



**PERCEPTIONS ON HIV/AIDS-RELATED STIGMA AND DISCRIMINATION IN  
SUKABUMI PRISON IN INDONESIA, AN EXPLORATORY STUDY**

**A Research project submitted to Van Hall Larenstein University of Applied Science  
in Partial Fulfilment of the Requirements for the Degree of Master in Management of  
Development, Specialization Rural Development of HIV/AIDS**

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The Netherlands

## **Dedication**

To all Indonesian's inmates and to my special person

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## Abbreviations

AIDS	: Acquired Immune Deficiency Syndrome
HIV	: Human Immune Deficiency Syndrome
ICRW	: International Centre for Research on Women
IDU	: Injecting Drug User
IEC	: Information, Education and Communication
MoH	: Ministry of Health
MoJ	: Ministry of justice and Human Rights
NAC	: National AIDS Commission
NGO	: Non-Government Organizations
PLWA	: People Living with HIV/AIDS
UNAIDS	: Joint United Nations Programme on HIV/AIDS
UNGASS	: United Nations General Assembly Special Session
UNODC	: United Nations Office on Drugs and Crime
USAID	: U.S. Agency for International Development
VCT	: Voluntary Counselling Testing
VHL	: Van Hall Larenstein Universities of Applied Sciences
WHO	: World Health Organization

## Abstract

HIV epidemic in Indonesia is under threat becoming generalized epidemic. This is due to spreading of concentrated epidemic from key population such as prisoner to general population. HIV/AIDS-related stigma and discrimination is as a driver to HIV epidemic.

Numerous programs and efforts have been conducted addressing HIV/AIDS issues in prisons; however, the significant growth number of inmates who are being infected with HIV remains high. A possible reason for this situation might be the lack of attention to social factors such as stigma and discrimination, which is underlying the inmate behaviours in causing the progression of the disease and determining the success on prevention, treatment, care, and support of HIV/AIDS programs in prisons.

The Ministry of Justice and Human Rights would like to improve HIV/AIDS prevention and treatment policies and programs in prisons by considering HIV/AIDS-related stigma and discrimination. From these perspectives we assume that understanding inmates' attitude and behaviour of HIV/AIDS-related stigma in the prison will contribute to the design of policies of the Ministry of Justice and Human Rights and implementation of programs related to HIV/AIDS prevention and treatment in prisons. However, the Ministry lacks information on HIV/AIDS-related stigma and discrimination among inmates and related staff members.

This study aims to provide insight of HIV/AIDS-related stigma and discrimination in the prison among inmates and related staff members by exploring the manifestations and sociological explanation of HIV/AIDS-related stigma and discrimination of inmates in the community level and the staff members in the institutional level. The findings might contribute to the strengthening of HIV prevention and treatment policies and programs in response to HIV/AIDS in the prisons to the Ministry and prison authorities. The study was conducted in the Sukabumi prison, Indonesia.

The findings show variation of the manifestations of HIV/AIDS-related stigma and discrimination in the prison. In the community level, some manifestations include verbal stigma and non verbal stigma. While in the institutional level, the manifestations of the stigma include the idea of isolating, refusing to involve the inmates in collective activities, transferring the HIV positive to another prison, and obligating HIV testing.

The respondents feel that the HIV positive inmates are different from them, they have a disease that has attached negative label. The respondents feel it is necessary to keep a distance from them. The stigma and discrimination will occur in relation to the power contexts such as in the prison.

Further research on HIV/AIDS-related stigma and discrimination in the prison is required to contribute in the development process of policy and programs in the prisons.



# PERCEPTIONS ON HIV/AIDS-RELATED STIGMA AND DISCRIMINATION IN SUKABUMI PRISON IN INDONESIA, AN EXPLORATORY STUDY

## I: THE HIV/AIDS EPIDEMIC IN INDONESIA

### 1.1. Background

#### Indonesia

Indonesia is classified as a low epidemic country for HIV and AIDS, as the HIV prevalence rate of 243 million populations was considered less than 0.2 % by UNAIDS in 2004. However, according to UNGASS in 2009, the total number of HIV infected people is estimated 333.200 people which mean an increase to 0.22 %. The Ministry of Health also stated that the incidence rate was increased almost three fold with 21.031 new cases of HIV in 2011 compared to 2005 (MoH, 2012).

These worrying statistics may be getting worst when look at the fact in Indonesia; that even though Indonesia is a low epidemic country, Indonesia has been reaching severe concentrated epidemics among key populations such as injecting drug users (IDUs), commercial sex workers, and inmates. They are as the main mode of HIV transmission in Indonesia which is related to unprotected sex and unsafe injecting drugs behaviour (NAC, 2012). The percentage of drug users is widely variable in Indonesia, some studies mention 130.000 people to be IDUs, while, another said it more than a million people are IDUs. The World Health Organisation predicted that 27 % of 105.800 IDUs were infected with HIV in 2010 and the Integrated Biological-Behavioural Survey in 2011 showed 36.4 % IDUs were HIV infected. Most IDUs are sexually active and many IDUs are also sex workers or are partners of sex workers. McBeth (2004) estimates 70 % of IDUs is having regular sex with commercial sex workers. The compounded risk behaviour among IDUs is increasing the susceptibility of the general population for getting an HIV infection by transmitting it to their regular partner.

These data lead to some prediction of the HIV epidemic in Indonesia; Karts (2006) even predicted by 2025 Indonesia will be experiencing generalised HIV epidemic as about 2 million people living with HIV. The Ministry of Health (2008) stated the number of people living with HIV will be reach 541.700 by 2014.

The spread of the HIV epidemic has a deep link with HIV/AIDS-related stigma and discrimination (Reidpath and Chan, 2006). UNAIDS (2005) mentioned that stigma and discrimination are a driver of HIV transmission and worsen the epidemic. While, United Nation Secretary-General Ban Ki-Moon, declared that 'stigma is the single most important barrier to public action and the chief reason why the AIDS epidemic continue devastate societies around the world' (Ban Ki-Moon cited in UNAIDS, 2011). Moreover, according to USAID (2006) stigma and discrimination are known as key factors which are essential in addressing an effective and sustained response for HIV prevention, care, treatment, and support as well as impact mitigation.

A Declaration of Commitment in 2001 highlighting the essential of tackling HIV/AIDS-related stigma and discrimination is stated by United Nations General Assembly Special Session on HIV/AIDS; mentioning that confronting stigma and discrimination is a prerequisite condition for effective HIV prevention and care. In line with the declaration, Jonathan Mann stated that HIV- related stigma and discrimination have undermined the ability of individuals, families, and societies to protect themselves and provide support and reassurance to those infected (Mann, J, 1987, cited in USAID, 2006).

Stigma and discrimination will cause effects to the levels of individual, community, and institutional. They will hinder individuals from being HIV tested; preventing person of recognizing him or herself and other family members as HIV positive; inhibiting people from using protection in intimate relations; deterring people from seeking treatment, care, and support; making people mislead other people; preventing quality care and treatment; increasing social inequalities; negatively affecting quality life of HIV positive people; and in turn will increase HIV transmission, morbidity, and mortality (USAID, 2006).

Stigma can be caused by low levels of HIV/AIDS knowledge and also indicates a moral dimension of the people (USAIDS, 2006). In Indonesia, comprehensive knowledge about HIV/AIDS is low, for example only 14,3% of aged 15-24 years had the comprehensive knowledge as indicated on NAC 2012; there is also notion in Indonesian's culture that considered sex as taboo issues which is characterised by silence, shame, and secrecy (Bennet, 2000). This low level of knowledge in combination with cultural taboos creates barriers to open discussion on sex-related issues in the communities which will lead to misunderstanding and misconception on HIV/AIDS related issue in the communities.

National AIDS strategies on HIV treatment, prevention, care and support for 2010-2014, which recognize the harmful effect of stigma and discrimination, has been declared as a guideline response to the HIV/AIDS epidemic (UNGASS, 2012), however, UNAIDS vision of zero discrimination, zero new infection, and zero AIDS-related death, creates challenge to meet the vision, as it requires governments' comprehensive response in social structures, beliefs and value systems to meet these challenge (UNAIDS, 2010).

Fortunately, HIV/AIDS-related stigma and discrimination are not static they change over time; It is generally considered that with the increase of HIV/AIDS knowledge and availability of treatment (Avert, 2010). World Health Organization in 2003 stated that 'As HIV/AIDS become disease that can be both prevented and treated, attitude will change, and denial, stigma, discrimination will rapidly reduce'.

### **The Institutional Context**

In order to improve effective policies and programs on HIV/AIDS-related stigma and discrimination issues, it is necessary to recognize the diversity of manifestations of HIV/AIDS-related stigma according to their contexts and levels such as individual, family, community, institutional, and country (Mahajan et al, 2008).

UNAIDS (2005) described some examples of discrimination against PLWHA in the institutional setting as follows:

- Education and schools

Denial of HIV infected or affected children to enrol school, the children are teased by their schoolmates, or discharge of HIV infected teacher.

- Employment and the workplace

The HIV/AIDS-related stigma in the workplace related to mandatory of HIV screening and testing, termination of employment for those HIV positive employees, stigmatizing HIV/AIDS employees.

- Health care systems

HIV- related stigma and discrimination among the health care provider include compulsory HIV testing, reduced health standard or denial of care and treatment, performed negative attitudes by health workers.

- HIV/AIDS programs

HIV/AIDS-related stigma occur unintentionally since designed the policies and programs, this is related to some programs and policies make classification between the 'general population' and 'high-risk populations' (Parker and aggleton, 2002).

- Religious institutions

There were some religious doctrines, moral and ethical related to HIV/AIDS stigma regarding to sexual behaviour, sexism, and homophobia; those HIV infected people have sinned and deserve getting "punishment" from God (Singh 2001).

- Prison

Some example of the discrimination in the prison setting include Involuntary HIV testing, break confidentiality of HIV status, referred the HIV positive inmates to other prison, and excluded of HIV inmates from collective activities. Studies found that severe manifestations of HIV/AIDS related stigma and discrimination are more likely addressing to key population such as drug user or inmate than the general population when the key population is HIV positive (Visser, Makin, and Lehobye, 2006). Inmates are experiencing multi-layered stigma which are having status as inmate who are often regarded as 'unworthy' and 'outcast' people (NAT, 2003), and having status as HIV positive people who are associated with a 'gay plague' or a 'junkie's disease' (UNAIDS, 2005).

Several studies indicating a percentage of HIV prevalence in Indonesia prison estimated 4-22% in 2001 (UNODC, 2008). According to the Ministry of Justice and Human Rights HIV prevalence rate in Indonesia prison varies considerably from 0 – 32 % depending on the location and the type of prison such as narcotic and non-narcotics prison (MoJ, 2010).

There are several explanations why the number of HIV positive inmates is high in the prisons. First, the inmates could be already infected before they were incarcerated and this

is related to the high number of IDUs being imprisoned as drug offenders. Second, the inmates have HIV infection due to several conditions and situations in the prison such as high risk behaviour of the inmates' for unsafe sex, unsterile needles and syringes which increase the risk of HIV transmission in the prison (UNODC, 2008).

The worrying statistics indicate that inmates are a most vulnerable and affected population who needs an urgent and comprehensive response. On the other hand a response is also required as the increasing number of HIV/AIDS prevalence in prisons will have serious impact to the general population as a whole when inmates are released and go back to the community.

The bases of a human right approach such as the right to health, human value, and dignity are part of national strategy to the HIV/AIDS response of many countries (UNAIDS, 2010). In line with the National AIDS Strategy 2010-2014 (NAC, 2009), The Ministry of Justice has developed strategy in National Action Plan on HIV/AIDS Prevention and Narcotics Abuse at the Correctional Technical Executive Unit in 2010-2014 (MoJ, 2010).

There are three basic aspects in the prison system included: enforcement and guidance of the law; rehabilitation and social services; prevention and treatment, such as education programs, Health service programme, and referral programme (Hidayati in MoJ, 2006).

## 1.2. The Research Issue

Indonesia is categorized as a low HIV epidemic country. However, HIV epidemic in Indonesia is under threat becoming generalized epidemic. This is due to spreading of concentrated epidemic from key population such as prisoner to general population. HIV/AIDS-related stigma and discrimination is as a driver to HIV epidemic. According to Daas (2001) the intervention on HIV/AIDS-related stigma and discrimination is not originally occur in changing beliefs and attitudes in the individual level, but in the community level. Prison as institution is also considered as a community for the inmate. Thus, the effective intervention to deal with HIV/AIDS-related stigma and discrimination should take place in prison.

