the relation between a man and a women as spouses, long-term partner, the relation with distant family members [including mother, inlaws, sister, aunt/uncle]. The pattern of these relations in the four cities have different characters and backgrounds, with values and attitudes much affected by local traditions and customs, set of believes and religion.

In the city of Timika, Papua Province, for example, the social order of a household is much influenced by a mercantilist tradition, whereas the women is bought by the man. The transfer of things, money, cattle to the women's family is an absolut condition to proceeding with a wedding. This system has an impact on the spousal relationship. For a husband that has not yet fully paid all of their marital offerings, are considered in debt to the woman's family and is obliged to finish up with these payments even if by installments. As long as the payment is not complete, the woman is still under the protection of her family. On the other hand, once payment is completed, the husband has full rights over his wife as her family has totally given her up. Although the husband were to be violent, the woman's family can not do anything about it, there is no bargaining position anymore. This tradition has a strong impact on whether the husband is open or not about his HIV status to his wife or/and his wife's family .

- "...If ever I were to open up to my wife, and she were to reveal my condition to her family, then the wife's family might just kill the husband..." (M, Timika, IRT)
- "...even when the husband runs away, and were to die alone, his head would still be chopped off if he was found..." (X, Timika, IRT)

Husbands that are honest about their HIV status, usually they are prepared to take their wives to be HIV tested at the clinic, and get tested together.

"...it's better to pretend to take the wives to the docter, get tested together, than having to admit being HIV positive, we could have a fight or a family feud..." (S, Timika, IRT)

The participants' obedience to their customs are pushing men and women into being more reclusive and keeping their status from their families (parents, inlaws, siblings, uncle, aunt, etc). The couple agrees to keep it as the couple's affair to handle.

"...just like me and my husband, mah... I have a deadly disease inside me, so do you take me as I am, sick and all, and not to report it to anyone in the family, so only the two of us would know about it, it's embarassing if they knew about it..." (M, Timika, IRT)

In Bali, there is a strong traditional kinship system [sistem kekerabatan] regulating every aspect of the 'banjar's population. These traditional customs have a strong influence upon the daily lives of a Balinese. The traditional leader is identified as the head of the Banjar and is very influential in deciding on which individual is accepted as part of the Banjar community [neighborhood]. Because the Banjar system and their leaders were seldom involved in HIV related issues, hence oftenly they make wrong decisions concerning their HIV positive constituent and causing them to be more sick or to die because of AIDS.

- "...indigenous Balinese are divided into castes, so the head of the Banjar is the person with the highest caste and the person everyone listens to. It donesn't matter if he's rich or poor or highly educated or not, but traditionally he is very influencial ..." (R, Denpasar, IRT)
- "...his family didn't want take his body, he is not accepted in this village, they said the hospital can do whatever it wanted, throw it into the water if they wanted ..." (F, Denpasar, IRT)
- "...most members of the Banjar don't know much about HIV and AIDS, not mention about addiction or sexuality, so they've never taken any decision concerning of their members related to HIV, usually they keep silent about it..." (G, Denpasar, IRT)
- "...being infected with HIV is always perceived as a disease of the permissive, it's a taboo ..." ( R, Denpasar, IRT)

This situation has caused most of Balinese participants to keep their status from their family and the Banjar.

"...if I were to say anything to our neighbour, an entire banjar would know. I am afraid to be evicted, so it's better to keep it a secret and just for my husband to know ..."(N, Denpasar, IRT)

For Balinese women married to a man with higher caste, it would be difficult to talk about their HIV status particularly to the inlaws. Because there is a perception that HIV is a dangerous disease, bringing misfortune and is easily transmited from common touch, many times women are outcasted from the husbands family even when it comes to taking care of their own children. That's why most couples prefer to keep their status to themselves.

The same would go when the caste of the women is higher than the man's ranking in society, with similar response from the woman's family, yet the man is more confident to be open about his status.

"...if the woman's caste is higher, the burden on the woman is not as bad as when her caste is lower than her husband's, although his family could as well request a divorce..." (V, IRT, Denpasar)

In Pekanbaru, Riau Province, similar difficulites are felt when it comes to disclosing their HIV status. The Malay [Melayu] culture which has a strong patrilineal traits, pushes men and women conceal their status. Those whom find themselves HIV positive would seclude themselves from their neighbours and social environment, they don't even want to be seen together with positive groups [KDS]. This reticence also influences health seeking decisions.

On the other hand, in Jakarta, the complex and varied social and cultural tapestry of the population which no longer has a dominating culture, causes society to be more tolerant and more accepting towards differences, pluralism and similarities. The sex industry and drug trafficking in Jakarta is so widrespread that there is no district in Wider Jakarta that is not affected by both industry. Therefore projects and services are made available in most parts of the city including information and HIV related services related to drug use and sexual transmissions. The drug industry in Jakarta can be found in specific pocket-area, the same with the sex industry, although most are not formally acknowledged. Yet, these industries are involving common people including drink seller, washer, ojek [moto-taxi], security officer, etc. This situation prepares people in Jakarta to accept the diseases from whatever the transmission modality. This condition creates an enabling environment for HIV positive people to live, to express themselves and to seek health care. During the group discussion, some female drug users indicated how their living environment is actually protecting them, as can be seen from these quotes.

"...usually when a police raid is underway, they tell us first, ...so that the next day when the police come, we seek reguge somewhere else, so it's better for us to hide somewhere else until the raid is over...kek..." (Y, Penasun, DKI Jakarta)

"....housewives [ibu-ibu] they feel pitty for us, so when the police is coming, they hide us away so that the police couldn't catch us..."(S, Penasun, DKI Jakarta)

#### **HIV Status And Condom Use Decision Making**

Women aware of their HIV positive status tend to be more able negotiate the use of condoms. Positive women also tend to take more responsibility don't want to add further burden upon their partners by infecting them. They also prefer to remind each other to use condoms when having sex. Even female sex workers, while clients might not know of their status, they still try to negotiate with their clients for them to use condoms.

