Life and death with HIV/AIDS: life stories from Karawang, West Java

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By way of introduction, I relate an event that affected my understanding of HIV/AIDS policy in Indonesia. It took place in Jakarta, in December 2006. I was attending the seminar ‘Cegah, Penularan dari Ibu ke Bayi’ (Stop Mother-to-Child Transmission), held to mark World AIDS Day. One of the speakers was the Head of the HIV/AIDS Sub-Directorate of the Ministry of Health, who was to address PMTCT policy in Indonesia. He began by stating that the HIV epidemic has been complicated by tuberculosis (TB) and injecting drug use, often resulting in the double infection of HIV and TB. In addition, perinatal transmission had now become a threat. He asked, ‘What is the effective way to prevent mother-to-child transmission risk?’ He then answered, ‘By not getting pregnant’. His statement struck me. Of course it did not represent official Indonesian PMTCT policy. Nevertheless, such ‘unstated policy’ (Singer and Castro 2004:xii) affects people’s lives.

Dear All,

Unlike RSCM [Cipto Mangunkusumo referral hospital] many other hospitals and doctors don't want to deliver surgery for PLHA in Indonesia.

The Indonesian national guideline is no use, because the local government has their own autonomy, this will open more space for Human Rights Violation. For example yesterday there was one PLHA who just got turned down to have a surgery. What should he do now? Is there still a doctor who works for humanity in Indonesia?

Sincerely,
Donny (27 June 2007)

These two examples reveal the gap between codified policy and practice. The second quote points to the unmet needs and rights of HIV-positive people due to stigma, fear, and denial among
healthcare providers – issues which will be discussed further in Chapter 5. As will be seen below, the implementation of HIV/AIDS policy in Indonesia is hampered by inconsistency between levels, problems of decentralization, and the personal views of government officials.

The epidemic in numbers

The HIV/AIDS epidemic in Indonesia is now in its third decade. In 2006, when I began fieldwork, the country was home to an estimated 193,000 PLWHA. The first case of AIDS was officially recognized in Indonesia in 1987. HIV spread slowly in the following years, with the government relying on passive surveillance and a case reporting system. As Figure 2.1 shows, the cumulative number of reported HIV/AIDS cases was around 2,500 at the end of 2001, while neighboring Malaysia, with a much smaller population, reported more than 40,000 cases in the same year.³ By the end of 2006, Indonesia counted 13,424 cumulative cases, compared to 76,389 in Malaysia.⁴ Many NGOs fear that the numbers for Indonesia are only the tip of the iceberg.

Until 1999, more than 80% of HIV/AIDS cases were sexually transmitted. Since 2000, transmission through injecting drug use has been rising rapidly, representing 2.4% of all reported HIV infections in 1999, 15.6% in 2000, and 38.9% in 2005.⁵ There were an estimated 190,000 to 247,000 injecting drug users (IDUs) at the end of 2006, many of them youths (Departemen Kesehatan 2007:29). The sharing of unsterilized needles among them has resulted in the rapid spread not only of HIV but of Hepatitis C. The testing of IDUs treated at drug rehabilitation centers in Jakarta has revealed extremely high HIV prevalence (45-48% in 2001).

³ Malaysia combines passive and active HIV surveillance through sentinel surveillance and routine screening activities. HIV screening is conducted among both high and low risk groups (UNGASS Country Progress Report Malaysia Reporting Period: January 2006-December 2007).
⁵ I collated data from the statistics of HIV/AIDS cases released every year by the Directorate General of CDC & EH, Ministry of Health. These reports were downloaded from http://www.aids-ina.org.
With the prevalence rate among sentinel groups (i.e. female and transgender sex workers) surpassing 5% in 2000, the World Health Organization re-categorized Indonesia as entering the ‘concentrated’ stage of the epidemic. Sentinel surveillance results and studies of vulnerable groups suggested that between 90,000 and 130,000 individuals had contracted HIV by 2002 – a quarter of them women (Riono and Janzant 2004:79).

The 2007 national estimate based on available data indicates that there are between 164,000 and 278,000 active female sex workers in Indonesia, and that their male clients number between 6.9 and 9.6 million (Departemen Kesehatan 2007:32). The 2007 Integrated Biological and Behavioral Surveillance reported HIV prevalence among female sex workers to be 10.4%, and among transgender sex workers, 24.4% (Departemen Kesehatan 2009: 38).

The number of infected women who are not sex workers is also increasing. Women accounted for almost 17% of all reported AIDS cases in the country in 2006, and 25.8% by the end of 2009 (National AIDS Commission Republic of Indonesia 2009:26).
Overlapping behavioral risks allow HIV to spread across groups. The high prevalence rate among IDUs entails increased risks for their partners and children. The bridge between female sex workers, their male clients, and the latter’s female partners is clear. Many male clients of waria also have female partners. Men who have sex with men (MSM) are another route of transmission to the general population, for homosexual men and male sex workers are also likely to have female sexual partners. Figure 2.2 depicts in simple terms the possible risks of HIV transmission between at-risk sub-populations.

Figure 2.2. Potential mechanisms for the sexual transmission of HIV

Source: Adapted from Riono and Jazant (2004:90)
Of the reported 13,424 HIV/AIDS cases in Indonesia at the end of 2006, 1.7% were among 15-19 year olds; 33.4% were among 20-29 year olds; 16.6% of cases were among 30-39 year olds; and 4.8% of cases were among 40-49 year olds.

Nationally, West Java province ranks third in cumulative HIV/AIDS cases after DKI Jakarta and Papua province: 940 by the end of 2006. In December 2006, Karawang district, with a population of 1.9 million, recorded 123 cases, the third highest in West Java province (Radar Karawang 2 December 2006). But national estimates suggest that the real figure was closer to 730 cases (Departemen Kesehatan RI 2007). In general, statistical reporting in Indonesia must be treated with caution. There are always discrepancies between government institutions. At the district level, local health offices often have difficulties collecting data due to late reporting, lack of coordination between sectors, and inaccuracy in recording.