Numerous programs and efforts have been conducted addressing HIV/AIDS issues in prisons; however, the significant growth number of inmates who are being infected with HIV remains high. A possible reason for this situation might be the lack of attention to social factors such as stigma and discrimination, which is underlying the inmate behaviours in causing the progression of the disease and determining the success on prevention, treatment, care, and support of HIV/AIDS programs in prisons.

The commitment of the Ministry of Justice and Human Rights in designing and implementing effective and comprehensive responses to the epidemic, as part of the national strategies on HIV/AIDS programme requires a sound combination of a health care and a social approach. Therefore, the Ministry would like to improve HIV prevention and treatment policies and programs in prisons by considering HIV/AIDS-related stigma and

discrimination; however, the Ministry lacks information on HIV/AIDS-related stigma and discrimination among inmates and related staff members.

From these perspectives we assume that understanding inmates' attitude and behaviour of HIV/AIDS-related stigma in the prison will contribute to the design of policies of the Ministry of Justice and Human Rights and implementation of programs related to HIV/AIDS prevention and treatment in prisons.

This study aims to provide insight of HIV/AIDS-related stigma and discrimination in the prison among inmates and related staff members. It is foreseen that the results of the study may contribute to the strengthening of HIV prevention and treatment policies and programs in response to HIV/AIDS in the prisons to the Ministry and prison authorities.

To achieve the aim of the study the following main research question has been formulated as: What are manifestations and sociological explanation of HIV/AIDS-related stigma and discrimination of inmates and the staff members in the prison?

In order to answer these questions, the sub-research questions focus on:

1. What are manifestations of HIV-related stigma and discrimination of the inmates at the prison's community and the staff members at institutional level?
2. What is the social process of HIV/AIDS-related stigma and discrimination among the staff members and the inmates?

In the next chapter concepts of stigma and discrimination will be studied in order to outline the design of the field research

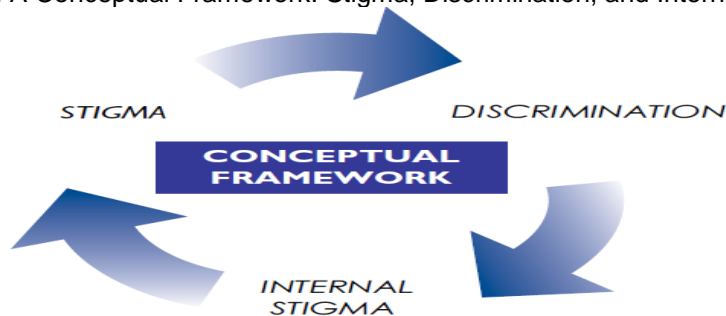
## II: LITERATURE REVIEW

This chapter will focus on concept of stigma and discrimination as well as further unravelling of manifestations of HIV/AIDS-related stigma and discrimination. This literature review aims to define the concepts that will be used in the research. This chapter also focuses on stigma and discrimination as a social process in order to explain and give in depth understanding of the concepts.

### 2.1. Defining Stigma and Discrimination

The word “stigma” is originally from Greek which means the marks of physical deformities of foreigner or person viewed inferior (USAID, 2006). Goffman, (1963) defined stigma as ‘an undesirable or discrediting attribute that an individual possesses, thus reducing individual’s status in the eyes of society’. According to USAID (2006) concept of HIV/AIDS-related stigma consist of three elements which emerged as part of a cyclical continuum: Stigma, discrimination, and internal stigma (see Figure 1).

Figure1. A Conceptual Framework: Stigma, Discrimination, and Internal Stigma



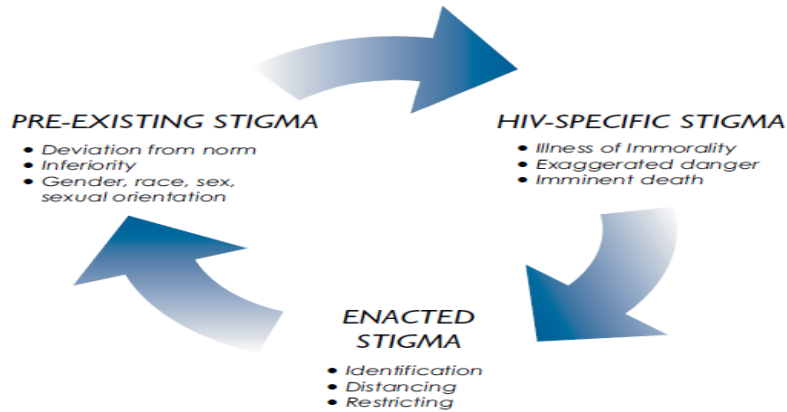
Source: USAIDS (2006, p.4)

UNAIDS (2005) refers to HIV/AIDS-related stigma as ‘the negative beliefs, feelings, and attitudes towards PLWHA and/or associated with HIV’. While, UNAIDS (2007) refers to HIV-related discrimination as ‘the unfair and unjust treatment of an individual based on his or her real or perceived HIV status’. Internal stigma refers to the perception of PLWHA based on other people or public perception on PLWHA; these situations related to people living with HIV whom has experienced stigmatized and discrimination from others (Avert, 2010).

#### Categories of Stigma

Stigma associated with HIV/AIDS could be categorized in three categories: pre-existing stigma, HIV specific stigma, and enacted stigma (USAID, 2006). These elements are interconnected and enrich each others. (See Figure 2)

Figure 2. Elements of Stigma



Source: USAIDS (2006, p.5)

### Pre-existing stigma

Pre-existing stigma is an essential element for understanding HIV/AIDS-related stigma and discrimination. Pre-existing stigma and discrimination on HIV/AIDS are related to the ways of HIV/AIDS-related stigma and discrimination occur and the contexts will be clearly revealed when the pre-existing stigma and discrimination are linked to sexuality, gender, race, poverty is explained in advance (Deacon, 2005). In line with Deacon, UNAIDS (2006) associated characteristics pre-existing stigma toward illicit drugs use, sexual orientation and class or economic status. Pre-existing stigma is classified as follows.

#### 1. Sexuality

There is perception to link closely HIV/AIDS-related stigma and discrimination with sexual stigma because in most countries the main HIV transmission is sexually transmitted, and the first HIV case is found among homosexuals in United State whom the sexual practice has consider of against public 'norm'; the cause of HIV epidemic is considered to be caused by homosexual people, as they are the only high risk population, and it is still common belief in the community (Parker and Aggleton, 2002). Pre-existing sexual stigma is associated with sexual transmitted diseases and sexual deviance is also stated by Mpundu (1999 cited in Parker and Aggleton, 2003). He also linked pre-existing sexual stigma to homosexuality, commercial sex workers, promiscuity, and drug users.

#### 2. Gender

Gender-related stigma is associated with HIV/AIDS-related stigma and discrimination. Mostly, women are being blamed for getting HIV infection and for spreading that disease to their partners and or to the community, female sexual behaviour such as commercial sex worker which is considered against normative sexual female behaviour, female commercial sex workers are also associated with wide spreading HIV infection (Parker and Aggleton, 2002).

### 3. Race and ethnicity

The disease is expressed as “African sexuality” and there is notion to link the “immoral behaviour” with the product of western countries (Parker and Aggleton, 2002). Marginalization related to race and ethnicity is triggering HIV/AIDS-related stigma and discrimination.

### 4. Class (Economic status)

HIV/AIDS-related stigma and discrimination is imposed by pre-existing stigma of social inequality in the community such as the poor, landless, and jobless (Parker and Aggleton, 2002). According Parker, Eston, and Klein (2000) found that stigma based on economic is causing HIV/AIDS-related stigma and discrimination; poverty increase susceptibility to HIV and AIDS create poverty.

### 5. Illicit drug use

Illicit drug user, particularly injecting drug use is highly stigmatised in the community. This is due to the most common sources of infection is from those behaviour (Avert, 2010).

### 6. Inferiority

Pre-existing stigma seemed related to the issues of deviation from ‘norm’ that is considering difference, inferiority, or weakness (USAID, 2006).

## **HIV-Specific Stigma**

Elements of HIV-specific stigma included (USAID, 2006): the illness of immorality, imminent death, and exaggerated sense of danger. There are some myths, metaphors, or prejudices in the community related to HIV/AIDS for example HIV/AIDS as death, as horror, as punishment, as guilt, as crime, as shame, and as “otherness”; as well as PLWHA metaphors such as a “woman’s diseases”, a “junkie’s diseases”, an “African disease”, or a “gay plaque”; those kind of metaphors enforcing emotional reaction based stigma such as fear, shame, and discriminatory behaviour in social interaction with PLWHA (UNAIDS, 2005). In turn, these notions are compounded and legitimized stigma and discrimination (Parker and Aggleton, 2003).

The fact that AIDS is life threatening diseases is causing stigma of the illness of death. Some notion in the community is referring AIDS as “dirty” related to pre-existing stigma, which is considered HIV to abnormal sexual orientation. Most of community perception in Mexico linked HIV with “lifestyle and risk”; AIDS is a homosexuality, bad, death. While the sense of danger mainly is caused by lack of information or misinformation on HIV/AIDS, a heightened, sometimes irrational, or sense of perceived risk (USAID, 2006).

## **Enacted stigma**

Enacted stigma is an action resulted from processing of perceptions and attitudes. Link and Phelan (2001) stated the concept of enacted stigma can therefore be considered as discrimination.



## **Discrimination**

According to USAID (2005) discrimination is a result from stigma. Discrimination which will create devaluation or reduction in opportunities in life of the stigmatized; therefore discrimination is a dynamic process. Individual that has stigma beliefs still can resist or decide not to act in the stigmatizing ways to other people. Contrary, individuals without stigma believes may show discrimination behaviours in situation that policies and rules are applied by institutional or country or in the situation based on a rationale assessment of risk such as health setting (Paterson, 2005).

USAID (2006) categorized discrimination in three categories: law and policy, application or practice of laws and policies, and human rights (USAID, 2006).

Understanding human rights is important such as to realise what rights one had, and to avoid of violation of rights. This is essential in relation to people living with HIV/AIDS, health service providers, group vulnerable to HIV infection.

Based on International human rights law, sex, race, language, religion, political opinion, birth or other status are guaranteed from free discrimination. In Resolutions 1995/44 and 1996/43, the UN Commission on Human Rights confirmed that the phrase "other status" is to be interpreted as incorporating health status, including HIV/AIDS (UNAIDS, 2000). Resolution 49/1999 of the UN Commission on Human Rights confirms that:

Discrimination on the basis of HIV or AIDS status, actual or presumed, is prohibited by existing international human rights standards, and that the term, "or other status" in non-discrimination provisions in international human rights texts should be interpreted to cover health status, including HIV/AIDS (UNAIDS, 2010).

Inappropriate application of provisions in public health laws has alerted by UNAIDS. The public health laws for casual communicable and often curable diseases may not be suited for HIV/AIDS (UNAIDS, 1999). According to World Health Organization isolation a person based on solely the fact that a person is suspected or known HIV positive is no public health rationale to justify it (WHO, 1987, cited in UNAIDS 2002).

In South Africa and Mexico established laws and policies on HIV/AIDS could combat discrimination within institutional setting; for example in the case of prohibiting discharge HIV positive military personnel (USAID, 2006).

In the practice of law and policies sometime there is negligence as in the case of loss of confidentiality and unequal application; mandatory HIV testing for key population (USAID, 2006).

## **Internal Stigma**

Stigma shows from stigmatizing people may be internalized by stigmatized people (PLWHA) as the real condition and situation of themselves.

Internal stigma is a complex process which is involved of one's sense of self, external and physical influences, PLWHA in turn may reinforce and legitimize internal stigma (Brouard and Wills, 2006). According USAIDS (2006) internal stigma is conceptualized as a three categories: the experiences of context which include the physical and environmental situations that people live; self-perception mainly in terms of self-blame and self-shame; and protective action include avoidance, self-exclusion, and subterfuge.

## **2.2. Further Unravelling of Manifestations of Stigma and Discrimination**

The stigma is manifested in verbal stigma (discourse) such as blame, gossiping, teasing, verbal harassment; and non-verbal stigma such as physical violence, ostracism, shunning, avoiding everyday contact, and denial of traditional rites or religious ceremonies (UNAID, 2010).