- "...my poor partner if I don't use a condom, he will get infected. Although he doesn't know my status, I feel bad if he doesn't wear a condom. But I'm always confused when he's asking why I'm always using a condom with him?..."(T, Penasun, Denpasar)
- "...if there is no condoms, we try to buy one first, espcieally with boyfriends...(B, SW, Pekanbaru)
- "...since the situation is at it is, it would be a pitty to get the client infected...(R, SW, Timika)

There are many ways a sex worker would negotiate with her client to use a condom,

- "...if the client refuses to use a condom, I would use all sorts of excuses, I've got my period, I don't want to join family planning, or I am afraid to get pregnant..."(R, SW, Timika)
- "...I would try to get the client to use a condom as much as possible...(D, SW, Jakarta)

On the other hand, for women with negative status and partners that are positive, they tend not to use condom, the same with positve concordant couples.

- "...when he's really not in the mood for a condom, it's a bit difficult to force him. Yes, once in a while, it's oK, or he can just eject outside (coitus)..." (G, housewife, Denpasar"
- "...he says that it doesn't feel good to use a condom, sometimes we use it sometimes we don't..." (X, FDU, Jakarta"

Housewives that are not aware of their partners' status, find it more difficult to negotiate the use of condoms. Partners feel awkward to use condoms when other form of contraceptive can be utilized. As condoms is perceived as an instrument for extra-marital relations, to use it would be perceived as not appropriate. When housewives know of their husband's status and have children, they reason the use of condoms to protect themself from HIV to ensure that someone would care for the children for a longer period of time.

- "...poor children if both parents are positive, who would care for them if both die?...(F, housewife, Denpasar)
- "...using condoms feels strange in a marriage doesn't feel right...(D, housewife, Pekanbaru)

#### Relational Pattern In The Public Sphere, Social Existence, And Access To Health Care

This study also looks at the way these women relate with the larger scope of society. Social existence refers to society acceptance of these women's profession or behaviors, the role they would play in society and rules, laws and regulations binding and affecting these women. This relation indicates not only her position and situation within the larger picture of society and social relations and interactions but also how the government is protecting its citizens including women from infections and increasing the life-quality of these women.

It tends to be more difficult for female drug users to express themselves and show their existence than sex workers. The helplesness of female drug users is mostly is attributed to the current drug law that still criminalizes and is punitive towards drug users. The criminalization of drug users in general is further pushing drug users towards isolation from society. Female drug users are victims of much physical violence, sexual and psychological, from husbands, boyfriend, drug dealer and police officer. The isolation makes it difficult for this group of women to protect themselves from all of the violence, the harms from the use of drugs including the risk of being infected.

The threats caused by the current laws, police raids, and exclusion from society, pushed female drug users into isolation. Therefore, they find it more difficult to seek appropriate health care. Service is still lacking particularly to accommodate the needs of female drug users. With the exception of Jakarta, the three other cities have not much accommodated their needs.

Meanwhile, female sex workers are still regarded as a secluded group from society, the "scum of society" and has no protection from current laws. In some places, their government is acknowledging the sex industry including brothels, others not formally but they do admit the existence of hotspots where such transactions are happening. For female sex workers "caught in the act" by the authorities, they would just be sent to the social affairs agency (Dinsos) for vocational training and released at the end of the training. These trainings don't change the criminal status at all, consequently when they are released they are confident, even more than the drug user group upon release. Health services from government, private clinics and NGOSs are accessible, particularly those located near the brothels. These services are also very appropriate because the staff are aware of their profession and serve them without prejudice.

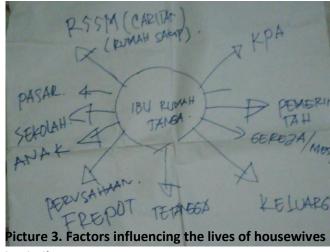
Socially, sex workers inside brothels posess a better bargaining position against their clients and authorities. They have the flexibility to refuse a client, particularly those that were violent or didn't want to use condom.

Housewives are unhampered in expressing their existence in society. Their status contains no controversy, they have more flexibility carrying their daily social lives . Unlike female drug users or sex workers, housewives have better access to healthcare, have more liberty in choosing and are free of any sort of stigma. Even so, face to face with the issue of HIV and AIDS and accessing health care, housewives are feeling uneasy. The housewife in Bali for example, after knowing hers or her husband's positive status, felt fear to be frank about it to her neighbours or Banjar. The death of her husband or child from AIDS, usually is explained as caused by anoher disease, more accepted by common people. Some housewives only knew they were positive after her husband or child was identified positive by a medical officer.

"...i have seen brochures on HIV, the pictures and thought it looks just like what had hit my husband, i was jus hopping i didn't get it...i went to the doctor and he tolod me i was positive .." (R, IRT, Timika)

"...i just found out about HIV [information and knowledge related to housewife related to HIV] after everybody was identified as positive ..." (J, IRT, Bali)

The discussion with housewives in Timika revealed that their existence was influenced by: family, religious leaders, traditional leaders and the mining company PT. Freeport. Picture 3 beside here is a diagram drawn by the participants themselves. These housewives clearly indicates these four parties as having an impact of all sorts of aspects of their lives. The family and the leaders are impacting the norms, social values, daily conduct while they also clearly express their dependency and that of their family towards PT Freeport in financial and property terms and also healthcare access.



in Timika, Papua

#### 3.4. Financial situation (economic)

Sex workers in Bali can afford to be more open about their profession compared to female drug users. Society finds it easier to accept sex workers than drug users. This openess is accredited also to the tourist industry that has a strong impact in Bali, as expressed by the following quotes:

"...sociey is more forgiving towards sex workers than to women who inject drugs, maybe related to the fact that sex workers also support the tourist industry..." (M, FDU, Denpasar)

"...there those people that don't say it in my face that I am a sex worker, but people usually know of my profession..." (S, SW, Denpasar)

Meanwhile the finances between couples including daily expenses among sex workers, housewives and drug users do depend on the couple's agreement, Sex workers are women with their own income, yet on how they spend it would depend on the consensus with their partners or husband. The same goes for some housewives.