Crisovan (2006) has argued that the relatively low number of women with HIV in Indonesia suggests that Indonesian women are either at lower risk of HIV than women in other parts of the world, or that they are not testing for HIV due to lack of knowledge, lack of empowerment (ibid. 2006:94), or lack of access to services. My study found that many HIV-positive women learnt their serostatus during antenatal care, just before giving birth, when their children became severely ill with HIV-related illnesses, or when their husbands/partners suffered severe opportunistic infections. Most women were infected by husbands who were IDUs and/or engaging in unsafe sex without their knowledge.

History of HIV/AIDS policy in Indonesia

This section describes the evolution of HIV/AIDS policy in Indonesia, and its constraints and gaps in practice. In contemporary societies, policy impinges on all areas of life so that it is virtually impossible to ignore or escape its influence. Policy increasingly shapes the way individuals construct themselves as subjects (Shore and Wright 1997:4). For anthropologists, policy can be considered a cultural phenomenon incorporating social processes and human action on different levels – local, national, and global – entailing power
relations between actors, institutions, and discourses across time and space (Shore and Wright 1997:14). Previous anthropological studies of HIV/AIDS in Indonesia, however, have often skirted the effects of policy on broader society – though they do outline the policy implications of their studies (Kroeger 2000; Crisovan 2006).

The following sub-sections present the history of HIV/AIDS policy in Indonesia, which can be divided into three periods: the period preceding the first National Strategy (1985-1993); the period of the first National Strategy (1994-2002); and the period of the second National Strategy (2003-2007). While my analysis focuses on policy up to 2007, many of the issues remain relevant today.

Prior to the first National Strategy, 1985-1993

Indonesia’s response to the epidemic precedes the first identified case of HIV in the country. In 1985 the Ministry of Health (MOH) created a working group to monitor the development of the epidemic in Southeast Asia and the world, and to gather epidemiological information. This working group was later expanded to involve other ministries as well as NGOs. After the first case of AIDS was reported in Bali in 1987, the MOH released a new regulation stating that reporting AIDS cases was obligatory for all health services. Laboratories were appointed for HIV testing. In 1987, the MOH formed the Komisi Penanggulangan AIDS (hereafter KPA) or National AIDS Commission, chaired by the Directorate General of Communicable Disease Control and Environmental Health (CDC & EH). Following this, the KPA developed the Short and Medium Term Guideline for AIDS (1988/89-1991). In June 1988, the Directorate General of the CDC & EH issued a guideline for reporting people with AIDS-related symptoms, including their identity.

In the early 1990s, the surveillance of certain sub-populations – e.g. sex workers – and the screening of blood donors revealed that HIV was spreading to provinces with previously very low prevalence.

\footnote{In line with decentralization after the fall of the New Order regime, KPA was also established at the provincial and district levels, which were called KPAD (Komisi Penanggulangan AIDS Daerah).}
The surveillance of sex workers\(^7\) took place without proper counseling. When individuals were found to be HIV-positive, they were immediately isolated in hospitals; the mass media sensationalized the news in stigmatizing ways (Latuihamallo 1994). In response, NGOs began developing IEC (information, education, and communication) materials on HIV/AIDS to raise public awareness about the rights of PLWHA. Several NGOs focusing on HIV/AIDS were founded in this era (Komisi Penanggulangan AIDS Nasional 2003:4). The epidemic in Indonesia now entered its exponential stage, with 18 reported cases in 1991, 36 cases in 1992, and 187 cases in 1993 (found in 11 provinces) (Kompas 10 April 1994).

Prior to 1994, HIV/AIDS was a distant reality for the Indonesian government and society alike. The first AIDS case\(^8\) formally recognized by the government was a foreign tourist in Bali in 1987, which generated the image of AIDS as a ‘foreigner’s disease’.

The Indonesian government’s initial response to combat HIV/AIDS – from the Ministry of Health, especially its Directorate of Communicable Disease – appeared in 1987 following the unveiling of the WHO’s Global AIDS Strategy. The latter outlined the objectives of local, national, and international action to prevent and control HIV/AIDS, and the need for all countries to work towards supportive and non-discriminatory social environments. This international context as well as the growing number of cases inside Indonesia convinced policy-makers that something had to be done.

In February 1994, the government decided that foreigners working in Indonesia would need a certificate declaring them to be free of HIV/AIDS. The number of AIDS cases among foreigners was (perceived to be) higher than among Indonesians (Kompas 19 February 1994). Protests came from some NGOs but many other groups supported the policy. It clearly showcased the government’s confusion in dealing with the new ‘disorder’.

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\(^7\) Surveillance targeted female sex workers, though there are also waria (transgender) and male sex workers. Starting in 2004, a behavioral surveillance survey was also conducted for waria and male sex workers.

\(^8\) According to Zubairi Djoerban, one of the first physicians to study HIV/AIDS and founder of the Pelita Ilmu Foundation, the first AIDS case in Indonesia was actually discovered in 1985, a 25 year old mother of three children who very likely was infected with HIV through a blood transfusion (Djoerban 1999:21).
The first National Strategy, 1994-2002

In the midst of this haziness about how to deal with the epidemic, Indonesia adopted its first National Strategy for HIV/AIDS. Presidential Decree no. 36 on the National AIDS Commission was issued on 30 May 1994; it was followed on 16 June by Ministerial Decree no. 9 on the National Strategy for HIV/AIDS Control. The latter was intended as a guideline for all government ministries, local governments, NGOs, and the private sector. The basic principles of the national strategy were:

1. Partnerships between government, NGOs, and society, the latter being the main actor with government support;
2. All efforts to fight HIV/AIDS must reflect religious and cultural values, maintaining and strengthening family welfare;
3. HIV/AIDS prevention must aim to change high risk behavior;
4. Everybody has the right to obtain proper information to protect him/herself and other people from infection;
5. All policies and programs must respect the dignity of PLWHA and their families;
6. Informed consent and confidentiality in HIV/AIDS testing;
7. All regulations at every level must be consistent with the National Strategy;
8. Health service providers must not discriminate against PLWHA.