HIV/AIDS-related stigma and discrimination manifest in different levels-and it is contexts (UNAIDS 2000). The manifestations of HIV/AIDS-related stigma and discrimination are manifested at interpersonal and institutional level. The interpersonal level of manifestations of HIV/AIDS-related stigma and discrimination is described at individual, family, and community level.

Qualitative research conducted by ICRW (2005) in several countries found four patterns of HIV/AIDS-related stigma in interpersonal levels as follows (Nyblade et al, 2003):

- Isolation: consist of two sub-manifestations which are social and physical isolation, and violence. Social isolation is manifested by reduction of daily social interactions, exclusion from family and community events, shunning or turning away by the public, and a breakdown in relationships (marital, familial, or friend). Physical isolation include separating sleeping quarters, marking and separating eating utensils, separating clothing and bed linens, no longer allowing the person to eat meals with the family, and even hiding an HIV-positive member of the family. Violence is the most acute example of isolation.
- Verbal stigma: This manifestation includes gossip, voyeurism, taunting, scolding, and being sworn at or called names. Voyeurism is a unique manifestations of verbal stigma which is people visit PLWHA in order to know how they can get the infection or to know how the sick appearance of PLWHA. Those people do not have concern of PLWHA, but in order to gossiping about PLWHA.
- Loss of identity and role: the stigma is manifested by loss of power, reputation, feeling of worthlessness, respect, and right in decision making on their own lives.

The manifestations of HIV/AIDS-related stigma and discrimination are caused by the belief in the community that PLWHA are become incapacitated, and judgmental attitudes on how they get HIV infection.

- Loss of access to resources and livelihoods: The manifestations of HIV/AIDS-related stigma and discrimination which may be experienced by PLWHA includes lose access to housing, health care, educational, legal, financial, other services; and a wide range of physical assets in the community. Livelihood options may also be limited if PLWHA lose their customer base which is caused by stigma.

In the individual levels the manifestations of HIV/AIDS-related stigma and discrimination appear when these actions are involving two people, these start when individuals are reinforcing their self-stereotype to other people (Link and Phelan, 2001). In contexts where HIV/AIDS is highly stigmatized by community, the manifestations of internal stigma include feeling of self-shame, self-blame, and worthlessness (UNAID, 2010). Furthermore, in several extreme cases the manifestations might occur from suicidal feeling to suicide (UNAIDS, 2005). Referring to conceptual of internal stigma, the manifestations could take forms of self-protective action: avoidance which includes avoiding making long-term plans, avoiding activities in general, and avoiding seeking health services or treatment; isolation and self-withdrawal meant that PLWHA are avoiding social activities and intimate relationships; Subterfuge and denial which include hiding or misleading others e.g. HIV status, sexual orientation (USAID, 2006).

In developing countries, mostly families act as a main caregiver when one of the family members falls ill in terms of giving care and support the PLWHA. However, some of the family give unsupportive responses. They are stigmatizing and discriminating the PLWHA. There is some tendency that women and non-heterosexual family members are mistreated compared to children and men. The manifestations of HIV/AIDS-related stigma and discrimination in the family contexts include avoidance, exaggerated kindness and being told to conceal one's (Avert, 2010).

The manifestations of HIV/AIDS-related stigma and discrimination in the community levels are effected by the type of cultural system on how communities response to the stigma and discrimination. Individualism of cultural systems creates idea on HIV/AIDS as personal responsibility that will be blamed for getting HIV/AIDS (Kegeles et al. 1989, cited in Avert, 2010). While, collectivism of cultural systems create notion in family and community that it is shame having HIV positive members (Warwick et al. 1998, cited in Avert 2010).

Institutional stigma and discrimination refer to stigmatized groups of people whom feel disadvantaged due to the amassing institutional practices, even without stigmatisation and discrimination from the individual (Link and Phelan, 2001). Manifestations of HIV-related discrimination in prison settings is including separation of HIV positive inmates from others, exclusion from communal activities, mandatory HIV testing, and unequal access to HIV prevention, treatment, care, and support compared to at community levels (UNAIDS, 2010).

Health workers particularly in prison setting are seen to discriminate the patients due to less prioritisation or purposely discrimination against the patients. However, these is due to a feeling of frustration on the health of the patients by the health workers whom seen the patients as 'doomed' to die (Avert, 2010).

### 2.3. Stigma and Discrimination as a Social Process

In line with Goffman, socio-cognitive approach of the stigma is also emphasizing on individual beliefs and attitudes (Link and Phelan, 2001). However, when those concepts are applied on HIV/AIDS-related stigma and discrimination which it is based on public incorrect perceptions; that the stigma is produced by shared values, prejudices and taboos of the public (Paterson, 2005), as also stated by UNAIDS (2000) that HIV/AIDS-related sstigma and discrimination are not solely the consequences of individual behaviour but are social and cultural related to actions of whole groups of people. Those concepts become constrained concepts (Parker and Aggleton, 2003).

Link and Phelan (2001) offered a wider concept of the stigma that combines individual and continuously changing social process. It is means individual beliefs and attitudes of stigma turned into collective beliefs and attitudes of stigma in the contexts of power differences on structural, social, economic, and political context (Deacon, 2005). Link and Phelan (2001) also explained that power context is may lead to legitimize inequalities of status within the social structure based on differential understandings of value and worth, the ability of oppressed, marginalized and stigmatized individuals or groups; in turn, stigmatized people mostly accept and internalize HIV/AIDS-related stigma and discrimination due to these inequality. In the social processes relative power between the stigmatized and the stigmatizing will be mainly determining the degree or the amount of stigma that felt by the stigmatized (Link and Phelan, 2001).

Social expectations, stereotypes, roles, status and power attached on women are different from men in relation to gender norms. Women are likely to experience the severest manifestations of the stigma (UNAIDS, 2010). Some societies may treat HIV/AIDS' women different with HIV/AIDS' men where women are economically, culturally and socially disadvantaged. There are some mistakenly notions in community that women to be the main transmitters of sexually transmitted diseases (STDs) to their spouse and or general population. Contrasting with women, men are to be 'excused' when they get infection, even though it is resulted from their behaviour (Avert, 2010).

As social processes, HIV/AIDS-related stigma and discrimination occur when four elements of stigma converge and co-occur within power contexts. The elements are described by Parker and Aggleton (2002) as follows:

#### 1. On distinguishing and labelling differences

Social selections make people distinguishing and labelling other people that differences considerably vary according to time and place. This selection creates group in community which will matter social when the community identifying the differences.

There are some social explanations on how the social selection of human differences is. First, substantial oversimplification is needed for creating groups, clear boundaries and limited variable for example 'black or white', 'gay or straight' individuals. Second, social selection of human differences is described by the attributes considered prominent different significantly according to time and place. For example, it used to be the characteristics of ape-like face; small foreheads and large faces, were considered to reveal the criminal nature of the people (Gould, 1981 cited in Parker and Aggleton, 2002).

#### 2. On associating human differences with negative attributes

The stigma happens when dominant cultural beliefs link undesirable attributes of labelled people with negative stereotypes.

#### 3. On separating 'us' from 'them'

Believing labelled people are considerably different from the rest, this makes a separation of 'us' and 'them'.

#### 4. Status loss and discrimination

People lose status and are being discriminated as the result of social process on labelling, stereotyping, and separating people. The process of stigmatizing creates social inequality in the community hence discrimination of those negative labelled individuals.

The negative labelled people are seen to be of a lower hierarchical status by the 'general population' which may lead to discrimination in the society, the example of loss of status in the context of social interactions within small groups is those people without negative labels talk more frequently, have their ideas more likely to be accepted by other people, and are more likely to be voted as a group leader rather than those with negative labels (Mullen et al, 1989 cited in Parker and Aggleton, 2002).

The notion of emphasizing HIV/AIDS-related stigma and discrimination as social processes that is linking the stigma with power and the legitimization of social inequality, will have impact to the challenged of HIV/AIDS-related stigma and discrimination in the community levels where the common stigma occurs. In keeping with this Daas (2001) stated the reduction of HIV/AIDS-related stigma and discrimination is mainly underlying in community based, these ideas will be enlighten the design of HIV/AIDS-related stigma and discrimination responses in powerful and effective ways.

Prison as an institution and also as a community for inmates could develop structural interventions based on human rights approach through advocacy and social mobilization in order to decreasing HIV/AIDS-related stigma and discrimination in prison and in general population when the inmates have finished the period of sentenced.

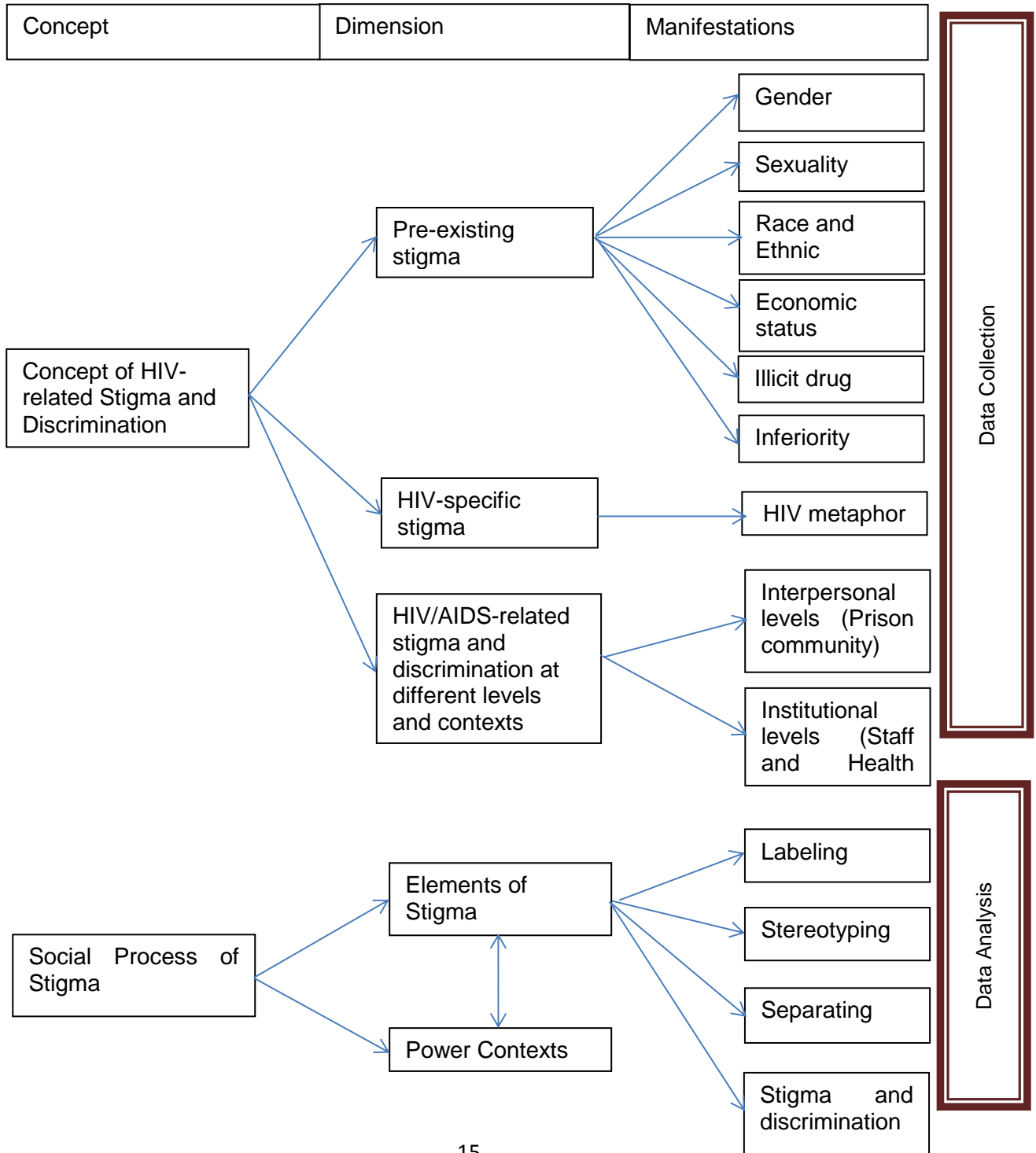
## **III: THE RESEARCH PROJECT**

### **3.1. The Problem re-described**

In line with the literature review presented in the previous chapter, the research will focus on three dimensions of HIV/AIDS-related stigma and discrimination which are pre-existing stigma, HIV-specific stigma, and enacted stigma or discrimination as well as on levels and contexts of stigma in an interpersonal and institutional context.