#### "...mutual management, but I contorl the money because I work for it..." (S, IRT Bali)

There are also sex workers who manage their own money without every notifying their partners about it. Yet sex workers don't always manage their own income, for example in Papua, most sex workers are non-native Javanese and management varies, there some that are independent, some

by their partners who feels that these women are too extravagant with their money and tend to wasted it, as stated by the following quote:

- "...most of us manage our own incomes..." (FSW Papua)
- "...I manages it, he gives it..." (WPS Papua)
- "...my husband manages because I too much of a spender, he's flexible..." (FSW Papua)
- "...the husband gives all of his income, if he needs some, he just asks..." (FSW Papua)

Household financial management mostly depends on the agreement between both parties. Among sex workers, housewives and drug users, just as among other couples. Therefore income and financial management issues may be the reason causing conflict just as among any couple. A housewife in Pekanbaru mentions that fights between husband and wife is about the problem of little income and greater expenditure, of which husband can't fulfill.

# "...financial problems...that's why we have problems with health cost..." Housewife, Pekanbaru)

Fights will get bigger as income becomes smaller and health cost or access to health care is harder causing more expenses, particularly when one of the couple is HIV positive. Because incomes are small, access to health care is hindered, consequently the condition of health worsens.

Yet, most housewives feel that the family economies will never suffice, even though the minimum needs are fulfilled, as showed in the following quote::

#### "...just as in any household, money is never enough..." (Housewife, Pekanbaru)

This shows that incomes intented to cover minimum daily needs inluding health care, depends a lot on the capacity of the family to manage their finances, whatever income they have in one month. So management doesn't depend on the amount of the income but on the expences.

#### 3.5. Health care for women

In order to gather a holistic description of the situation, the study also included indepth interviews with program officers in all of the regions. They are NGO activists, AIDS Commission staff and health workers. The interview looks at the government's role and that of local NGOs in the response to the AIDS epidemic in each region.

The dominant issues since the first AIDS case in 1987 are stigma and discrimination. The stigma felt by people infected with HIV not only comes from society but also from health workers and policies enacted by the government.

"...stigma doesn't only come from society but also from nurses, doctors and our policies which are still discriminating ..." (Narasumber, Pekanbaru)

# "...as soon as his doctor found out that my friend was positive, he immediately put on his gloves and mask while prior to knowing it, he didn'....." (Narasumber, Pekanbaru)

Women have long been the target of health programs, since the New Order regime. The government developed healh care for women that would reach RT, RW and even the remotest village. The main program being health care for mother and child [KIA] centered at the Public Health Center [Puskesmas] which is also supported by society and Posyandu [integrated health post] in each RW. KIA is a public effort to increase the state of health of women, especially mothers and their child so that the future generation of Indonesians are healthy and of high grade hence their health is well garded since young.

Although healthcare for women is service and program widely known for a long time, yet HIV program tailored for women not only are not accessible but also there are not too many in numbers. Whereas most participants are also active in NGO-managed support groups, they are not feeling strong enough to deal with their HIV status including the isolation by society and discriminiation by the health system. Almost all support groups [KDS] in all four cities are using similar methodologies with their members, basically it's discussing issues around infection prevention, the course of the infection and safe behaviors with condom use and steril injecting paraphelia. Yet, this forum is not used to discuss social exclusion faced by women and their families including extended families [parents, in laws].

In Pekanbaru, one of the participants that is member of a KDS felt reluctant to go along with this study as she was wearing a T-shirt stating HIV issues. She felt nervous that people would know about her involvement with KDS and HIV related activities, that they would be suspicious and isolate her.

The public health system is facing a grave problem of accessibility including: number of clinics, Puskesmas and hospitals providing HIV and care for OI which only few are availale. Most services are dominated by private clinics and hospitals run by NGOs. Meanwhile so many of these women's needs are not being met. In Bali, services for sex workers are so few, in fact access is available only to one clinic ran by a local NGO in Denpasar. They admit feeling comfortable with the services in that clinic, at the same time, they are unable to elaborate their other needs and not all participants are aware of this clinic. In Timika, most healthcare for positive people has been made available by PT. Freeport and not from public facilities. On the other hand, the government of DKI Jakarta, has a better response for its positive citizens. The government has developed at least 30 Puskesmas and 10 Referral hospitals with HIV care for drug users and sex workers and specially tailored programs for women, initiated by some NGOs, hence access by women is widely and openly available.

Local policies in each provinces and/or city/district has not yet accommodated nor sided to victims of HIV and AIDS. For policies supposedly accomidating, the implementation has been poor and limited. Consequently, services that should have been made available by the government, are not made widely accessible, hence until now there is not one province that is free of HIV and AIDS<sup>9</sup>.

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<sup>&</sup>lt;sup>9</sup> Laporan triwulanan Dirjen P2ML, Departemen Kesehatan RI Edisi Juni 2009

#### 4. DISCUSSION

The findings that occured during the interviews and discussion, were categorized into four issues: [1] sexual relations [2] response to HIV status [3] financial situation [4] access to health care