The above principles clearly show that the government, at least on paper, embraced a rights-based approach to control the epidemic. But more than anything else, this reflected the influence of a handful of NGOs. The National Strategy outlined the scope of the response, consisting of IEC, prevention, testing and counseling, treatment, services and care, research, and monitoring and evaluation. It further discussed the role and responsibility of government and society, highlighted the need for international cooperation, and addressed issues of funding.

As is well known, the Soeharto regime was authoritarian in the implementation of its development programs. The first National Workshop on AIDS was held in August 1994 to draft a Plan of Action. The Five Year Plan for 1995-2000 was immediately questioned by NGOs for its inconsistencies in basic principles. The government, for instance, designated a single gatekeeper to oversee both funds from abroad and internal resources, which NGOs
perceived to be inconsistent with the partnership principle (Kompas 8 September 1994).

The KPA was charged with coordinating the HIV/AIDS control program, both nationally and locally. The Coordinating Ministry of People’s Welfare, aided by several other ministries, headed the KPA. To implement Presidential Decree no. 36, the Department of Internal Affairs issued a Circular Letter in July 1994 instructing all provincial governments to issue monthly reports on their local HIV/AIDS situation. Concerned that this could lead to the identity-tracing of PLWHA, some NGOs and members of parliament questioned the policy (Kompas 26 August 1994).

Implementation of the National Strategy progressed slowly in the period 1994-2002. The only department that seemed serious about dealing with HIV/AIDS was the Ministry of Health, while other ministries played only minor roles. The Ministry of National Education, for instance, was only in the planning stages for including HIV/AIDS in elementary and secondary school curricula.

As of now there is no special program for PLWHA. In our planning, perhaps in the budget for next year there will be training for PLWHA. Dinsos (Dinas Sosial or Social Affairs Office) is usually only doing HIV/AIDS campaigns for the public (Dinas Sosial officer, August 2006).

The lackluster performance of the KPA at both central and local levels can be attributed to its lack of human resources and commitment. It was thus up to NGOs and international donors to tackle the problems – from HIV testing to ARV therapy to PMTCT – in many parts of the country. As a staff member at the district health office commented:

Though HIV/AIDS is before our eyes, threatening... it does not make them prioritize it. The priority is still routine works from Bupati (District Head).... Ideally, KPAD is for those who really care, have concern, are committed.... As of

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10 KPAD is Komisi Penanggulangan AIDS Daerah or Local AIDS Commission.
now, KPAD will work if there is a budget.... They do activities only to spend the budget. For example, undertaking meetings for socialization with more than 100 million rupiah (US$ 11,000). I think it’s just a waste of money but no result... no action that touches the issue... (Staff of Dinkes\textsuperscript{11} Karawang, September 2006).


The slow government response can be seen in the availability of medicines for HIV/AIDS patients. The Directorate General of Food and Drugs could not keep up with the rapid development of medicines for opportunistic infections; each new drug had to be registered before being made available in pharmacies and drug stores. Up to the end of 1995, only Zidovudine\textsuperscript{12} was available in pharmacies, while others (e.g. Didanosine, Lamivudine, or Zalcitabine\textsuperscript{13}) had to be obtained from multinational companies. The Pokdisus AIDS (Kelompok Studi Khusus AIDS or Special Study Group on AIDS) at the University of Indonesia’s Faculty of Medicine thus worked with international NGOs to make these medicines available in their clinic, though the cost was still high (Kompas 15 December 1995). At the local level, many Local AIDS Commissions remained inoperative due to the lack of human resources and funds. Most had neither organizational structure nor programs, and paid no attention to HIV/AIDS issues (Kompas 2 August 2001).

Despite the stigma surrounding HIV/AIDS, a number of Muslim leaders joined in the efforts to stem the epidemic. The

\textsuperscript{11} Dinkes is Dinas Kesehatan or Health Office at the provincial/district level.
\textsuperscript{12} Zidovudine is a drug used for antiretroviral therapy, the first approved to treat HIV. Taking zidovudine with other ARV drugs reduces one’s viral load to extremely low levels and increases one’s CD4 counts (http://www.aidsinfonet.org/fact_sheets/view/411) accessed on August 2, 2011.
\textsuperscript{13} Didanosine, Lamivudine, or Zalcitabine are drugs used in ARV therapy, with similar functions as Zidovudine.
Indonesian Ulama Council\textsuperscript{14} (\textit{Majelis Ulama Indonesia}) met to discuss HIV/AIDS issues, including condom use. The Council agreed that persons who are single and HIV-positive must abstain from sex, while those who are HIV-positive and married to an HIV-negative partner should disclose their status and use condoms.

With prevalence in certain risk groups exceeding 5\% (see Chapter 3), the WHO in 2000 declared the epidemic in Indonesia to be at a concentrated stage. Prevalence among female sex workers in Riau, West Java, and Papua was 6.4\%, 5.5\%, and 24.5\% respectively, while a significant increase among IDUs showed that the means of infection had shifted from sexual intercourse to drug use. The Department of Health at the end of 2002 estimated that the number of IDUs in the country was between 124,000 and 169,000 (Riono and Jazant 2004:79).

As the number of infected people increased dramatically, the government declared the \textit{Gerakan Nasional Penanggulangan HIV/AIDS} or National Movement to Fight HIV/AIDS in April 2002. The KPA was revitalized by involving more stakeholders, including NGOs, researchers, experts, and civil society organizations. The MOH now estimated that between 90,000 and 130,000 Indonesians were infected with HIV (Kompas 24 April 2002).

In this period, we see government emphasis on prevention through IEC (information, education, and communication) for certain high risk groups. Such materials usually focused on the ABC\textsuperscript{15} approach – avoiding premarital sex, enhancing family resilience, and religiosity. Condom use campaigns primarily targeted female sex workers and their clients as well as other risk groups such as seafarers and truck drivers. But the focus remained on female sex workers. The government’s approach also reflected gender bias: the term used for prostitute in the first National Strategy was \textit{wanita tuna susila} (or WTS), literally ‘amoral woman’. HIV/AIDS was very much ascribed to them.