In order to understand the manifestations of HIV/AIDS-related stigma and discrimination in these dimensions, the research included a study of stigma as a social process. This process will be explained through the convergence and the occurrence of the stigma. The concept is described in the conceptual framework of the research as follows: (see figure. 3)

Figure 3. Conceptual Framework of the Research



A case study in the Sukabumi prison, in Indonesia will be used to gain an in-depth understanding of the research topic. The Sukabumi prison is selected for the accessibility of this institute by the researcher. The research will be conducted to provide knowledge on HIV/AIDS-related stigma and discrimination at interpersonal levels by interviewing inmates of the prison community. An institutional perspective will be explored by conducting interviews to security, administrative, and support staff members such as health worker. In addition the key informants were also interviewed. The characteristics of the respondents such as age, education, types of crime, and length of sentence will be asked by the researcher as supporting information of the research analysis.

### 3.2. Sukabumi Prison

Figure 4. Sukabumi prison



Source: <http://poskota.co.id/berita-terkini/2010/09/12/278-dapat-remisi-13-napi-langsung->

HIV prevalence in Sukabumi prison estimated at 1 %, while the national HIV prevalence counted is 0.22% (MoH, 2012). This prison is a place of detention for those people who are awaiting court and who have been convicted for a crime. The criminal cases relate both to general crime as well as to special crime such as drug offending. As Sukabumi prison is the only prison in this district adults and juveniles, females and males are detained in the prison.

The Ministry of Justice and Human Rights supervises the prison as their working unit in the district area. The highest level of authority in the prison is held by one chief whom is assisted by prison staff. The staffs are categorized as security, administrative, and support staff such as health workers. The staffs that have daily direct contact with the inmates are the health workers as well as the security staff.



The prison has 17 rooms of different sizes for the male inmates. Eight big rooms which each room is around 9x6 m, it was modified to become a two storey which was occupied by 70-80 inmates, Five medium rooms, each room is around 5x6 m and is occupied by around 20-30 inmates, and four small rooms which each room is around 3x6 m is occupied by approximately 10-15 inmates. It is mean the average space of living is around 1 m for every inmate. In addition, there are two small rooms around 3x3 m and 2x3 m; it was used for inpatient room. One for the Tuberculosis patient, and another room was for severe diarrhoea patients who need infusion. Every room has a small toilet.

The Female inmates are hold in separate facilities adjacent to prison for male. The room size is around 54 m<sup>2</sup>. They are supervised by female staff in the morning and by male staff in the afternoon.

The prison has a pumped well, but the inmates said sometimes the quantity and the quality of the water was not good. When the researcher carried out the research it was observed that many inmates visited the clinic in prison due to skin ulcers problem. The inmates were given three times a day a meal. Due to the quality of the food, some of them bought the food from prison's cafeteria or the food was given by their families. They said that as inmates they usually give support each other including sharing food e.g. noodles. In the prison noodles was considered as valuable food. This is due to for some poor inmates; they will not afford to buy the food.

The inmates' behaviour toward the staff was very respectful. They only talked when the staff asked a question or when the conversation was started by the staff.

The general community surrounding outside the prison is involved in several programs with the prison such as religious leader in ceremonial religion, Non-Government Organization in activities that increase inmate knowledge and skills. The family members of an inmate are allowed to visit the inmate according to a schedule provided by the prison authorities.

Playing sport every Friday was compulsory for all the inmates, except the sick inmates. There were working activities for the inmates such as making furniture, lattice, and mats, as well as a barbershop. The social activities which also involved the inmates are among others: religious rituals and ceremonies, education, and health programs such as group counselling and several kinds of health education programs.

### **3.3. Process of Data Collection**

The research started with a desk study for collecting and reviewing literature based on the research topics, the researcher also purposed research permission in Sukabumi prison to the Ministry of Justice and Human Rights. The process took around one month. Prior to the primary data collection the researcher also conducted a phone call to a health worker in the prison in order to get a general view about conditions and situations in the prison. Primary data was collected by conducting interviews with key informants, female and male

inmates, female and male prison staff members, as well as health workers in order to make a balanced perspective from both genders.

During the first week of doing research in the prison, the researcher met the chief and several prison authorities to inform them about the research activities. The chief of the prison and other staff members are quite open and offering supports that might be needed by the researcher. The researcher conducted a pre-test interview with two inmates and one staff member. The participants in the pre-tested research are different from respondents at the research. This activity was to check whether the research design is appropriate; it resulted that interviewees understood the question.

The selection process of the respondents is determined randomly, the researcher asked the list of inmates and staff members' name and age then chose the respondents based on the list. The age is considering important for selection the respondent that the age difference is useful in the research, in order to get wide range perspective on the issues. The researcher also takes the HIV positive inmates for being the respondent. The total number of inmates was around 630 of which 12 were female inmates. Four male inmates and four female inmates were interviewed. The number of staff members was 60 people, two female and two male staff members were interviewed. The health workers in the prison were one male medical doctor and one male nurse, both of them were interviewed.

A qualitative research was conducted through open questions based on a structural check list. Three sets of different questions were prepared and used for this research to cover the respondents that are inmates, administrative and security staff, as well as the health worker. The questions were designed to cover the key domains of the topics in order to ensure proposed HIV/AIDS-related stigma and discrimination. Once a final draft of an English version of questions was complete, it was translated into Bahasa Indonesia - the national language of Indonesia. Although, in the interview process some of the respondents used traditional languages, the situation could be handled by the researcher without additional translation as the researcher understood the respondents languages.

In the beginning of the interview, the researcher introduced herself, then she explained the purpose of the interview and answered related questions about possible research issues that may arise with by the respondents. An ethical issue was taken into consideration by guaranteeing anonymity of interviewees, and also they were made aware that their participation is voluntary. As the interviews were recorded using a tape recorder, the researcher explained the purpose of recording. Once respondents agreed on their participation and the recording of the interview, the respondents signed the consent form before the start of the interview,

The interviews were conducted from 30-60 minutes. Afterwards the researcher listened to the recorders then marked and transcribed the respondent's answers. Some of the interviews were repeated in order to check and clarify the respondents' answers that were not clear for the researcher.

During the interview the researcher asked questions to find out the respondents opinion on the research issues and asked the respondents (inmates and staff) perceptions about what the community think about these issues in order to compare the respondents' perception with the community reaction on the issues.

The interviews conducted individually to create conducive environment in the process of interviewing due to HIV/AIDS might be seen as sensitive topics for discussing. Through this methodology the researcher hoped that the respondents will talk freely, do not feel shamed or afraid

### **3.4. Limitation**

The first attempt of interviewing in the pre-test interview was quite hard to do because the researcher was quite nervous about how the questions had to be addressed to the respondents. This situation was due to this being the first time for the researcher to do a check list interview; also some of the respondents needed the question phrasing in a different way so they could understand the questions. However, the rest of the time, the situations could be handled and the respondents were keen to answer the questions and give information.

The interviews were planned to be conducted individually without any supervision or intervention from others. This is for creating conducive environment for the process of interviewing considering the nature of the research to HIV/AIDS might be seen as sensitive topics for discussing. However, due to the limitation of the space, the interview was conducted in the clinic (health worker room), the room size was 4 x 5 m. During the interviews session, sometimes there was a health worker in the room.

The interview was conducted in the noon, after the health workers finished examining in order to get space for interviewing. Some of the inmates' respondent sometimes stop talking or lose the concentration when there were people entered the room. Some of the interview sessions were conducted while the staff was working in their room that other staff may heard and the respondents may had difficulty to express their perspective.

The inmate respondents were surprised when they were called to the clinic, in the prison sometimes the inmates felt afraid if the staff asked them to come to the prison department include the health department (the clinic). It took time to explain the inmates that the purposed of it was for research interview. Some of the inmates were afraid that the called was about their HIV status, since some of the respondents were waiting the result of HIV testing

### **3.5. Data Analysis**

The findings of the research will be analysed and interpretative based on the research framework and conceptual framework. The result will be presented according to the perception of the respondents.



## IV: FINDINGS

This chapter presents the findings of the research from the field work.

Firstly the general information about the respondents is presented. Secondly findings about HIV/AIDS-related stigma are presented as manifestations of HIV pre-existing stigma, HIV-specific stigma, as well as the manifestations of the stigma and discrimination in interpersonal and institutional levels are presented. Thirdly, the social process of HIV/AIDS-related stigma and discrimination are presented.

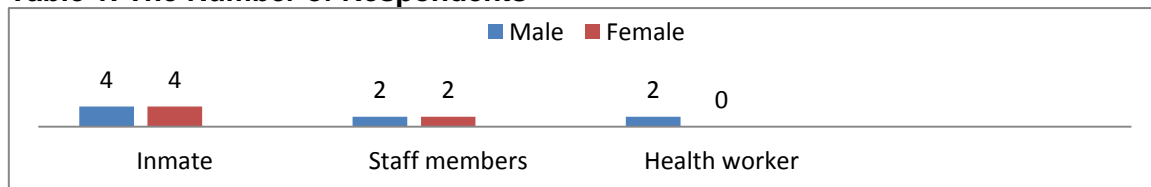
The characteristics of the respondents such as age, education, types of crime, and length of sentence are presented by the researcher as supporting information of the research analysis.

The findings on manifestations of HIV pre-existing stigma, HIV-specific stigma are described from the interviews with the respondents (being inmates, staff, and health worker), while the manifestations of the stigma and discrimination in interpersonal level are described from the inmates and the manifestations in institutional levels are described from the staff members as well as the health worker. The findings from the three key informant of inmate, security staff, and health worker are presented..

### 4.1 General Information of Respondents

The general information of the respondents includes the total number of the respondents, age, level of education of all the respondents, as well as the type of crimes, length of sentence and length of served sentence of the inmate respondents.

**Table 1. The Number of Respondents**



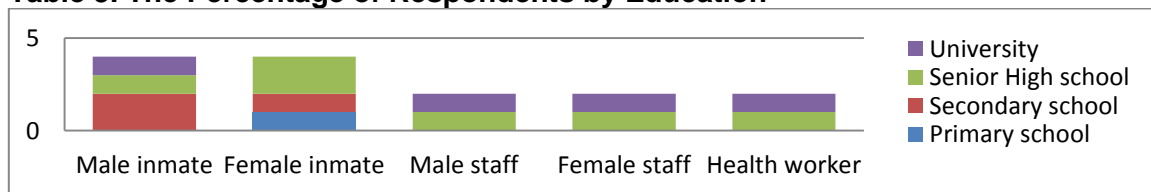
The number of inmate respondents is eight respondents which is four out of 618 male inmates and four out of 12 female inmates. While, the number of staff respondents is four which is two male and two female out of 60 staff members. The total number of health workers in the prison is two male people. Both of them are selected as a respondent for this research.

**Table 2. The Percentage of Respondents by Age Group**



The majority age of the inmate respondents is 20-30 years (five out of eight). While, the majority of the staff member respondents (three out of four) are 40-50 years. While the age of the health worker respondents are from 20-30 years and more than 30 years old.

**Table 3. The Percentage of Respondents by Education**



The figure shows that male inmate respondents have higher education over female inmate respondents, one male inmate respondent have a university degree, while two female inmate respondents only have senior high school degree. The lowest level of education is held by female inmate respondent. One female inmate has primary school degree, while the male inmate respondents have secondary school degree.

The education levels of prison population is sometimes creating challenge for health workers when they should deal with HIV/AIDS-related issues, the informant of health explains that many HIV/AIDS programs in the prison including communication, information, and education programs. However, it is difficult to design and deliver an appropriate the programs in the prison due to the education levels of the audiences are different.

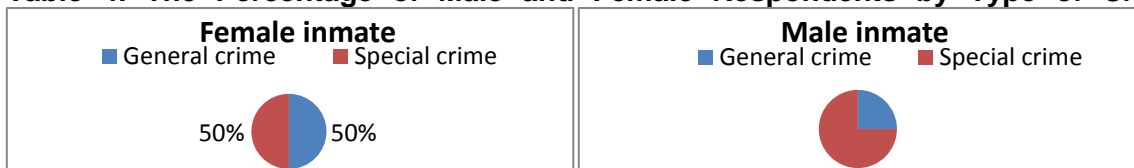
The minimum education requirement for being staff in the prison is senior high school. It shows in the figure that two staff members have senior high school degree while other staff members have a university degree. The doctor has university degree and the nurse have the same level education with a senior high school degree.