Sexual relations	Response to HIV status	Financial situation	Access to health care
Decision making: whereas the woman has a bargaining position [economy, i.e. an income], she can control the sexual relation including the use of condoms [does not apply to sexual relation between sex workers and their clients, control is totally in the hands of the clients, as they have paid for the services]	Social status or caste indicates the openness of HIV status to society and to the extended family  - Similar status within the couples - Similar communities [drug user, sex worker-client]	Financial management of the couple depends on the consensus within the couple.  Financial insufficiency most of the times is the main topic of arguments among couples.	Health care access is limited to charity based organizations [NGOs] than the public health system. Sex workers prefer going to private clinics that are near the brothels than a primary clinic. [without considering the sustainability issue, that these private clinics, although free at the moment will not be available for long].
Patriarchal doctrines:  Control from society; control from extended family;  Religious doctrines Traditional doctrines	Solidarity among women [a feeling of sisterhood], e.g. supporting each other for testing	Drug users and housewives have less control over finances than their sex workers counterparts.  Mostly because sex workers are the breadwinners while drug users and housewives depend on the income from their partners/husbands.	Basic health care for women are available in all Puskesmas and through other women organizations [PKK, Posyandu], yet not including HIV related services. Available HIV services are built as parallel systems from the public one.
	Housewives are expressing a lower bargaining position compared to their counterpart [sex workers and drug users], hence they are less empowered particularly in terms of talking about their	Expenses in all groups, particularly since of the spouses is positive, tend to be greater than their income, as they are allocated for health care.  - the role of the extended family: is limited, thus can not support nor intervene	

Sexual relations	Response to HIV status	Financial situation	Access to health care
	status even to their families.	within the couple's intimate sphere	

The analysis looks at patterns of relations in each issue. In a sexual relation, women that are not sex workers have a stronger bargaining position to decide on safe sex for her thanthe other groups. The demand for an open sexual relation so as not to infect each other with HIV shows that there are intimate values adopted by the couples that are not affected nor influenced by the social norms commonly accepted. These social norms are based on patriarchial value that looks at the position of women as being weak whether it's inside the family or in the public sphere. The tendency of women to compromise their interests or men, pushes them further towards sexual psychological and physical violence and into a vulnerability towards being HIV infected by men.

Therefore, the social norms that generaly applies to society in relation to sexual relation does not apply to concordant positive couples. These couples have forged new values agreed among themselves, values that are not always in accordance to social norms in general. These values are personal and guides the relation between these man and woman, whether in a formal or informal relation. Formal couples are those married and acknowledged by both extended families, while informal couples are those that are not married but are committed to each other. Both couples managed to build a relation that is equitable, open, each other knows about each HIV status, accept each others social, economic status and when one is HIV positive, does not hold contempt. The understanding and acceptance grows futher when both are from similar group and environment for example both are drug users, or from the same brothel [the woman as sex worker, the man as the moto-driver or pimp.

The couple deals with conflict openly and strive to resolute their problem among each other, without the involvement of external parties whether it's society [public sphere] or extended family. This model of resoultion shows that they are very secretive, exclusive and avoid any external influences. This relation, that has shown great strength can be categorized into a relational pattern of its own, differing from other patterns which applies to general society, extended family and traditionally binded scope in society even from the more general domain, the public sphere.

The domestic and public relational patterns are intertwining at some point and interacting, hence influencing each other. The guiding values appliable in both domains are common and similar, conservative and doesn't give much room for inputs from the intimate sphere. The domestic-public relational pattern is highly affected by the culture and local customs in a society therefore influences the attitute, action and policy making process in the region. Meanwhile the relational pattern in the public sphere result in a more general change at social and policy levels which also would have a influence at intimate level. For example, the domestic-public sphere looks at prostitution as being unlawful. The perspective is based on domsetic values which later on are interpreted as policy that demands the dismantlment of localized brothels. These values are

different from those held by sex workers, clients, pimps and those that are economically and socially dependent to the brothel. The same goes with the war on drugs enacted in with the drug laws of 1997 which has pushed drug users status into being acknowledged as criminal.

Both relational patterns indicates that there is a relational pattern at intimate level that is not affected by the domestic nor the public relational pattern. As the difference between the domestic-public sphere and the intimate level is obvious, meaning that there is no co-relation between both relational level.

The approach and methodology of the HIV response almost completely concentrating on the individual and rarely takes the collective and communal for a massive change which engages the support of a larger community and social system. Hence the problem of stigma and discrimination for almost 22 years has not been solved as it should be, as these two problems are in the public-domestic sphere. Meanwhile the AIDS response concentrates itself in the intimate sphere [intiate relational patter] as it depends on an individual approach. As stigma and discrimination is still high and prevalent in Indonesia, emphasises that current approach have failed to bring radical change. It also refflects that society has not been given an active role in the response. When the first AIDS case was found, and most of society responded with isolation towards the victims, AIDS activists did not present the problem in its entierety to society and limited the response with and individual and exclusive approach. Consequently, society was never educated to come face to face with the HIV and AIDS phenomenon, forgetting that is has the natural ability to respond and protect itself from various infections and diseases and the capacity to demand the government for its accountability for a health care system that is of good quality of its people.

Local wisdom and social capital of the Indonesian society has not been seen as a factor and a strength to be reckoned in response to the AIDS epidemic. Meanwhile society has long showed the ability to face major social, clinical, political problems as one unit; the ethnic dynamic in Papua, the strength and influence of the Banjar in Bali, the solidarity and kegotongroyongan of the malay culture in Pekanbaru and the diversity of Jakarta, all are strong fabric of society which includes communities affected by HIV and AIDS, that should be the fundamental for a strong, univeral and mainstreamened HIV and AIDS response. The social and cultural approach needs to be equally considered as much as the clinical approach when handling AIDS related cases. The monopoly of 'interest groups' whether clinical, public health or NGO backgrounds have build a gap between HIV infected people and society in general. At the same time, affected groups and society weakened as the gap enlarged and no demand and pressure for a public health system or in other words demanding for the accountability of the government to provide access to HIV care that is univeral in its truest sence.

#### 5. CONCLUSION

 The lack of access to HIV and AIDS healthcare for women compared to other health programs indicates that HIV program have not integrated within the public system. Which means that mainstreaming HIV, despite the investment and decades of efforts have not produced accessible and universal HIV and AIDS care.