\textsuperscript{14} Ulama are Muslim scholars, the plural form of the word \textit{alim}, which means the learned one.

\textsuperscript{15} ABC stands for Abstinence, Be faithful, and Condom use – a global approach to prevent the spread of HIV.
The first National Strategy (1994-2002) gave lip service to human rights, democratization, and civil society. Policy papers routinely mentioned the necessity of including diverse participants to reach all layers of society: individuals, groups, social organizations, the private sector, and international institutions. But little happened in practice.

The Special ASEAN Summit on HIV/AIDS in June 2001 declared the fight against the epidemic a priority. On the world stage, the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS adopted the declaration ‘Global Crisis–Global Action’, re-emphasizing the commitment of UN member states to fight the epidemic, to enhance collaboration between them, and to fundraise globally (Kompas 7 July 2001). Indonesia signed the UNGASS Declaration in June 2001, thereby committing itself to implementing its recommendations. The declaration stated that strong leadership...
at all levels of society was essential, and called for the active participation of civil society as well as the private sector.


The rapidly changing epidemiological situation required revision of the original National Strategy, leading to the formulation of the second National Strategy on HIV/AIDS for 2003-2007. Indonesia also supported policies and international statements on HIV/AIDS including the UNGASS ‘Declaration of Commitment’ which resolved that, by 2003, regulations and other provisions should be ratified to eliminate all forms of discrimination and confirm the basic human rights and freedoms of PLWHA and members of other vulnerable groups.

In the 2006 Country Report on the follow-up to the UNGASS Declaration of Commitment on HIV/AIDS, the Indonesian government reported:

Indonesia is stepping up the response to the epidemic. In 2004, the government allocated US$ 13 million, a 106% increase over the HIV/AIDS budget for 2003.... The National AIDS Commission was reorganized and strengthened. Twelve ministries and local governments have translated the National Strategy into strategic plans and annual work programs.

The Ministry of Health is taking steps to revive the national sentinel surveillance program which had not functioned properly since administrative decentralization was introduced in 2001. Most high prevalence provinces now also have reliable estimates of the number of people at high risk who are living with HIV/AIDS. A unified monitoring system, AIDS Info (the HIV/AIDS Joint Database), was launched in October 2005. The information within AIDS Info will eventually cover all HIV/AIDS programs in Indonesia as well as HIV/AIDS data that is updated on a monthly basis, HIV estimates, HIV prevalence and behavioral surveillance data.

However, there are not enough people at risk being reached by prevention programs (less than 10%), and too few have access to VCT (18% of IDUs and 14% of sex workers). Among vulnerable groups, knowledge about HIV/AIDS is improving, but it is still inadequate: just 43% of men who have sex with men and 24% of female sex
workers could correctly identify ways of preventing sexual transmission of HIV... (National AIDS Commission 2006:7).

The ‘Sentani’ Commitment’ serves as Indonesia’s overarching vision for addressing the epidemic. The statement was adopted on 9 January 2004 during a meeting between the Coordinating Minister for People’s Welfare and ministers and provincial leaders from the six provinces most affected by HIV/AIDS. It established seven objectives:

1. Promoting condom use in every high risk sexual activity;
2. Preventing HIV among IDUs;
3. Providing antiretroviral therapy to at least 5,000 PLWHA by the end of 2004;
4. Reducing the stigmatization and discrimination of PLWHA;
5. Establishing and empowering provincial/city/district AIDS commissions;
6. Developing laws and regulations conducive to HIV prevention, care, and support programs;
7. Scaling up efforts for information, education, and communication.

Like UNGASS, the Sentani Commitment was not a legally binding document.

The second National Strategy of 2003-2007 added some new principles, namely gender equality and equity, harm reduction for IDUs, condom use as dual protection, and HIV/AIDS as a social problem. The strategy outlined seven priority areas: 1) prevention; 2) care, treatment, and support for PLWHA; 3) HIV and sexually transmitted infection surveillance; 4) operational studies and research; 5) creating an enabling environment; 6) multi-stakeholder coordination; and 7) sustainable response.

The second National Strategy recognized that ‘infection-risk groups are groups of people who are linked to high-risk behavior, such as sex sellers [penjaja seks, a more neutral term than the previous WTS] and their clients, IDUs, and people detained in correctional centers’ (Komisi Penanggulangan AIDS Nasional 2003:10). It also stated:

16 Sentani is the capital city of Jayapura District, Papua Province. It is located about 45 km from the provincial capital, Jayapura.
17 Condoms as dual protection means they can be used against HIV infection as well as pregnancy.
Vulnerable groups are groups of people who, because of the nature of their work, their environment, low level of family support and welfare, or health status, are vulnerable to HIV. These groups may include highly mobile people, women, youth, street children, poor people, pregnant women, and blood transfusion recipients (ibid.).

In accordance with the Sentani Commitment, the KPA launched a national program – the Acceleration of Comprehensive HIV/AIDS Response – in 100 districts/cities in 21 provinces in 2005. Each district/city was to provide a minimum standard of service based on its specific problems. The minimum standard was defined as follows:

- Behavioral change communication, including promotion of the condom use program;
- Prevention of HIV/AIDS through combating STIs;
- Prevention of HIV/AIDS among IDUs;
- VCT services;
- Care, support, and treatment;
- PMTCT services;
- Public communication about HIV/AIDS.