The education levels of staff is to be expected to give contribution in creating conducive environment for the inmate e.g. the security staff also can give information on HIV/AIDS, as they have direct contact with the inmates. As indicated by the informant of the staff.

*“We have a lot of responsibility in the prison, although our main job is in security matters but sometimes the inmates are asking about health matters...in this situation the security staff should also understand and know a lot of things including health issues. Although, HIV/AIDS-related issues is also new for us and majority of us have average level of education but we should learn that*

issues. The prison is a small and restricted community. The levels of inmates education is varied, any raised issues may cause unsafely and uncertainty in this community. This situation is also not good for maintaining conducive environment in the prison, as our main job description”.

**Table 4. The Percentage of Male and Female Respondents by Type of Crime**



The type of crime for the majority of male respondents is a special crime, which is drug offending. This accounts for 75% of male respondents. While for the female respondents the special crime refers to human trafficking. The general crime was robbery, and fraud.

**Table 5. The Number of Respondents by Length of Sentence**

Years	Male		Female	
	Prison Sentence	Served Sentence	Prison Sentence	Served Sentence
< 1	-	3	-	3
1 - 2	2	1	1	1
3 - 5	2	-	1	-
>5	-	-	2	-

The length of prison sentences for female respondents is a higher portion than male respondents. Three out of four female respondents have prison sentences over five years. This is related to special crime for human trafficking that is punished with nearly seven years, while drug offending is punished with about one-two years. The number of respondents who have served sentences less than one year showed the same number for both female and male respondents (three out of four).

## 4.2. Pre-existing Stigma

Pre-existing stigma is an important concept to understand HIV/AIDS-related stigma and discrimination. Manifestations of pre-existing stigma and discrimination on HIV/AIDS relate to gender, sexuality, race and ethnic, class or economic status, illicit drug, and inferiority.

### Gender

The gender dimension is an important factor related to stigma and discrimination on HIV issues in the community. In some community, the community members have some different perceptions on roles of women and men.

Seven out of eight male respondents and three out of six female respondents mention that women and men have the same responsibility for spreading the disease to their partner

and the community. While two out of six female respondents mention that women are responsible for taking responsibility. Only one male and one female respondent mention that it males are responsible for spreading the disease to their partner(s) and the community.

The respondents who claim women and men have the same responsibility for spreading the disease is due to their consideration that gender is not an issue for who are taking the responsibility for spreading the disease. One reason for the gender not being an issue in spreading the disease is the behaviour of the person, having influences such as drugs and/or promiscuity.

Both male and female are responsible for spreading HIV infection in the communities, as declared by a 28 years female respondent. The respondent was living in capital city, which the ways of she explains the perceptions on some issues has been influenced by the actual situation in the city. She says:

“I saw many women and men had HIV in my neighboring, nowadays, in the big city everything seems equal”. Furthermore, she explains:” In my opinion, men and women have responsibility for contracting and spreading the disease. Women have infection because of their job as a commercial sex worker or maybe being a house wife getting the infection from their husband if their husband was involved with a commercial sex worker or having an affair with many women. Men usually get the infection through using drugs or having sex with commercial sex workers. In turn, men and women may spread the disease to their spouse or to the general population”. “

Another respondent states that his wife died due to AIDS-related disease. He is blamed by his mother and father in-law that he is the ones who have been spreading the disease. He thinks it is not fair, since both of them are drugs user.

While the respondents who states women are the ones who are causing the spreading of the disease is due to women being a commercial sex worker. As stated by a 26 years old female respondent. She has been punished around 6 year’s sentence for human trafficking case. She says:

*“Nowadays, many women are involved in commercial sexual working, particularly since in the villages it is difficult to find a good job. Moreover, many women’s villagers have a lower education...they have limitation of choices, only few kind of job are available for them”.*

The respondents who states that men have the responsibility for spreading the disease is often considered due to the behaviour of men using drugs and also being a partner of commercial sex workers, while women are considered usually to be only a victim of these men as the majority of women are house wives, as explained by a 47 years old female



respondent. The respondent is a widow that has a life history of four time marriages. She explains:

*"I think men are the responsible for spreading the disease, in my community...some of the men are paying for sex to commercial sex workers. They have money and power to do such kind of behaviour, while women never do such kind of behaviour".*

When the researcher asked about the history of her marriages, whether her husband has died of long terms disease, she explains that two of the husband passed away due to work related accidents, and the others were divorced, she says that both of them are healthy but she do not know the recent health status of the husbands.

### **Sexuality**

Most of the respondents (13 out of 14) state HIV infection is related to sexuality. Three respondents link HIV infection to commercial sex workers and 10 respondents' link HIV infection to promiscuity. HIV is linked to commercial sex workers as explained by a 27 years male respondent:

*"People living with AIDS usually have discharge from their genital. It is normally recognised as syphilis. They have bad behaviour. They usually having sex with female commercial sex workers, they get the HIV infection from those commercial sex workers".*

Another respondent is expressing the concern for his health status related to HIV/AIDS. As said by a 39 years male respondent:

*" I am from the village...It is amazing living in the prison that we can know something that we will never learn in our home town...People are talking about HIV/AIDS...that people with promiscuity are susceptible to HIV, I am remembered what I have done...I used to changed sexual partners, then I am agreed to be taken blood for HIV tested by the health worker...but I don't know my status yet...Always across in my mind about of being positive...I am curious and always worried".*

This respondent also tells that he has been married for five times. Due to their economic condition, the recent wife who is 25 years old went to another country for working as a maid since 2 years ago. He says the situation that make him involved in promiscuity.

One of the respondents who states HIV infection is linked to promiscuity is a 29 years male respondent whose has punished for drug offending. He says that men are usually have a lot of sexual partners even the ones who are already married, people who are involved in drug offending also have tendency to do such behaviour as they are in "the same group" as drug user have a lot of friends that are easily to change sexual partners among them.

### **Race and Ethnic**

Race and ethnic have some roles in creating HIV/AIDS-related stigma and discrimination in the community. Two respondents refer HIV as a western product which is related to the western lifestyle, while one female respondent states that HIV is closely linked with the Maluku ethnic group or community in Indonesia.

A manifestation of HIV being a western product is stated by a 50 years old male respondent:

*“Young people have changed their behaviour, it is different from my era...nowadays, even in the villages many people are involved in such kind of behaviour...they are paying for sex with commercial sex workers, using drugs...I think it is related to western lifestyles that they have watched on television, as a result we can see many young people have AIDS”.*

The 26 years female respondent who mentions HIV is linked to Maluku tribe's due to the respondent's experience of living in Maluku Island. She knows some people living with HIV/AIDS in that area. She works in private sector in the Maluku, it is very long distance from her hometown but since a lot of job opportunity there, she went to that area.

### **Class (Economic Status)**

Ten out of fourteen respondents states that class or economic status of rich or poor people is not related to their susceptibility of HIV. Three respondents say that poverty will increase susceptibility of HIV in the community. While one respondent mentions that wealthy people will increase susceptibility of HIV.

The respondents who mention economic status of people is not influencing susceptibility of the people to HIV argue that the rich people have a lot of opportunity to spend their money e.g. buying illegal drugs, while the poor people are likely to be involved as a commercial sex workers to fulfil their expenses.

The respondents who refer to the poor people who have high susceptibility argue the rich people have power and better knowledge to avoid the infection. They can protect themselves e.g. using sterile needles and having protected sex by using a condom. While the poor people are due to their economic condition as -poor women will accept any kind of job that is offered or available in that time, which is usually as a commercial sexual work. Drug users from poor families may share unsterile needles when using drugs. Poverty is a cause for people contracting the HIV infection, as stated by a 21 years female respondent, she was working as administrative staff at private office and have been imprisonment for fraud case:

*“Poor women who have no job will be involved in commercial sex working; poverty has pushed them to engage with that work in order to earn money for*

*living. Female commercial sex workers usually got the infection because of their job, they do not have power to use condom”.*

While the respondent who says the rich people who have high susceptibility explains that they have a lot of money for buying drugs and paying for sex with commercial sex worker.

### **Illicit Drugs**

All of the respondents (14 of them) mention that HIV has a close link to drug users especially injecting drug users; this is due to the main mode of HIV infection in the community through this kind of behaviour, as said by a 31years male respondent:

*“People living with HIV/AIDS are used to having tattoos, piercing and using drugs... young male adult have such kind of a lifestyle...the drug users are sharing needles in their group...especially that kind of behaviour will make them get the HIV infection”.*

The respondent also told a story about the family. The respondent says that he met with his spouse in a drug users group in 2005, after that time they married. However, in February 2011 his wife died due to tuberculosis related to AIDS. Then, he got HIV tested and also found positive in March 2011. The family is giving support; HIV/AIDS is not a new disease for this family, as one of his brother also died due to the disease in 2004.

The staff informant states that since one third of the inmate cases (around 200 out of 600) is drug offending, it is worrying situations for spreading the disease in the prison. He says that he always tell to his staff to be increasing attention to such kind of people. Beside that he states that many programs related to HIV/AIDS issues have been conducting in the prison since a lot of inmates related to drug offending.

### **Inferiority**

Three female respondents also say that people living with HIV/AIDS seem as thought inferior to other people. This notion is due to those people having practiced sexual deviance that considered against the ‘norm’ in the community such as a female commercial sex workers. They say most of the commercial sex workers are women that most of the fault is in women hands. As mentioned by a 47 years old female respondent:

*“Having HIV is humiliation... devaluation of life...women who have HIV do not have dignity in our community, they have ruined our normality...many women are involved in sexual working...they are disgusting”.*

This female respondent also tells a story. She says that in her community there is a female neighbor who never involved in any activities that held by the community, she think it is due to her job as commercial sex worker that the woman is shamed. In the last few years the neighbor was sick and no one of the community members were visiting her. She says it is due to people have known that the women have HIV infection.

### 4.3. HIV- Specific Stigma

Some of the manifestations of HIV-specific stigma in the community which relates HIV to the illness of immorality, imminent death, exaggerated sense of danger, and link HIV/AIDS to metaphors such as death, as horror, as punishment, as crime, as shame, and as “otherness”; as well as PLWHA metaphors such as a “woman’s diseases” and as a “junkies diseases” also is found in this research.

The inmate informant in the prison explains his concerned. He says that the majority of the inmates will have opinion that HIV infection is the result of immoral behaviour which is related to free sex or drug offending. In this community many people are related to that kind of behaviour. However, people are still afraid to talking about the disease. They do not want to offend their friends in the prison.

Ten out of fourteen respondents say that HIV is a virus, a contagious disease. While the others respondents describe HIV as a horror, as a death, as a junkies disease. The respondent who feel HIV is a horror and danger explains that HIV is a new disease and the respondent get information about the disease from the neighbors. “HIV is like horror” a female respondent 47 years old whose have primary school degree mentions.

*“But actually I do not know exactly what it is....but I am afraid of that disease...it feels dangerous...”*

This respondent seems very nervous when answering the question in the first time of interview. She mentions that she do not have an any ideas about what the HIV/AIDS issues are, however, after the researcher explains that the interview mainly asked about her perspectives of living in the prison, and make the situation more relax with talking about her family, and friends in the prison, as well as on how she could involve in her case, that she begins quite open and keen to talk even more.

Another respondent refers HIV/AIDS as a death, explains that the disease is closely linked to death as every person living with HIV/AIDS will die soon due to there being no medicine for it. The 29 years male respondent says that he used to involve in illicit drug, although know that some of his friends that related to drug died due to disease related AIDS; he could not escape from using drugs.

The respondent who referred HIV to junkies’ disease is linking people living with HIV/AIDS with their lifestyle being junkies before they get the infection. As explained by 27 years respondent:

*“Young people usually have free lifestyles, they are taking drugs and drink every night, without realized it, they will find their HIV status is positive in the end”.*

Another respondent links the disease as shame. The 31 years respondent explains that having HIV is shamed. Someone who have HIV infection will not talk of their status to

other people, even to their spouse or families because they know that they will be blamed for having bad behaviour.

The majority of respondents express HIV as the disease of “such type of people or otherness” (eight out of 16). They explain the disease is only infecting to ‘such type of people’ e.g. commercial sex workers, drug users. As stated by a 47 years old female respondent, she says only certain people with bad behaviour such as female commercial workers will have the disease, the common people like her will not have.