- In general, women are at a disadvantegous position within the initimate domain as most discover about their status after the death of their partners, sickness of child or when their partners expose their status. The result is that it becomes to late for women to protect themselves and the child they carry.
- It is difficult for participants to be open about their HIV status in the domestic domain, which shows that the issue of HIV and AIDS is still a very much covert issue. Participants that were actively involved in this study are those that have good rapport with the researchers' contact persons. The issue of confidentiality has been the major setback in this study in terms of finding participants willing to talk about their status. This difficulty is an indication HIV and AIDS programs have long been build based on indivualistic and exclusive approaches.
- Although at the moment, Indonesia's epidemic is still categorized as a low level epidemic yet there are areas with strong concentrated epidemic in the provinces of DKI Jakarta, West Java, East Java, Bali. The current projections are showing that Indonesia may be on its way towards a national generalized epidemic just as the level that is happening in Papua. Hence, the approach that has been implemented thus far has not been able to respond to the various aspect of HIV and AIDS. Therefore there is a need to correct and carry on radical changes to the approaches of the current response to the AIDS epidemic in Indonesia.
- There are two patterns of relations in the Indonesia society: intimate and domestic-public relation.
- Both relational patterns have contradicting values and guidance. The intimate relational pattern contains values agreed only within the couple and is constantly guiding their decision for healthcare, preventive actions and how they relate to society. The awareness not to infect other people with HIV only applies within the intimate domain. The domestic-public relational pattern includes the extended family, common society, traditional groups and public institutions. The domestic-public relational pattern contains values that are affected by traditions, familial values and public policies. These values are guiding the interaction of the couples with society and is the social capital to building a communal system in society [kegotongroyongan]. Between these relational patterns there is no connecting 'gate', hence there are no common values between the intiate sphere and the dometic-public sphere.
- The domestic-public sphere and social capital of society are seldomly looked by HIV and AIDS programs. The approach implemented are concentrating within the intimate sphere and relational pattern by limiting the approach to small group of at risk population, consequently the issue of stigma and discrimination is delt within the domestic and public spheres with no general resolution to the problem.

#### 6. Recommendation

 Program intervention that engages HIV risk groups, should go beyond these groups and involve common society as major actors in the HIV response, starting from planning, prevention and care in order to build a communal system based on local values [gotong royong] and to ensure sustainability.

- The social order of society such as banjar, ethnic groups, tradition-based social system should all be the social capital for the development of HIV and AIDS program accross the country. Program development should aim at pushing for social changes to ensure that domestic-public values accommodate the needs and situation of women.
- Activities with key population affected by HIV together with common society such in banjar, RT/RW, traditional leader and other members of society should be carried as a mean to educate society about HIV prevention and care for positive people. This process would progress into a social movement that involves common society and risk groups, discussing their needs, problems and other health issues.
- The strengthening and empowerment of women aims at pushing women demanding their sexual partners to be open about their health status to ensure that she will be able to protect herself and her future child. The openness of status by male partners should happen within the domestic domain to prevent transmission within the intimate domain.
- To mainstream HIV issues for women into healthcare system already attending and involving women such as family planning, healthcare for mother and child [KIA], immunization, etc. Then HIV and AIDS. Therefore the issue of HIV and AIDS can be easily acknowledged by common sociey and mainstreamed into the public sphere and not make it an exclusive issue and separated from other health system.

# **PROFILE**

ID			
Name			
City			

# **Identity**

1	Age		Year
2	Ethnic group of origin	•	
3	Religion		
	01. Islam		
ļ	02. Protestant		
	03. Catholic		
	04. Hindu	L	
	05. Budha		
	06. Kong Hu Cu		
	99. Other, please mention		
4	Last education		
	00. Didn't go to school	Г	$\neg$
ļ	01. SD /Ibtidaiyah	L	
ļ	02. SLTP / Tsanawiyah/sederajat		
	03. SLTA / Aliyah/sederajat		
	04. Diploma		
	05. S1		
ļ	06. S2		
	07. S3		
	08. Pesantren		
	99. Other, please mention		
5	Occupation		
Ų	00. Not working		
ļ	01. Housewife		
ļ	02. Student		
Ų	03. Civil servant		
ļ	04. Private sector		
ļ	05. Housemaid/manufacturer worker		
ļ	06. Sex worker		
ļ	07. Merchant/entrepeneur		
ļ	08. Artist [singer, dancer or other form of art]		
ļ	09. Docter / psychologist / teacher / journalist / researcher		
Ų	99. Other, please mention		
ļ			
ļ			
Ų			
l.			

6	Curi	Current status with last partner									
	1.	Exclusive	4	4 Divorced							
		relationship									
	2.	Living together	5	Widowed							
	3	3 Married 6 Separated						Since [in years]			
			l	1				_ •			
								Until [year].	•••••	•••••	
7	Part	ner's occupation									
		00. Not working					_				
	(	01. Housewife									
		02. Student						<u> </u>			
		03. Civil servant									
		04. Private sector									
		05. Housemaid/manufa	cturer	worker							
		06. Sex worker									
		07. Merchant/entrepend									
		08. Artist [singer, danc									
		09. Docter / psychologi				earch	er				
		99. Other, please mention	on		•••						
8	Niin	nber of children, step ch	nildren	adonted chi	ldren		Ασ	e of children (	vears)		
O	01	1 child	laren			child:	years)				
	02	2 children				2nd child:					
	03	3 children		$\neg$		rd child:					
	04							n child:			
	05	> 4 children				-	5th c	child:			
	06	No children					6th c	th child:			
	88	Don't know									
9	Ave	rage salary per month			Rp.		•	To Rp.			
10	Part	ner's verage salary per	month		Rp.			To Rp.			
11	Wha	at are your greatest expe	enses?		For how	v muc	ch [in a	verage] ?			
		a			a.						
		b			b. Rp						
		c			c.	Rp.					
		d	d.	Rp.							
12	Hea	lth issues									
	1	Health problems in las	st 6 mo	nths?							
		Н	eadach	ies/migrain			YA	1		TIDAK	
		Digestive probl					YA	1		TIDAK	
		Musc	les/bon	e problems			YA	A		TIDAK	
			Α	ny wounds			YA			TIDAK	
	Ever operated						YA			TIDAK	
	Others										
			Please	ment	ion						
	2	Any mental problems	?								
				ssion/stress		7	Yes	No			
				ver anxiety			Yes		1	No	
			Co	nstant fear		7	<i>Y</i> es	No			
				Insomnia	Yes			No		No	
		Problems with e			Yes			1	No		
		Bulimia,	anore.	xia,binging							