The second National Strategy also endorsed measures for improving PMTCT, noting that ‘use of ARV during pregnancy, safe delivery, and the use of breast milk substitutes can all help to prevent MTCT’ (Komisi Penanggulangan AIDS Nasional 2003:12). It also called for improving infrastructure for health services, VCT, PMTCT, care of PLWHA, and home-based care (ibid.). In August 2006, the National Guidelines on PMTCT were released by the Directorate of Family Health within the MOH. It clearly emphasized the rights of HIV-positive women to reproductive health: the latter must have access to health services offering various (reproductive) choices such as ARV treatment, normal delivery, caesarian delivery, and contraceptives – but not abortion, which remained an illegal (though ambiguous) practice. The statement in the guideline is as follows:

It would be better if HIV-positive women are not forced or advised not to get pregnant or to terminate their pregnancy (abortion). They must obtain accurate information about HIV transmission risk to the baby, so they can make up their mind after consultation with their husbands and families (Departemen Kesehatan RI 2006:22).
International funding agencies have been central in the development of Indonesia’s HIV/AIDS control program. In 2002, Indonesia became a recipient of the Global Fund, which then appointed the Ministry of Health as the principal recipient to coordinate the funds for the six identified priority provinces. A number of NGOs were designated sub-recipients, allowing them to strengthen and expand their activities. Two other bilateral agencies, AusAID and USAID, were involved through two implementing organizations, IHPCP (Indonesia HIV/AIDS Prevention and Care Project) and FHI (Family Health International) respectively. These two agencies influenced government policy and programs both nationally and locally, conducting research, surveillance, interventions, and advocacy in several high prevalence provinces. The main focus was on high risk populations such as sex workers, MSM, IDUs, and more recently, prisoners. In Karawang district, FHI collaborated with Dinkes (Dinas Kesehatan or Health Office) to conduct interventions among female sex workers, and with local NGOs to undertake harm reduction programs for IDUs, prisoners, and MSM.

International agencies such as the WHO, UNDP, UNICEF, ILO, UNESCO, and UNFPA\(^\text{18}\) also addressed HIV/AIDS issues in their programs. For instance, the ILO encouraged prevention programs for migrant workers and in workplaces, while the UNFPA supported a prevention program for adolescents in and out of school. The Global Fund in 2003 put its weight behind a PMTCT pilot project in Jakarta through its collaboration with the NGO YPI, while UNICEF in ensuing years pushed the Ministry of Health to address PMTCT by providing training and undertaking rapid assessments in several provinces. UNICEF was also involved in the formulation of the National Guidelines on PMTCT.

Indonesia’s HIV/AIDS policy has evolved since its initial impulse to blame foreigners in the country. Due to the influence of NGOs, the first National Strategy (1994-2002) embraced a rights-based approach to control the epidemic, though implementation was hampered by conflicting interpretations among government agencies.

institutions. Implementation lagged behind until early in the twenty-first century, when the number of HIV/AIDS cases skyrocketed. The second National Strategy (2003-2007) therefore aimed to establish a more comprehensive approach to fight the epidemic, with strong support from international donors (Komisi Penanggulangan AIDS Nasional 2003).

**Socio-cultural context of policy**

Understanding how health policies change – or do not change – requires analysis of the context in which policies are made and implemented (Buse, Mays, and Walt 2005:11). Policy-making and implementation were heavily influenced by the Indonesian socio-cultural context, including the country’s bureaucratic culture. This section outlines the political, religious, and moral factors that have affected HIV/AIDS policy in practice.

**Democratization**

The New Order regime was authoritarian and centralized. Public policies were initiated by the central government, mostly by President Soeharto himself. Hence there could be no comprehensive policy on HIV/AIDS until Soeharto himself gave orders to tackle the epidemic. Yet, given the nature of Indonesian bureaucracy, cooperation between different departments was difficult; each had its own agenda. The KPA needed inter-departmental coordination but this was difficult to achieve, as can be seen from its less than impressive performance in implementing the first National Strategy for HIV/AIDS. The head of the Planning Division of the Health Office (*Dinkes*) in Karawang stated in an interview:

Sector egocentrism at *Dinkes* is high. Therefore, compared with dengue fever, diarrhea, bird flu, etc., it is difficult to do advocacy for HIV issues. The emphasis is still on curative rather than preventive [interventions]. In addition, [there is] lack of leadership in determining the priority of *Dinkes* programs.
Though the first National Strategy seemed progressive and innovative, critics conjectured that this was only on paper. In practice, the government was more swayed by moral and religious ideas that Islamic nations do not engage in HIV/AIDS-related risky behavior (Kroeger 2000). Fortunately, NGOs – the Kusuma Buana Foundation, the Pelita Ilmu Foundation and the Mitra Indonesia Foundation to name a few – were able to continue their prevention efforts, even though the government often perceived them as ‘opposition’ parties. Physicians from Pokdisus AIDS at the University of Indonesia were also available to explain prevention and treatment methods to civil society groups. These NGOs worked to meet the needs of PLWHA and spread awareness of HIV/AIDS among the general population.

The downfall of the Soeharto regime in May 1998 altered the political landscape. The new government espoused political democratization and decentralization; especially the latter gave significant powers to local governments to pursue their own policy agendas. ‘Less state’, however, did not automatically imply ‘more democracy’ (Schulte-Nordholt 2003:580). Moves towards democratization coexisted with continuities from the old regime.

The 1999 presidential elections brought Abdurrahman Wahid – a prominent figure from Indonesia’s largest Muslim organization – to power. A moderate Muslim democrat, his administration encouraged civil society organizations to work as partners and watchdogs of government. The number of NGOs working on HIV/AIDS issues now grew, their activities encompassing prevention, testing, care, support, treatment, and advocacy. Wahid was impeached in mid-2001 and replaced by his vice president, Megawati Soekarnoputri, the first woman to become president of Indonesia.

The new policy of decentralization entered into effect in January 2001. Managerial and financial responsibility for public healthcare, previously with the central government, now devolved to the districts. Healthcare became increasingly privatized. Kristiansen and Santoso (2006) have argued that local healthcare services’ lack of transparency and accountability turned them into for-profit enterprises, while the greater role of the private sector has shifted attention away from preventive healthcare and the health concerns of poor people.
Given the rapid pace of decentralization, national, provincial, and district officials often lacked clarity on their policy-making authority as well as on how local efforts should be funded and implemented. Nevertheless, provinces and municipalities issued their own regulations (Peraturan Daerah), decrees (Surat Keputusan), and strategies to combat HIV/AIDS. East Java and Riau provinces passed provincial regulations, while a district head (bupati) in Riau decreed condom use and routine check-ups for at-risk groups. Two districts in East Java – Banyuwangi and Malang – passed local regulations in 2007 and 2008 respectively; three districts in Papua – Maumere, Merauke and Jayapura – already did so in 2003.