Thirteen out of 16 respondents state HIV as a blame and resulting from immoral behaviour. They also state those people deserve to get the infection as a punishment of their immoral behaviour, as explained by a 39 years male respondent:

*“As far I know...the such type of people that are usually having the disease, are drinking, using drugs, having sex with commercial sex workers...although, such type of people know they are doing the wrong things, but they are still involved in that kind of behaviour. So, I think they get the disease because of their immoral behaviour, it is punishment from God”.*

#### **4.4. Manifestations of HIV/AIDS-related stigma and Discrimination**

The manifestations of the HIV/AIDS-related stigma in this chapter are presented into three groups, the inmates group for getting the information on the manifestation related to the inmates as a prison community, the staff and the health workers group to get the information on the manifestation of HIV/AIDS-related stigma and discrimination in the institutional level.

##### **4.4.1. Inmate Respondents**

One of the respondents disclosed his HIV status. Some of the respondents are know there is HIV positive inmate in their room, but the other inmates do not know. Due to this situation the manifestations are presented based on the perception of experienced situation by HIV positive inmate and the perception of situation by inmates with undisclosed status.

##### **Perception of Experienced Situation by HIV positive inmate**

One of the respondents’ declared his HIV status to the researcher. The respondent has disclosed his HIV status to several inmates. The respondent explains the reason of that decision:

*“I choose to disclose my HIV status since I believe people in the prison will be more aware about the disease rather than the place where I come from, and I fell more comfortable to state my condition to them rather than let them know my status from somebody else. They will not respect and trust me if they know*

*my status from others. It also gives me confidence while I am living among them”.*

During the interview it seems that he is eager to answer the researcher questions. In the prison he stays with around 70 inmates as the roommate, majority of them are inmates' related drugs offending. He knows that these inmates have high risk condition of getting HIV infection. He wants to give some insight about HIV/AIDS to these inmates. He realizes that although some inmates show normal attitude, the other inmate have negative attitude towards him related to his HIV status.

The manifestation of HIV/AIDS-related stigma and discrimination that has been experienced by the respondent is avoiding everyday contact, he explains:

*“Most of the inmates show normal behaviour...they are not afraid of me, we usually talk and shake hands...they give support and remind me to take the medicine, they would like to share room, food utensils, and the toilet with me. However, few people still are afraid to talk with me...I know from their eyes, they avoid eye contact and keep a distance when they are talking to me”.*

Although the respondent declares the status to the researcher and several inmates, he do not tell his status to his wife. After the death of the first wife in February 2011, he have a relationship with a 20 years girl who have being a friend of his family, in January 2012, only 20 days since they had met, they decided to married. The wife hears rumors about his HIV status and asks, but he denied it. Condom is never used during their intercourse. He is afraid that the wife will suspicious of his HIV status. The reason he is afraid to disclose the status is being of left out. He gets the information on HIV from NGO-related HIV/AIDS issues which also encourage him to get HIV testing. He argues after sometimes will declare his status indirectly through this NGO. The wife has gone for working in the capital city since he entered the prison three months ago. He says their relationship is good.

While, in terms of HIV/AIDS-related stigma and discrimination from the staff, he says that he never have direct contact with the staff due to the number of inmates is hundred while only six-eight security staff who look out the inmates. He says until the time of interview the security staffs do not know his HIV status. He argues that it is not necessary to tell them about his status because they never have a daily contact.

In terms of the manifestations of internal stigma, the respondent explains that before he enters the prison, he was asked by one of the NGO member to involve as a HIV volunteer in the NGO. His ideal is to give the insight to people living with HIV/AIDS that their life is worth and give motivation for living to them. He also have a future plan after finishing the period of punishment for searching work, and living as other people. These situations related to his families' situations that they are accepting and giving support, although they have known his HIV status, the situations make him feel confident undergoing the life.

## Perception of Experienced Situation by Inmates with Undisclosed Status

Some of the inmates are sharing their living story in the prison. The respondent is a male 29 years old. He used to active in peer education programs. He says that he is not afraid staying in the same room with the HIV positive inmate, however, some of the situations make he is afraid. He knows that most of the inmates have skin ulcers. However, when he notices that those HIV inmates have some skin ulcers, it makes him quite afraid of being get the HIV infection. He explains:

*"I know someone in my room is HIV positive...I don't mind to stay in same room with him, but, sometimes...I am worried...I put my shower equipment in some place, and when I come back it has been moved from there...I am afraid he used my tooth brush, razor...In the night, I am quite worried of his sweat and blood from his wound that it may come into contact with my skin, as in the prison we have to sleep very close to each other. In fact, if I can choose I want to move to another room".*

The female respondent who used to involve in peer education programme has no objection having everyday contact with HIV positive inmate, however, she is worried if the inmate have shown significant or severe symptoms. She explains:

*"Living with HIV positive inmates will cause no harm, we can have everyday contact with them as long as we do not have blood contact with those people...if they are sick, I am willing to take care of them...but, if they have a lot of wounds on the skin or tuberculosis...then I think it is better to put them in separate room".*

The respondent says it used to peer education program in the prison that is conducted by NGO related HIV/AIDS. She says that some of the inmates are chosen to be peer educator that they are given counseling every Tuesday. She feels it is useful to increase her knowledge on HIV/AIDS. However, since around five months ago it has stopped. She argues that as an inmate she do not know the reason of the situations.

Four respondents say that talking about the HIV positive inmates' condition among the other inmates is necessary. They argue it will create a possible idea and action on taking precautions towards those sick inmates.

The health informant says that some inmates have already get information on HIV/AIDS related issues. He argues these inmates will have better understanding of the disease and will accept HIV positive inmates the same as other inmates. However, for some inmates who do not understand the disease those inmates will feel afraid, making some rumours or gossiping about, keeping a distance, and isolating those that are HIV positive inmates from everyday life in prison. He explains:

*“In the prison we have a different characteristics, some people are not aware on the situations here, ...every people are busy with their problems...but, some people who have get the information on HIV/AIDS are aware and have a good knowledge and attitude towards HIV positive inmates in the prison”.*

Another respondent feels afraid of staying in the same room with the HIV positive inmate. She mentions a lot of things are quite different when she is staying with the HIV positive inmate. She also refers to some behaviour that according to her is a safety behaviour when staying in the prison with the inmate. She explains:

*“In the prison we should accept all the situations...including sharing room with others, although I am afraid of being infected all the time...I just take care of my equipment, if that inmate want borrow my dress then I will let them keep it...those inmate has very sensitive feelings, she are always angry and offended easily...I think it is because of the disease...I feel hesitation having a conversation with her, moreover, I think it is wise and safe to keep a distance from her”.*

The key inmate informant who knows the HIV positive inmate, expressing his perception on the prison situation related to the HIV positive inmate. He is not living in the same room with the HIV positive inmate, however he usually have some conversations with him. He says that inmates are in different stages; there are a new people who are in the court proceedings, they are not aware the situation of others and the prison yet; and the inmates who have punished by the court, especially the inmates which long period of sentences usually aware on the situations surrounding them. They show a normal behaviour towards the HIV positive inmate, one of the reason is related to the education on HIV/AIDS that the prison authorities have given and another reason is they have same feeling, as same as an having inmates' status.

Another respondent is male with drug offending cases. He also mentions that in the prison people have their own businesses. It is good to keep everything in secret and silence. The situation in the prison is unpredictable if someone has a problem with others it will cause further miserable, it is better that inmates showing respect to others.

The male respondent tells that he does not know of other HIV inmates' status, he explains about his opinion if he know there are HIV positive inmates in the prison:

*“If I have HIV friends it does not matter for me...I am not afraid living in the same room and sharing food utensils with them...they are also human who need respect and support...I have known from counselling that it is fine living with them as long as we take care of ourselves...avoiding blood contact with them”.*

The respondent is a female. She comes from a wealthy family; she is married with the owner of the palm plantation. The respondent joined with her brother and father in the



prison due to involved in fraud case. During the interview she need quite sometimes to think before answered the questions. The researcher is encouraging her to talk more open by repeating that the interview want to know her perception and will not cause any harm to her and others since it is anonymous interview.

She states HIV transmission is through blood contact, however, she still has some doubt about her safety of getting the HIV infection if she shared a room or food utensils. She explains:

*“I get some information that HIV transmits through sex and blood contact...but I think it is necessary to keep aware about our safety...if there is another room, it is better for us that they are moved to that room...I don’t want to share food utensils and toilets with them, just in cases something happens...people have different characters, I am just afraid there are bad people that want to spread the disease purposely to me”.*

One of the respondents explains that the HIV positive people are better living in the villages rather than in the cities, since people in the villages do not know anything about HIV/AIDS, moreover, he mentions that even people in the village know the HIV status of the people, they have a better social cohesion. As a result the HIV positive people will not be isolated or gossiped in the villages, but will be given support. These situations were contrast with people in the cities.

Moreover, he also refers that communities in the prison are almost same with the cities’ communities, since a lot of counselling sessions in the prison that inmates will aware about the disease. The inmates will perform the same behaviour as the cities’ dwellers to the HIV positive inmates. They will be gossiping and isolating the HIV positive inmates.

Some of the expressions in his face are very clear that he does not like the HIV positive inmate surrounding his environment. He says that he feels afraid of being infected if he has to be involved in everyday contact with people living with HIV/AIDS, the respondent explains:

*“Actually, I don’t mind if I should shake their hand and have a conversation with them as I realized that they are also human...but...I should keep aware and keep a distance with them...just in case something happens...I don’t want to be in the same room with them; eating together and sharing the toilet it seem dangerous for me...in the social gathering it is better for me to sit outside the room far from them”.*

Five out of eight inmate respondents state that they want to know the background of why people get the HIV infection and the recent condition of the HIV positive inmates. They argue it is important to know their story and condition that they can take a lesson from that and also give support and care needed to those HIV inmates. While the other respondents

comment that it is not important to know the condition, since it might open the bad memories and nothing can be done further even they have known their condition.

All of the inmates' respondents (eight of them) think that other inmates will also have same opinion as them towards HIV positive inmates. As stated by a male respondent:

*"I think other inmates will reject an HIV positive inmate...if find those inmates, they will be reported to the prison authorities in order to isolate them...the inmates will feel afraid of being contagious of the disease. Prison is a small community, the information about someone will spread quickly in this community, people will talk behind ones back and keep a distance to those people".*

The inmates also say that the staffs are likely to take action toward HIV positive inmates, they argue the staff will not let the inmates treated by the disease. The inmate says the staff will isolate or move those inmates to another prison. However, the inmates' respondents say that physical violence towards HIV positive inmates will not be manifested.

#### 4.4.2. Staff Respondents

The findings among the staff members on the manifestations of HIV/AIDS-related stigma and discrimination are presented.

Some of the staff state that they do not know about the HIV status of the inmates. As explained by the staff informant:

*"Sometimes I want to know who are the HIV positive inmate, I think it is important to know the status of the inmates...but, since the doctor told it is secret, I do not ask anymore.. All of the security staff also do not know the HIV inmate status, even though, they may listen the rumors on that issues in the prison".*

One respondent mentions that if there are HIV positive inmates, they should be put in separate room. The respondents also will refuse to involve those inmates in work activities in the prison. The respondent argues it is in order to guarantee other inmates safety. As the respondents put it

*"It is better to put them in a separate room...if they have a visitor it is wise also to separate their room ...So, they will not transmit the disease to others. It is also a danger to involve them in work activities...While working; we are sharing drink and food, using the same food utensils. I don't want to put other inmates at risk...moreover, there is sharp equipment, and if those inmates get hurt and bleed it will be dangerous to others".*

Another respondent is male respondent. He has almost 20 years working experience in the prison. He says that many things have changed in the prison included the disease. He states that it used to only skin ulcers and respiratory diseases which spreading among the inmates. Nowadays, many people are talking about HIV/AIDS in the prison. He is afraid that the disease will also spread in the prison.

This male respondent says that he get the information in counseling session about HIV/AIDS related issues in the last two months from the health workers. The respondent seems curious about the disease. He asks the researcher about what exactly the diseases, but the researcher says that the further information of the disease can be discussed later with the health workers in the prison.

One of the staff respondents explains that the responsibility of security staff will be increased when there are HIV positive inmates, since they will be ordered to increase their attention to those inmates.

The respondents also indicate that to those inmates who have drug offending cases, the attention is higher than to the inmates with regular crimes. This is due to this inmates are categorized as a high risk group of inmate for getting and spreading the HIV infection in the prison.