		Suicide attempt	Yes	No	
		Halucination	Yes	No	
		Others	Please mention		
13	A	Ever tested for HIV?	Yes	Never	
	В	If yes, what were the results?	Positive	Negative	
	С	Did you share the results with your partner?	Yes	No	
	D	If yes, what were the reaction upon knowing the results?	01. Anger 02. Sad 03. Confused 04. Wanted to get tested too 05. Surprised 06. Left me 07. Tried to console me 08. I forgot 09. If others, please mention		
E If you did not share the results with your partner, why not?  01. Afraid to be a bur 02. Afraid to be aband 03. Afraid of being act family 04. Not ready 05. Afraid partner wil 06. I want to handle the orange of		donned cepted by the partners'  I get angry his by myself essi			

## Thank you for your time and filling up these forms

#### **Respondents Codes**

Column 1 : City

A: DKI JAKARTA B: DENPASAR C: PEKANBARU D: TIMIKA

#### Column 2 : Group

1 : Female IDU

2 : Female sex worker

3: Worker

4: Housewife

Column 3 & 4: informant's ID

01 - 10

# FGD guidelines

### **Group: Sex Workers**

Issue	Aspec	Basic findings	Questions	Probing instruments
Men – Women Relationship	Sexual relation	Sexual relation with the client  Perception of partner towards the respondent's profession	How many clients to do you serve in a day?  How about the style, does the client decides on the way the sexual intercourse is carried on? Or do you decide upon it? How do you manage to keep your clients satisfied?  What about the sexual intercourse with your partner? Are you free to express your sexual desires? Do you use condoms? Who decides on using condoms  If you are not feeling like having sexual intercourse, are you free to express yourself? If not, why? If yes, does your partner accept it?  According to you, how does your partner feel about you having sex with other people?	
	Modalities of conflict resolution	Conflict management: with partner  with peers	What is usually the reason you would have an argument with your partner?  With your partner, how do you resolute the argument? Who compromises the most? Why?  Do you have conflicts with your peers? What about? How do you solve the problem?	

	Communication, interaction	Communicating about HIV status	For partners whom HIV status is different, does your partner know that one of you is HIV positive? Since when did he know of your status? How did he react upon it?	
			How do you maintain the HIV negative status of your partner? Are you using condoms?	
			Is there a commitment to continue with this relationship should one of you enter the AIDS phase?	
Social construction	Community participation	Acceptance by family and general community/society	their attitude?	
		σοιπιαπιεγγοσοιείγ	What are community activities/organizations in your living area? Do you participate?	
			How do you think society perceives your current sitution [profession, risk behaviors, etc]	
	Roles in society		Do you play an active role in your community? E.g. head of neighborhood organization [ibu RT], Puskesmas [Primary health clinic] worker, or any other role?	
	Existence and appreciation by society	Self appreciation	How does your family perceive your current situation?  What is the attitude of society concerning your current	
	Jociety	Feeling of happiness or perception of	situation, profession?	
		happiness	Who is the person you trust the most in your current life? Why do you trust this person?	
			What makes you feel appreciated by family, friends and society?	
			How do you want family, friends, society perceive you, accept	

			you?	
	Rules related to profession/situation	Rules for sex workers	Are there any rules or policies that you feel are obstructing your work?	
			Are there any rules or policies that you feel are obstructing your trying to be healthy/not being infected?	
Control over economic resources	Financial management/decision making	Control over financial resources, life decision making, career, etc	How do you allocate the money either from your work [as sex worker or other profession if there are]? Try to rank as many expenses as possible.	Verify with profile form
	Involvement in financial management		Do you have a financial plan? Is anyone assisting you with managing your finances? Who? How far is this person involved in the management of your finances?	Resource control map (economy, decision making
			How much control do you have over your earnings?  Is there anyone that has influenced your decision in purchasing something that you didn't agree, or planned before?	love, career)
			Is there anyone else from you family, husband, partner/boyfriend, pimp that is influencing decision making related to your finances?	
		Control over assets, inheritance, property and wealth	Do you have any assets? Inheritance, property, land, house? If not, why? If yes, how far are you able to manage these assets?	
			Is there a relation between traditional rights or inheritance rights?	
Availability of services for women	Access to services [easy to access, cheap, appropriate working hour]	Easy access to services	Where do you usually go for healthcare? Are there any places outside the brothel complex that accepts you? How is the service? Can you openly reveal your status and complain about your illnesses? Is your partner involved in your	Data of service available near the brothel complex

			recovery when you're sick? How far is he involved?	
	Readiness of service		How well are the facilities of the health clinic that you would	
	provider [attitude,		frequent when sick? What are healthcare needs that are not	
	facilities]		facilited at that clinic? How are the service providers treating	
			you? Do they provide the information you need?	
Program for		Programs designated	Are there other programs you are participating, either from	
women		for sex workers	NGO, community organizations, or the government, etc? Do	
		accommodating	these programs accommodate your problems [health, social,	
		power	economic, legal, etc]?	
			If you have any children, do these programs help out with	
			problems related to your children?	