Though Karawang has – as yet – no local regulations on HIV/AIDS, its government has cooperated with an international NGO to establish an HIV/AIDS health service. As a staff member of the local Aids Control Counsel stated:

There is a KITA\textsuperscript{19} clinic, an information clinic on AIDS. I was suggesting at that time [that there should be] information and therapy in the AIDS clinic. It’s collaboration between Dinkes and FHI, there is funding support (KPAD staff).

In a meeting attended by Pantura Plus and Karawang district officials on 1 September 2006, the Vice-District Head agreed to take steps to meet the needs of PLWHA.

We are going to discuss this problem in the next few days. Mr. Sumantri is suggesting that we write a letter to RSUD\textsuperscript{20} to provide a medicines service, so you don’t have to go to Jakarta. We will try… hopefully we can meet your expectations (Mrs. Eli, Vice-District Head).

If possible, tomorrow we write a letter to Bupati [District Head]. With these data Bupati can give orders to RSUD to fulfill the needs of friends here… KPAD has authority to do that… RSUD has been trained, but still there is hesitation or maybe lack of commitment… (Vice-Head of KPAD).

\textsuperscript{19} KITA stands for Klinik Informasi tentang AIDS or AIDS Information Clinic, which is located at the Puskesmas Karawang.

\textsuperscript{20} RSUD is Rumah Sakit Umum Daerah or Provincial/District Public Hospital.
In this ‘more democratic’ political landscape, NGOs are important advocates of public policy. Pantura Plus organizes meetings and workshops with local civil servants to keep HIV/AIDS on the agenda. It also approaches individual government officials who are concerned about HIV/AIDS, involving them in its activities.

This informal approach is often quite effective in bolstering local government support for HIV/AIDS programs. In an interview in early October 2006, a local health official showed me the *Dinkes* Karawang budget for 2007, which included budgets for HIV testing, CD4 testing, and medicines. While he was the Head of the Planning Division, he often voluntarily helped Pantura Plus to provide health services to PLWHA. Good personal relationships between NGOs and local officials can affect local policy on HIV/AIDS.

*Religion, morality, and the ‘safety of marriage’*

Indonesia is the largest Muslim country in the world. Though Islam is not the state religion, about 90% of Indonesia’s citizens are registered as Muslim. This means that Islamic views on various aspects of life have a strong influence on state policy. For instance, regarding the husband-wife relationship, Marriage Law no. 1/1974 states:

**Article 31**

1. The rights and status of the wife are equal to those of the husband in the household and the community.
2. Each party is entitled to pursue legal action.
3. The husband is the head of the family and the wife is the housewife.

**Article 34**

1. The husband has an obligation to protect his wife and provides for the household based on his ability.
2. The wife is responsible for taking good care of the household.
3. Should the husband or wife neglect his/her obligations, each can petition the court.
We see that husbands as household heads, breadwinners and protectors have higher status than their wives, who must respect and serve their husbands and attend to domestic work. The law also allows for polygamy within the limits set by Islamic conservatives (Katjasungkana and Wieringa 2003). Unequal gender roles are thus reinforced by the state.

The HIV/AIDS epidemic in Indonesia is colored by Islamic views on gender, sexuality, and disease. Until very recently, those infected with HIV were perceived as depraved individuals. Two recent studies in Indonesia have confirmed that the dominant discourse on HIV/AIDS blamed two main groups: white male foreigners and female sex workers. Even the latter often avoided foreign clients (Kroeger 2003; Crisovan 2006). The mass media played a key role in the construction of HIV/AIDS in society: it was a ‘foreigner’s disease’ and a ‘homosexual disease’. When two female Indonesian sex workers were found to be HIV-positive in November 1991, this caused a media sensation. Since then, HIV/AIDS has also been seen as a ‘prostitute’s disease’ (Sciortino 1999:197-223). Being HIV-positive in Indonesia means being an immoral, sinful, and accursed individual. HIV/AIDS is a disease of the ‘other’.

The common perception is that HIV is transmitted through ‘free sex’. Crisovan (2006), who conducted research in Yogyakarta, uses an example to illustrate this. There are four people who have tested negative for HIV and are engaging in ‘free sex’, but only within their circle. Crisovan asked 20 students and five professors if any of them will contract the disease. All answered, ‘Yes’. Crisovan continued by asking, ‘How?’ Most of the replies mentioned ‘free sex’, God/Allah, and/or showed a complete lack of understanding of transmission routes (ibid.:154).

The image of HIV/AIDS as a fearful disease is evident in government and some NGO educational materials for prevention, which employ images of human skulls, coffins, ghosts, etc. This was particularly true in the 1990s. Quite apart from the debate over whether such fear campaigns actually work, they reflected the prevailing social construction of HIV/AIDS in Indonesia.

Social attitudes towards sensitive and controversial issues became more liberal in the reform era, regarding for example

21 Among Indonesians, the common term is seks bebas – literally translated as free sex. It refers to promiscuous sexual practices, particularly premarital and extramarital sex, often associated with young people.
condom use and harm reduction approaches for IDUs within intervention programs. Yet conservative forces in society remained opposed to these programs, which were considered incompatible with Indonesian cultural and religious values. For example, it was assumed that the condom use campaign would encourage ‘free sex’. Condoms were also associated with the longstanding and unpopular family planning campaign. The following observation from the field sheds light on the problem:

I attended an HIV/AIDS educational campaign for high school students held by Pantura Plus in Karawang. Around 25 students – male and female – participated. A few were from the nursing academy. Each student obtained a package of IEC materials on HIV/AIDS. One of the resource persons was a program officer from Family Health International–West Java Province. She was the first speaker, and explained what HIV/AIDS is all about, particularly modes of transmission and ways to prevent infection. When she explained the ABCD\(^{22}\) approach to prevention, the slide showed only the letters AB_D. The letter C was covered up. In her explanation, she did not mention condoms. In contrast, one of the IEC brochures clearly depicted the ABCD approach (including condoms). Almost all students read it. In the discussion, a student asked whether condoms were guaranteed to prevent transmission. The woman’s spontaneous response was, ‘Finally, here we are! Earlier, I didn’t want to talk about it’ ('Akhirnya sampai juga ke situ! Padahal tadi maunya gak disinggung').