Another respondent is young female staff with four years working experience in the prison. She has been moved several times as part of the job rotations. She says that along time ago, when she worked as administrative staff she knew some of the HIV positive inmates due to her job to made administrative report for the prison.

One of the staffs' respondents is working as administrative staff. She mentions that in the health programs under her supervision she knows some of the HIV positive inmates. During the interview she answered questions fluently. She explains some of the situations related to HIV/AIDS in the prison:

*"I think it is a hard task to make people in the prison understand about HIV/AIDS that they will not feel afraid...along time ago, we had HIV positive inmate and some of the security staff asked for isolating that inmate, after a long discussion than we agreed that it was better to transfer the inmate to narcotic prison in the province, we hope the inmate will be given proper treatment and have a safe environment".*

The majority of staff respondent (three out of four) state it is better to transfer the HIV positive inmates to narcotic prison for security purposed and they also argue that those inmates will get better treatment.

All of the staff respondents state that working in the prison has increased their susceptibility of HIV. Three of the staff respondents are afraid of getting infected while working. As stated by female staff respondent:

*"I realized the possibility of getting the HIV infection while working in the prison is the same higher as those people who are working in the hospital. Everyday I stay in the inmates' room...I should pay attention to all the situations that might happen...sometimes I feel afraid but I convince myself that everything will be normal if I do not make something dangerous"*

Three respondents agree that HIV testing should be compulsory to all inmates. As one of the respondent said:

*"I think it is good to conduct compulsory HIV testing for all the inmates that we know an HIV inmate's status, we can protect ourselves from that disease by avoiding physical contact to hinder from blood,...if we know...maybe we can also give advice about how to deal with that disease to those HIV positive inmates and also give some information to other inmates about the disease, as our job...we need to create a conducive environment for all the prison population".*

However one of the respondents does not agree upon the notion of compulsory HIV testing for the inmates. She explains:

*"I think it will be difficult to conduct the compulsory HIV testing in prison...we don't have the budget for doing that test...if we have money is much better to use the money for other program, that the result more apparent such as constructing the prison building".*

When the researcher asks about the issues of confidentiality, she says that it is not necessary to know the status of others since HIV status is secret issue for other people.

In terms of the budget, health informant says that there is no specific budget for conducting HIV/AIDS programs in the prison. However, some of the NGO such as Global Fund collaborate with the Ministry for supporting HIV/AIDS programs in the prison through funding support.

#### **4.2.3. Health Worker Respondents**

The health respondents hold the opinion that it is not necessary to put HIV positive inmates in a separate room, except if the inmates have an opportunistic infection such as tuberculosis (TB). The patient with TB will be put in isolating room for two-four weeks.

One of the respondents says in the prison they usually conduct voluntary counseling and testing (VCT), as a process before the inmate take HIV testing. In the first time the inmates enter the prison, the health workers conduct health screening. The high risk inmates such as the inmates with drug offending case, particularly the ones who ever been used sharing needles, the health worker encourage the inmates to take VCT program. The health

workers in the prison have been trained as HIV/AIDS counselors by the Ministry since around 2007.

The respondents mention that standard sterilization of medical equipment for people living with HIV is the same as other patients. One of them says that the HIV positive inmates never been reported to have invasive treatment such as to treat the open wounded or for having the transfusion, moreover, in the prison there is no dentist which is usually need a lot of equipment for sterilized. In addition, the respondent says that when taking blood for HIV testing, his use one pair of hand gloves. Sometimes he still feel afraid of being contacted with contaminated blood, but he believes that universal precautions when deal with HIV patients is enough for guaranteeing his safety.

The health respondents state that the health workers agree to give HIV drugs once a week for assuring confidentiality of the patient. The roommate of the patients and the security staff will be aware if the patients come to the clinic everyday for taking the medicine. The HIV positive inmates usually come to the clinic in the afternoon, after the other inmates is examined. The health worker put the HIV medicine separately that nobody will see the medicine. There is no sign in the HIV positive inmate's health record paper. The health respondents say it is necessary to keep the HIV inmates status secretly, this is due to the respondents hold belief that some of the prison communities (inmates and staff members) are not prepare to deal with the HIV positive inmates.

The medicine is given by the HIV positive inmate's family to the health workers in the prison once a month. The medicine comes from the prescription of the doctor in the district hospital, since the inmate had been taken the drug before he entered the prison. The security staff in the front office is just acknowledging from information which is given by the inmate's family that the drugs are for lung disease treatment.

The health workers conducted HIV seminar for the staff prison that also involved others such as the health worker from health district and health workers from narcotic prison. The seminar conducted in order to give them some insight on HIV/AIDS issues. The program mainly is funded by the NGO. However, the health worker is worried about the continuity of the program. He says that to make people aware and understand about the issues need three-four times of seminar in a year.

One of the respondents also does not agree to some notion of giving HIV treatment is wasting resources e.g. time and money, especially when concerning the limitation of the resources in the prison. He explains:

*"HIV patients also need treatment...they are human, even in some severe cases like very lower CD4 count, the patients condition may improve...there are always some hope in treating the HIV patients, we should try our best don't let the patient notice the health worker desperate, it will decrease their moral".*

The respondents explain that some organization have been given support to HIV/AIDS' programs in the prison, however for some reason it is stopped. The respondent hope the situation in the prison will be improved in terms of increasing the number of health workers and other resource. Since only two of the health workers in the prison compared to around 630 inmates, they feel tired and also afraid might the quality and the quantity of the health service will be decreased and will be quite different like the ones in the district hospital.

One of the respondents says it is hard work as a health worker in the prison, they should face some limitations in resources for conducting the health programs, and sometimes they must manage to divide the resources such as the budget. He says as a health worker in the prison, they should capable become a manager besides as a doctor or nurse too. He admits that sometimes in a day more than 25 patient come to the clinic, if that happen he will postpone other health programs. He also mentions that since there are no facilities for examining the blood or sputum of the suspected TB patient, the nurse has to go to other facilities for several hours, and it is influencing other health program in the prison.

One of the example of situation related to health service in the prison is the inmates should wait for quite long time to be examined by the health workers and due to the space limitation sometimes the privacy of the inmates is neglected.

The health respondents say their knowledge of HIV/AIDS issues has improved in the prison. Since 2007 the health workers have been trained on seminar related to HIV/AIDS, it is conducted two-three times a year which sometimes is held by the Ministry of justice, the Ministry of Health, and sometimes from the NGO. One of the respondent also involved as active member in national NGO in HIV/AIDS-related activities that he says that it is very useful to get the knowledge and experience from that activities.

The respondents do not agree upon the idea of compulsory testing in prison. They argue that there is already a system or procedure before someone takes HIV test in the prison. Another concerned of the respondent is after the inmates is found HIV positive, the problem come up due to the funding for the follow up treatment of the HIV patients such as for checking CD 4 count in the laboratory. While in terms of the medication, he says that the HIV medication is given free by the government of Indonesia.

## V: DISCUSSION

First, the findings on some manifestations of the pre-existing stigma and HIV specific stigma among the respondents are discussed in this chapter.

The manifestations of pre-existing stigma on the gender and economic status show interesting figures. In terms of gender, majority of the respondents (10 out of 14) believe that both men and women may spread the disease to their spouse or to the general population. The finding is different from the literature which declares there is gender inequality in the community that women are to be blamed for spreading the disease (Parker and Aggleton, 2002). However, this finding can not represent the community's perspective due to the limitation number of the respondents.

Class or economic status of the HIV positive people is not considered as an issue by the respondents, as the finding indicates the majority of the respondents (10 out of 14) state rich and poor people have the same susceptibility to HIV infection. The finding is different with Parker, Eston, and Klein (2000) which explain that poverty increase susceptibility to HIV infection. However, the research finding is not representing the community's opinion due to the limitation number of the respondent.

The findings on the pre-existing stigma that link HIV to gender, sexuality, ethnic and race, economic status, illicit drugs, and inferiority as well as the finding of HIV specific stigma among some of the respondents that link HIV with the illness of immorality, imminent death, exaggerated sense of danger (USAID, 2006), and the metaphors such as HIV/AIDS as death, as horror, as punishment, as guilt, as crime, as shame, and as "otherness"; as well as a "junkie's diseases, will be enforcing emotional reaction based stigma and discriminatory behaviour in social interaction with HIV positive inmates in the prison as stated by UNAIDS(2005). These may indicate that the respondents still hold the incorrect beliefs, and lack of information or misinformation of HIV/AIDS issues, as stated by USAID (2006).

One of the examples is the female inmate respondent. She gets the incorrect information from her neighbour about HIV as a danger and considers the people living with HIV link to commercial sex worker. She also says that female sex workers as inferior in the community where she come from. Her beliefs is manifested in her interaction with the HIV positive inmate that she is avoiding everyday contact due to her fear of getting HIV infection by sharing at dress.

She thinks that the HIV positive inmates are different from her. Those inmates have a disease with attached negative label, which is caused by her belief of the pre-existing and the HIV specific stigma that make her shows the manifestations of HIV/AIDS-related stigma and discrimination in the prison.

Second, it is important to understand the condition and situation in the prison to understand the manifestations of HIV/AIDS-related stigma and discrimination as a social

process among the inmates in a community level and among the staff members and health workers in the institution level in the prison. There are some issues of condition and situation of prison communities are being concerned by the researcher that are discussed in this chapter.

In terms of space for living, the average space of living for each inmate is around 1 meter. Some of the inmates feel afraid of being contaminated with the blood from skin ulcers of the HIV positive inmates; they want to live in separated room with those inmates. This situation cannot be categorized as a manifestation of the stigma since the medical issues condition are very specific in this situation due to the limited space available for each inmate. This condition forces inmates to sleep close together without being able to prevent bodily contact. Some type of the skin infection which is common in the prison is scabies as it was observed that 10-15 scabies' patients visited the clinic in a day. Scabies infections may produce blood and may come into contact among the inmates in that room and thereby transfer the infection.

Moreover, the fact that inmates have no space to keep private belongings such as razor blades and tooth brushes makes some of them being worried about their safety related to HIV infection in case other inmates will use their personal equipment. This finding indicates that some inmates aware on the HIV transmission e.g. using contaminated razor blades.

The finding show that, some of the respondents who used to be involved in peer education programs show they are more aware on the issues related to HIV/AIDS. The female and male inmates used to train by the NGO. However, for some reason the NGO is not involved again in the HIV/AIDS training in the prison.

In terms of the prevention programs in the prison, although the number of the female inmates is less than two per cent of prison population (600 male inmates), some of the female inmates are involved in the peer education programs and the training session. That will raise the issues of HIV/AIDS in the prison from the perspective of the women themselves.

In the findings it can be seen that in terms of budget there is no specific budget for conducting HIV/AIDS programs in the prison. One of the respondents also mentions that it is better to allocate the budget for other activities. It could be men that HIV/AIDS is not seen as an important issue in the prison. To tackling the issues of budget, the Ministry has collaborated with the NGO to support the funding in HIV/AIDS related programs in prison. However, the project is situational. It is necessary also to allocate the specific budget for HIV/AIDS related programs from the Ministry, in order to assuring the continuity of the programs in the prison

Some of the inmates are worried to talk about some of the issues in the prison including HIV/AIDS issues. The respondents say in the prison people have a different condition and situation and it is better not to discuss individually that it may offend them. This may



indicate that in the prison community it might be appropriate to bring the HIV/AIDS issues in the group discussion which is facilitated by the prison staff. For some extent this situation will create safety situation for some of the prison communities, but sometimes the inmates show quite a hesitance for talking openly to the prison's staff. One of the possible solutions for creating open discussion is by involving the NGO in the prison as a facilitator for training or group discussion.

According to the findings 25 % of male inmates are related to drug offending cases. In the prison the education programme are mainly given to the inmates with drug offending case. To some extent the situation is effective that the education is given to the high risk group, as stated by NAC (2012). It is expected that the group is hindered from the HIV infection that in turns it will protect the prison communities from the infection. However, HIV/AIDS-related stigma may occur unintentionally since designed the policies and programs, this is related to some programs and policies make classification between the 'general population' and 'high-risk populations' (Parker and Aggleton, 2002). In this case, the other inmate will create negative label to the inmates who follow the education programme in HIV/AIDS, as a HIV positive inmates, in turns the other inmates will keep a distance to those inmate group and it begins the stigma and discrimination in the prison. The health workers argue that it is the effective ways in working in the limited resources in the prison.