## Group: female drug users

Aspec	Basic findings	Questions	Probing instruments
Sexual relation	Perception of partner	What about the sexual intercourse with your partner? Are you free to express your sexual desires? Do you use condoms? Who decides on using condoms  If you are not feeling like having sexual intercourse, are you free to express yourself? If not, why? If yes, does your partner accept it?  According to you, how does your partner feel about you having sex with other people [if occasionally you are doing so, for financial reasons for example]?	Men – Women Relationship
Modalities of conflict resolution	Conflict management: with partner	What is usually the reason you would have an argument with your partner?  With your partner, how do you resolute the argument? Who compromises the most? Why?	
	with peers	Do you have conflicts with your peers? What about? How do you solve the problem?	
Communication, interaction	Communicating about HIV status	For partners whom HIV status is different, does your partner know that one of you is HIV positive? Since when did he know of your status? How did he react upon it?  How do you maintain the HIV negative status of your	
	Sexual relation  Modalities of conflict resolution  Communication,	Sexual relation  Perception of partner  Modalities of conflict resolution  Conflict management: with partner  with peers  Communication,  Communicating	Sexual relation  Perception of partner  What about the sexual intercourse with your partner? Are you free to express your sexual desires? Do you use condoms? Who decides on using condoms  If you are not feeling like having sexual intercourse, are you free to express yourself? If not, why? If yes, does your partner accept it?  According to you, how does your partner feel about you having sex with other people [if occasionally you are doing so, for financial reasons for example]?  Modalities of conflict management: with partner  What is usually the reason you would have an argument with your partner?  With your partner, how do you resolute the argument? Who compromises the most? Why?  Do you have conflicts with your peers? What about? How do you solve the problem?  Communication, interaction  Communicating about HIV status  For partners whom HIV status is different, does your partner know that one of you is HIV positive? Since when did he know of your status? How did he react upon it?

			Is there a commitment to continue with this relationship should one of you enter the AIDS phase?	
Social construction	Community participation	Acceptance by family and general community/society	Are you neighbours accepting your living near them? What is their attitude?	
			What are community activities/organizations in your living area? Do you participate?	
			How do you think society perceives your current sitution [profession, risk behaviors, etc]	
	Roles in society		Do you play an active role in your community? E.g. head of neighborhood organization [ibu RT], Puskesmas [Primary health clinic] worker, or any other role?	
	Existence and appreciation by	Self appreciation	How does your family perceive your current situation?	
	society	Feeling of happiness or perception of	What is the attitude of society concerning your current situation, profession?	
		happiness	Who is the person you trust the most in your current life? Why do you trust this person?	
			What makes you feel appreciated by family, friends and society?	
			How do you want family, friends, society perceive you, accept you?	
	Rules related to profession/situation	Rules binding female drug users	Are there any rules or policies that you feel are making life as a female drug user difficult?	
			Are there any rules or policies that you feel are obstructing your trying to be healthy/not being infected?	
Control over	Financial	Control over	How do you allocate the money either from your work [as sex	Verify with

economic	management/decision	financial resources,	worker or other profession if there are]? Try to rank as many	profile form
resources	making	life decision making,	expenses as possible.	
		career , etc		
	Involvement in		Do you have a financial plan? Is anyone assisting you with	Resource
	financial management		managing your finances? Who? How far is this person	control map
			involved in the management of your finances?	(economy, decision making
			How much control do you have over your earnings?	love, career)
			Is there anyone that has influenced your decision in	
			purchasing something that you didn't agree, or planned before?	
			Is there anyone else from you family, husband,	
			partner/boyfriend, pimp that is influencing decision making related to your finances?	
		Control over assets,	Do you have any assets? Inheritance, property, land, house?	
		inheritance, property and wealth	If not, why? If yes, how far are you able to manage these assets?	
			Is there a relation between traditional rights or inheritance rights?	
Availability of	Access to services	Easy access to	Where do you usually go for healthcare? Are there any places	Data of service
services for	[easy to access,	services	outside the brothel complex that accepts you? How is the	available near
women	cheap, appropriate		service? Can you openly reveal your status and complain	the brothel
	working hour]		about your illnesses? Is your partner involved in your	complex
	2 11 6		recovery when you're sick? How far is he involved?	
	Readiness of service		How well are the facilities of the health clinic that you would	
	provider [attitude,		frequent when sick? What are healthcare needs that are not	
	facilities]		facilited at that clinic? How are the service providers treating	
			you? Do they provide the information you need?	
Program for		Programs designated	Are there other programs you are participating, either from	
women		for sex workers	NGO, community organizations, or the government, etc? Do	

accommodating	these programs accommodate your problems [health, social,	
power	economic, legal, etc]?	
	If you have any children, do these programs help out with	
	problems related to your children?	

## Group: worker

Issue	Aspec	Basic findings	Questions	Probing instruments
Men – Women Relationship	Sexual relation	Perception of partner	What about the sexual intercourse with your partner? Are you free to express your sexual desires? Do you use condoms? Who decides on using condoms  If you are not feeling like having sexual intercourse, are you free to express yourself? If not, why? If yes, does your partner accept it?  According to you, how does your partner feel about you having sex with other people [if occasionally you are doing so, for financial reasons for example]?	Men – Women Relationship
	Modalities of conflict resolution	Conflict management: with partner	What is usually the reason you would have an argument with your partner?  With your partner, how do you resolute the argument? Who compromises the most? Why?	
		with peers	Do you have conflicts with your peers? What about? How do you solve the problem?	
	Communication, interaction	Communicating about HIV status	For partners whom HIV status is different, does your partner know that one of you is HIV positive? Since when did he know of your status? How did he react upon it?  How do you maintain the HIV negative status of your partner? Are you using condoms?	

			Is there a commitment to continue with this relationship	
Social	Community	Acceptance by family	should one of you enter the AIDS phase?  Are you neighbours accepting your living near them? What is	
construction	participation	and general community/society	their attitude?	
		,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	What are community activities/organizations in your living	
			area? Do you participate?	
			How do you think society perceives your current sitution	
			[profession, risk behaviors, etc]	
	Roles in society		Do you play an active role in your community? E.g. head of	
			neighborhood organization [ibu RT], Puskesmas [Primary	
			health clinic] worker, or any other role?	
	Existence and appreciation by	Self appreciation	How does your family perceive your current situation?	
	society		What is the attitude of society concerning your current	
		Feeling of happiness or perception of	situation, profession?	
		happiness	Who is the person you trust the most in your current life?	
			Why do you trust this person?	
			What makes you feel appreciated by family, friends and society?	
			How do you want family, friends, society perceive you, accept you?	
	Rules related to	Rules binding female	Are there any rules or policies that you feel are making life as	
	profession/situation	worker	a female worker difficult?	
			Are there any rules or policies that you feel are obstructing your trying to be healthy/not being infected?	
Control over	Financial	Control over	How do you allocate the money either from your work [as sex	Verify with