The above example reveals the awkwardness of promoting condom use to adolescents, despite the fact that the speaker was working for an international NGO that distributes condoms to its target groups. The awkwardness is three-fold. First, promoting condoms means talking about sex in public. Second, adolescents are not supposed to be having sex before marriage. Third, adolescents are not perceived to be a high risk group. These so-called cultural and religious values are also routinely invoked by bureaucrats, who are often far removed from the daily realities of Indonesian people.

\(^{22}\) The letter D stands for ‘no Drugs’, considering the rapid increase of HIV infection among IDUs in recent years.
I don’t agree with the condom use campaign to prevent AIDS. That is not the objective, but how our young generation can stay away from free sex.... The condom use campaign is not appropriate for Indonesia.... It's an international standard. We have our own way with our religious and national principles.... What's happened is moral decadence. So don’t lead them to condom use (Minister of Youth and Sports, Kompas Cyber Media, 12 August 2005).

Families and communities find it very difficult to talk openly about sexuality. Parents rarely discuss sexuality with their children due to cultural, psychological, and communication barriers, and also because parents have never had the experience of receiving such information from their own parents (Utomo 2003:9). Parents cannot openly discuss sexual health issues due to lack of knowledge and feelings of malu or shame (Hidayana 2000). Hence sexuality is often regarded as a ‘natural’ thing, which everybody will eventually learn in marriage. It is hardly surprising that young people get most of their information about sex through gossip, friends, movies, foreign and porn magazines, and the internet. Their knowledge of sexuality is limited since sex education – apart from the biological aspects of reproduction and abstinence – is generally not taught in schools.

Sexuality, then, rightfully belongs to marriage. State and religion affirm sexual relationships within marriage as ‘legitimate’, thereby implying it is ‘safe’ and ‘healthy’ (Sciortino 1999:218). Nevertheless, open communication about sex between husbands and wives is discouraged by prevailing religious and gender norms. An informant told me that although she found it disgusting, she obeyed her husband when he asked for oral sex; she reassured herself that it was the wife’s duty to please her husband in bed. Jacubowski (2008) has argued that women’s lack of power and self-esteem – and their economic dependence on men – limits their ability to negotiate for safer sex. And given contemporary marriage patterns in Indonesia – particularly in contexts of polygamy, early marriage and contract marriage – marriage is no guarantor of safe sex (Jacubowski 2008:94).
Condoms for sex workers: rethinking risk

Since the onset of the HIV/AIDS prevention program, female sex workers (FSW) have been the main target group, particularly in the lokalisasi (brothel or red light district). Numerous interventions – from education on HIV/AIDS to life skills courses to promoting condom use – have targeted this ‘high risk’ group. While the condom use campaign has been the ‘star’ among the interventions, its results have been disappointing. The 2002 Behavioral Surveillance Survey for West Java reported that 45.8% of ‘indirect FSWs’ (women who work in massage parlors, discotheques, bars, nightclubs, saunas, karaoke lounges, etc.) had used a condom in their last encounter. For ‘direct FSWs’ (women who work in the lokalisasi or brothel), the figure was only 19% (Biro Pusat Statistik 2003:23). In addition, there are freelance sex workers floating on the streets, at railway stations, food stalls, etc. Among male clients, only about 5% had used a condom in their last encounter (Biro Pusat Statistik 2003:23).

We have to be cautious with the above numbers, which refer only to commercial sex workers’ latest encounters. The 2002 Behavioral Surveillance Survey for West Java revealed that only 20% of indirect sex workers and 3% of direct sex workers had used condoms over the past week. The same survey found that 62% of indirect sex workers and 31% of direct sex workers were aware of how condoms prevent transmission.

Condoms in Indonesia were first introduced through the family planning program in the early 1970s but had limited success there. Condoms became a politically and religiously sensitive topic when HIV prevention programs began promoting them to prevent disease rather than conception, for this implied premarital and extramarital sex.

The question is why promoting condom use – a strategy that has dominated HIV/AIDS prevention efforts for two decades – has had almost no impact.

I asked Zaki – an outreach worker from Klinik KITA – about promoting condom use among female sex workers. He said it was difficult to raise awareness among them and their

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23 Other high risk groups like MSM and IDUs only later became target groups of HIV/AIDS programs, in 2002.
clients. When he distributed condoms freely, FSWs were enthusiastic to accept them. But Zaki believed they had economic motives, to sell the free condoms to their clients.

I met Yuni at *lokalisasi* SR in Karawang town one evening. She comes from a village in Subang and has been a sex worker for four years. Yuni admitted that she has had gonorrhea twice. Offering condoms to her clients is almost like mission impossible. Most customers do not like to use them, and Yuni thinks that money comes first. After sex without a condom, she cleanses her vagina with soap and scrapes out all the fluids with her fingers. She uses regular soap or betel vine soap. Yuni believed such practices protect her genitals from itches and sexual diseases.