The HIV positive inmate says he does not declare the HIV status to the security staff, he argues it is not important to disclose the status due to that fact that he never gets involved in everyday contact with the staff. However, one of the possible causes for this situation is that he is afraid that the staff member will perform manifestations of the stigma as they have power to do that in the prison.

One of the manifestations of the stigma and discrimination towards the HIV positive inmates in the prison is loss of role. As the inmates have productive role to involve in prison communities' activities. E.g. the HIV positive inmates are refused in working activities in the prison. The manifestation will cause the stigma in institutional level, as stated by UNAIDS (2005). One of the causes is some of the staff members still have incorrect belief related to HIV transmission, and another possible cause is the belief that HIV positive inmates are become incapacitated.

The inmate who declare his HIV status says that some of the inmates show some of the manifestations of the verbal stigma such as gossiping and nonverbal stigma such as avoiding everyday contact, as the manifestations of the stigma that categorized by UNAID (2010). Another manifestation of the stigma as categorized by Nyblade et al (2003) is isolation include physical and social isolation and verbal stigma such as voyeurism. Some of the inmates' respondents do not want to sharing room, food utensils, toilet, clothes, and refusing to attend social or religious ceremonies with the HIV positive inmates. He believes that they are afraid of making everyday contact due to his HIV status. The finding shows every Tuesday in the prison is conducted training on HIV/AIDS issues, but since the participants of the training mainly are the inmates related to drug offending case it may the

other inmate with different case are not involved in the training. As a result these inmates respondent still have limited incorrect knowledge on HIV transmission.

The power context among the inmates is the power to create stigmatizing and discriminatory situation. One of the examples from the finding is the HIV positive inmates with drug offending case usually perform their own group as a drug user group. Due to one third of the inmates is a drug offending case; this group relatively have power in the prison. The HIV positive inmates belong this group will get less or no manifestations of the stigma and discrimination than the HIV positive inmates from outside the group

One of the manifestations of the stigma in the prison is isolating the HIV positive inmates. The argument is for protecting other prison's communities from the HIV infection. However WHO (1987) has against the idea by stated that public health rationale to justify isolation based on the HIV status of the people is not right.

Another notion from the findings of the most staff respondents (three out of four) is transferring the HIV positive inmates to the narcotic prison; they argue that the inmates will have better treatment. However, it will cause stigma and discrimination, as stated by UNAIDS (2005). There is implication that prison communities (inmates and staff members) will have an idea that the HIV inmates must be related to illicit drug, this action will legitimize the stigma of pre-existing and the HIV specific stigma towards HIV positive inmates. This situation will also mean that the staff member still afraid to take care of HIV/AIDS inmates.

The notion of compulsory HIV testing for the inmates as a key population that have high risk to get the HIV infection will be manifested as the discrimination in the prison, as stated by USAID (2006) that obligatory HIV testing for the key population will cause loss of confidentiality and unequal application. That it is necessary to inform the prison communities that the idea of compulsory testing is incorrect.

In terms of the issue of confidentiality, the health worker says that it is not allowed to declare health status of the patient to others, except in certain condition such as patient requested.

The health workers mention that working in the prison is challenging. They should deal with the limited resources in the prison e.g. human resources, budget. The finding shows that only two of health workers have to work with around 630 inmates. They say the situations may be causing the low level of quantity and quality of health service in the prison. These situations are worrying since it may cause unintentional discrimination in terms of reduced health standard as well as performed negative attitudes by health workers due to overload of work (UNAIDS, 2005).

The health workers say that conducting HIV/AIDS programs in the prison is not easy due to the characteristics of the audiences are different. They should make restructuring the contents and create varieties of method when deliver the counselling that the audiences

will understand the issues much better. Regular program for increasing capacity building of the staff includes security staff members and health worker are important to build their knowledge and capabilities on the HIV/AIDS issues.

The health worker also holds the opinion that the inmates and the staff members are still not well informed about HIV/AIDS issues, as the training session only covered several inmates once a week and the quantity of training session for the staff is not adequate, once in the last three months. This situation makes he is afraid it may cause some manifestations of the stigma and discrimination toward the HIV positive inmates in the prison. In the situation of stigmatizing communities, this may not support the program of community organizing and community building that involving the HIV positive inmates for social change in response to the HIV/AIDS prevention and treatment in the prison e.g. challenging the stigma of the prison communities, involving the inmates in designing the HIV/AIDS programs. The greater involvement of HIV positive inmates in the programs may help to scale up the HIV/AIDS prevention and treatment programs by reducing the power of resistance in the prison.

The HIV positive inmates are asked to come to the clinic for taking the HIV medication every week in order to cover the HIV status of the patients. However, there are some implication for the patients that sometimes they may not come to take the medicine because of afraid others will know they status, this will decrease the adherence of the patients and may increase the possibilities of drug resistance.

Finally, in terms of the researcher's stigma towards the manifestations of HIV/AIDS-related stigma and discriminations in the prison, during the interview sometimes the researcher may unintentionally ask stigmatizing questions or declaring her opinions that may influence to the manifestations of HIV/AIDS-related stigma and discrimination of the respondents. The researcher also have been working in the prison for some period that make the researcher sometimes not aware on some manifestations of the stigma in the prison, as a result it could be assumed that undiscovered manifestations of the stigma in the community level among inmates and in the institutional level among the staff members and health workers in the prison have not been observed by the researcher.

## VI: CONCLUSION AND RECOMMENDATION

### 6.1. Conclusion

Some of the manifestations of the stigma and discrimination of the respondents are based on the incorrect belief and knowledge of the pre-existing and HIV specific stigma.

The manifestations of HIV/AIDS- related stigma and discrimination in the community level among the inmates are varied. Some of the inmates show the manifestation of verbal stigma such as gossiping, voyeurism; and non verbal stigma such as avoiding everyday contact, physical and social isolation.

The respondents feel that the HIV positive inmates are different from them; they have a disease that has an attached negative label. The respondents feel it is necessary to keep a distance from them. The stigma and the discrimination will occur in relation to the power contexts such as in the prison. Among the inmate, there is some inmate dominant group that have power to create stigmatizing and discriminatory condition in the prison.

It is important to understand the condition and situation in the prison to understand the manifestations of HIV/AIDS-related stigma and discrimination as a social process among the inmates in a community level and among the staff members and health workers in the institution level in the prison.

Some of the condition and situation in the prison such as limited space of living, no space for keeping the personal belonging, inmates prefer to move the HIV positive inmates with significant symptoms such as skin ulcers or TB to another room. These make the analysis of the stigma and discrimination in the prison context quite different. It should be differentiated between the manifestation of the stigma and the health issues e.g. personal hygiene.

In terms of the budget that the Ministry is not yet allocated the specific funding for HIV/AIDS programs in the prison. This may be considered that HIV/AIDS related issues are not important issue in the prison.

The health service situation in the prison with the limited resources e.g. limited space for examining patients, low number of health workers, no specific budget for conducting HIV/AIDS programs, will cause low quantity and quality of health service. However, in this context it can not be classified as the manifestations of the stigma and discrimination among the health worker in the prison.

Some of the manifestations of the stigma toward HIV positive inmates are the idea of isolating, refusing to involve the inmates in collective activities, transferring to narcotic prison. The idea of compulsory HIV testing for all inmates may cause the manifestation of the stigma and discrimination in institutional level. The manifestations of the stigma will be

occurred since the institution has a power to determine the inmates' condition and situation.

Some of the respondents show that they have knowledge on the HIV/AIDS-related issues; however, some of the respondents still perform incorrect beliefs and reactions that have been manifested in the stigma and discrimination toward the HIV positive inmates.

## 6.2. Recommendation

Based on the research findings and conclusion there are some recommendations which are instructed in the following.

With respect to policy development in The Ministry the following general points can be made:

- The existence of anti discriminatory policy from The Ministry that is supported by legal framework as an effort to tackle HIV/AIDS-related stigma and discrimination is needed to protect the rights of HIV positive inmates.
- The issues in terms of protection of confidentiality of HIV status, obligatory HIV testing, refusing in collective activities, transferring to another prison should be included in the designing of the policy.
- HIV/AIDS should be considered as an important issue by allocating the specific budget for HIV/AIDS programs in the prison.
- Increasing capacity building of the prison' staff to build knowledge on the HIV/AIDS-related issues in the prison.
- In the policy level the prevention programme should be made to foster tolerance and social solidarity among the inmates. While in terms of treatment the policy should assure the protection and safeguard of health care rights of the patients based on the principles of confidentiality and respect human rights.

With respect to the prevention and treatment HIV/AIDS programs in the prison, the following points can be made:

- The prevention programs should be made to challenge popular myths and stereotypes that prevent the manifestations of HIV/AIDS-related stigma and discrimination in the prison communities.
- The programs should be developing services and providing social support for encountering the incorrect beliefs stigma in the communities.
- Designing the programs that will not create the manifestation of the stigma among the communities
- The involvement of female inmates in every effort of the development of HIV prevention, treatment programs in the prison.
- Developing efforts to tackle the manifestations of the stigma and discrimination that HIV positive inmates is not difficult to open their HIV status. This secrecy causes them to limiting their social interaction and makes them difficult to fully involved in prevention and to access the treatment.
- Developing the network to create links between prison programs and community HIV prevention and services.

With respect to future research some of the issues needed to learn about:

- The manifestations of hidden and institutional of HIV/AIDS-related stigma and discrimination in the prison.
- The determinants factors of the manifestations of HIV/AIDS-related stigma and
- Discrimination and the factors for reducing the stigma and discrimination.
- The effect of the stigma for the HIV positive inmates in terms of prevention, treatment, care and support, and for the communities that the price the society should pay.

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## Annex 1. Questions

### **General questions for three group (inmate, staff, health worker) of the respondents:**

The characteristics of respondents: age, education, cases, length of sentence and length of served sentence of the inmate.

What are the perspectives towards HIV/AIDS-related stigma and discrimination linked to gender, sexuality, race/ethnics, class (economic status), illicit drug, and inferiority?

How is the HIV/AIDS associated with by the respondents?

How are the respondents' attitudes and behaviours toward HIV positive inmates?

How the environment or socio-culture in the prison is related to HIV/AIDS issues?

### **Specific for the inmate:**

What are the perceptions or experiences of HIV positive inmates in the prison?

What are the perceptions of prison communities (other inmates, staff members) toward HIV positive inmate?

### **Specific for staff member:**

What actions they should take toward HIV positive inmate?

Do the respondents ever see personally other staff members react in negative ways toward HIV positive inmates in the prison?

Do they agree to conduct compulsory testing in the prison? Why?

### **Specific for the Health worker:**

Do HIV positive inmates should be put in the separate room with other patient when they are sick?

What is the standard sterilization of medical equipment for HIV positive inmates?

How is the procedure to give HIV medicine to the HIV positive inmates in the prison?

Do the respondents feel hesitate or afraid to give invasive treatment towards HIV patients?

Do they agree to conduct compulsory testing in the prison? Why?

## Annex 2. Informed Consent Form

You are invited to participate in a research about Perceptions and Narratives on HIV/AIDS-related stigma and discrimination in the prison.

The research aims to provide insight of HIV/AIDS-related stigma and discrimination in the prison among inmates and related staff members. The research may contribute to the strengthening of HIV prevention and treatment policies and programs in response to HIV/AIDS in the prisons to the Ministry of Justice and Human Rights and prison authorities.

You selected as a possible participant in this study because you are the inmate or staff member of the prison. If you decide to participate in the research, we will conduct interview, it takes about 30-60 minute. You have rights to refuse answering the questions and to leave the interview at anytime.

Your name will not be recorded; your information and participation in this research will be treated confidentially. However, there is some possible risks may occur if someone understands your association to this research.

You will not receive any payment for participating in the research. You are free to leave this research at anytime. Should you choose to participate, you are free to change your decision at anytime and leave the research.

### Further Issues or Questions

If you have any question, please do not hesitate to contact the researcher. If you have any additional questions later, please contact Rita Komalasari at Ministry of Justice and Human Rights, Pangkalan Bun Prison in Central Borneo, Phone number: 081315825145, who will be happy to answer them. You will be offered a copy of this form to keep.

You are making a decision whether or not to participate. Your signature indicates that you have read the information provided above and have decided to participate. You may withdraw at any time without penalty or loss of benefits to which you may be entitled after signing this form should you choose to discontinue participation in this study.

Signature of Respondent and Signature Date