economic	management/decision	financial resources,	worker or other profession if there are]? Try to rank as many	profile form
resources	making	life decision making,	expenses as possible.	
		career , etc		
	Involvement in		Do you have a financial plan? Is anyone assisting you with	Resource
	financial management		managing your finances? Who? How far is this person	control map
			involved in the management of your finances?	(economy, decision making
			How much control do you have over your earnings?	love, career)
			Is there anyone that has influenced your decision in	
			purchasing something that you didn't agree, or planned before?	
			Is there anyone else from you family, husband,	
			partner/boyfriend, pimp that is influencing decision making related to your finances?	
		Control over assets,	Do you have any assets? Inheritance, property, land, house?	
		inheritance, property and wealth	If not, why? If yes, how far are you able to manage these assets?	
			Is there a relation between traditional rights or inheritance rights?	
Availability of	Access to services	Easy access to	Where do you usually go for healthcare? Are there any places	Data of service
services for	[easy to access,	services	outside the brothel complex that accepts you? How is the	available near
women	cheap, appropriate		service? Can you openly reveal your status and complain	the brothel
	working hour]		about your illnesses? Is your partner involved in your	complex
			recovery when you're sick? How far is he involved?	
	Readiness of service		How well are the facilities of the health clinic that you would	
	provider [attitude,		frequent when sick? What are healthcare needs that are not	
	facilities]		facilited at that clinic? How are the service providers treating	
			you? Do they provide the information you need?	
Program for		Programs designated	Are there other programs you are participating, either from	
women		for sex workers	NGO, community organizations, or the government, etc? Do	

accommodating	these programs accommodate your problems [health, social,	
power	economic, legal, etc]?	
	If you have any children, do these programs help out with	
	problems related to your children?	

## Group: housewife

Issue	Aspec	Basic findings	Questions	Probing instruments
Men – Women Relationship	Sexual relation	Perception of partner	What about the sexual intercourse with your partner? Are you free to express your sexual desires? Do you use condoms? Who decides on using condoms  If you are not feeling like having sexual intercourse, are you free to express yourself? If not, why? If yes, does your partner accept it?  According to you, how does your partner feel about you having sex with other people [if occasionally you are doing so, for financial reasons for example]?	Men – Women Relationship
	Modalities of conflict resolution	Conflict management: with partner	What is usually the reason you would have an argument with your partner?  With your partner, how do you resolute the argument? Who compromises the most? Why?  Do you have conflicts with your peers? What about? How do	
		with peers	you solve the problem?	
	Communication, interaction	Communicating about HIV status	For partners whom HIV status is different, does your partner know that one of you is HIV positive? Since when did he know of your status? How did he react upon it?  How do you maintain the HIV negative status of your partner? Are you using condoms?	

			Is there a commitment to continue with this relationship	
			should one of you enter the AIDS phase?	
Social construction	Community participation	Acceptance by family and general community/society	Are you neighbours accepting your living near them? What is their attitude?	
		,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	What are community activities/organizations in your living	
			area? Do you participate?	
			How do you think society perceives your current sitution	
			[profession, risk behaviors, etc]	
1	Roles in society		Do you play an active role in your community? E.g. head of	
			neighborhood organization [ibu RT], Puskesmas [Primary	
			health clinic] worker, or any other role?	
	Existence and appreciation by	Self appreciation	How does your family perceive your current situation?	
	society		What is the attitude of society concerning your current	
		Feeling of happiness or perception of	situation, profession?	
		happiness	Who is the person you trust the most in your current life?	
			Why do you trust this person?	
			What makes you feel appreciated by family, friends and society?	
			How do you want family, friends, society perceive you, accept you?	
	Rules related to	Rules binding	Are there any rules or policies that you feel are making life	
	profession/situation	housewife	with a family member HIV positive, difficult?	
			Are there any rules or policies that you feel are obstructing	
			your trying to be healthy/not being infected?	
Control over	Financial	Control over	How do you allocate the money either from your work [as sex	Verify with

economic	management/decision	financial resources,	worker or other profession if there are]? Try to rank as many	profile form
resources	making	life decision making,	expenses as possible.	
		career , etc		
	Involvement in		Do you have a financial plan? Is anyone assisting you with	Resource
	financial management		managing your finances? Who? How far is this person	control map
			involved in the management of your finances?	(economy, decision making
			How much control do you have over your earnings?	love, career)
			Is there anyone that has influenced your decision in	
			purchasing something that you didn't agree, or planned before?	
			Is there anyone else from you family, husband,	
			partner/boyfriend, pimp that is influencing decision making related to your finances?	
		Control over assets,	Do you have any assets? Inheritance, property, land, house?	
		inheritance, property and wealth	If not, why? If yes, how far are you able to manage these assets?	
			Is there a relation between traditional rights or inheritance rights?	
Availability of	Access to services	Easy access to	Where do you usually go for healthcare? Are there any places	Data of service
services for	[easy to access,	services	outside the brothel complex that accepts you? How is the	available near
women	cheap, appropriate		service? Can you openly reveal your status and complain	the brothel
	working hour]		about your illnesses? Is your partner involved in your	complex
			recovery when you're sick? How far is he involved?	
	Readiness of service		How well are the facilities of the health clinic that you would	
	provider [attitude,		frequent when sick? What are healthcare needs that are not	
	facilities]		facilited at that clinic? How are the service providers treating	
			you? Do they provide the information you need?	
Program for		Programs designated	Are there other programs you are participating, either from	
women		for sex workers	NGO, community organizations, or the government, etc? Do	

а	accommodating	these programs accommodate your problems [health, social,	
	power	economic, legal, etc]?	
		If you have any children, do these programs help out with	
		problems related to your children?	

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