One of the answers, perhaps, lies in the problem of translating the notion of ‘risk’ into concepts that can be understood by members of so-called ‘high risk groups’ who tend to be poor and less educated. Many if not all NGOs working on HIV/AIDS have ‘unconsciously adopted Western notions of disease and “risk” through their utilization of Western funds, programs and texts’ (Crisovan 2006:191; see also Fordham 2005). In a workshop on HIV/AIDS prevention for MSM in 2002, I criticized the simple translation of the concepts used in the programs. ‘Risk’ is one of the terms that is simply transliterated as ‘resiko’. I questioned how waria or FSWs who had probably never learnt English could understand such a term. How do you explain resiko to your target group? Why do you promote safe sex to avoid the ‘risk’ of HIV transmission? The meaning of resiko remains abstract. Perhaps the word ‘bahaya’ (danger) would be more concrete for many people. Hewat (2008) found that HIV/AIDS and STIs were labeled as a ‘danger’ among young people in Manokwari, Papua. Danger is associated with something visible, with physical pain, and is avoidable. Another example is the term ‘infection’, transliterated as ‘infeksi’ for STIs – which in Indonesian becomes IMS (*infeksi menular seksual*). The term infeksi, however, is too medical even for well-educated people. I would suggest the term ‘penyakit’ (disease), which is more understandable and keeps the term PMS (*penyakit menular seksual*) as a synonym for STD or STI.

Risk analysis has become a technique within public health discourse to produce particular kinds of subjects and to govern

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24 This prevention program is part of Aksi Stop AIDS (ASA).
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populations such as the homeless, the poor, single mothers, and so on (Nguyen and Peschard 2003:457-458). On the basis of her research in Yogyakarta, Crisovan (2006:188) has criticized the dominant Indonesian approach to HIV/AIDS prevention for under-utilizing indigenous knowledge and perceptions. Crisovan argues that breaking down Western assumptions of ‘risk’ would allow HIV/AIDS programs to better direct information to the general public. Fordham (2005:44-45) reflects on the Thai experience:

Just as normative AIDS discourses define the parameters of the AIDS epidemic, the language and concepts in which these discourses are couched have become second nature for many working in the AIDS arena: a description of real essentialised realities of ‘risk’, ‘risk behaviour’, ‘promiscuity’ and of an underclass of villagers with ‘low knowledge’ and ‘no morals’, of ‘indirect’ commercial sex workers… Critically, this language began as little more than simple descriptive ‘shorthand’ concepts, yet… these became essentialised to constitute a world of danger, powerlessness and promiscuous behaviour that is ‘really’ out there, and one in which the intervention of outside experts is necessary if the underclass is to negotiate it successfully.

Focusing on ‘risk groups’ and ‘risk behavior’ often decontextualizes the real lives of people.25 For instance, the public health approach assumes that waria sex workers are similar to gay and bisexual men (Joesoef et al. 2003:609). But in reality, ‘Men who have sex with waria are not considered homosexual by the general public, waria, or by themselves’ (Oetomo 1991:94). Moreover, people do not necessarily identify with the risk groups that they allegedly belong to. Nor are they necessarily concerned about their future health, prioritizing day-to-day survival instead.

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25 Schiller, Crystal, and Lewellen state: ‘In the construction of AIDS risk groups, “culture” has been used as a distinguishing criterion defining membership in “high risk groups” and as an explanation of why members of these groups continue to practice “risky behavior”. …the widespread interest in culture as an explanatory variable… has tended to reflect a usage of culture that distances and subordinates’ (1994:1337).
HIV/AIDS and reproductive health

Structurally, in terms of the health system, HIV/AIDS programs and reproductive health programs are separate from one another. HIV/AIDS programs are directed by the Directorate General of Communicable Disease, particularly the Sub-Directorate of HIV/AIDS, while reproductive health programs are directed by the Directorate General of Public Health, specifically the Directorate of Family Health. Although STIs and HIV/AIDS have their place within reproductive health programs, they are the least addressed issues in the various sexual and reproductive health services. Conversely, HIV/AIDS programs emphasize prevention and treatment among high risk populations and generally fail to address the reproductive and sexual health needs of PLWHA.26

The history of reproductive health policy in Indonesia can be traced back to the 1950s when the government implemented Kesehatan Ibu dan Anak (KIA) or the maternal and child health (MCH) program, integrated into community health centers or Puskesmas. The family planning program27 was initiated in the early 1970s, and in a decade it encompassed all provinces in Indonesia. With its two-child norm, the program was internationally acclaimed as a success despite internal criticism from women’s and human rights activists. The question was whether the family planning program paid attention to women’s health, or whether it was solely used to control population growth.

The principles of the 1987 Nairobi Conference on Safe Motherhood were adopted in Indonesia’s national program. The majority of rural women in Indonesia deliver at home with assistance from traditional birth attendants or midwives. The village midwife (bidan desa) program, launched in 1989, had trained and placed

26 In the years immediately following the 1994 International Conference on Population and Development (ICPD) in Cairo, many AIDS activists felt excluded and ignored by the sexual and reproductive health and rights (SRHR) community. This perception was heightened by a sense that the SRHR community was trying to ‘take over’ HIV/AIDS, while not taking the issue seriously (O’Malley 2004:60; Gruskin, Ferguson and O’Malley 2007).

27 In the Old Order era (1950-1965), family planning activities were initiated by individuals through non-profit organizations such as Perkumpulan Keluarga Berencana Indonesia (PKBI) (see Sarwono 2003).
about 50,000 midwives in villages across the country by 1997.\textsuperscript{28} The program was implemented primarily by the Ministry of Health, with cooperation from other ministries, especially the Ministry of Internal Affairs and the Ministry of Women’s Roles, and with support from various international donor agencies such as the World Bank, UNICEF, the WHO, and AusAid. This was followed by \textit{Gerakan Sayang Ibu} (GSI), or the Mother Friendly Movement, which emphasized community participation to decrease the maternal mortality rate. It received strong backing from the New Order government and had significant impact (Shiffman 2003:1202).

In the wake of the 1994 International Conference on Population and Development (ICPD) in Cairo, the Indonesian government convened the National Workshop on Reproductive Health to reaffirm Law no. 7/1984 on the Ratification of CEDAW (Committee on the Elimination of Discrimination against Women) and Law no. 23/1992 on health. Following this workshop, the Reproductive Health Commission was formed in 1998 to develop an appropriate reproductive health package, to enhance routine data collection, and to support men’s involvement in reproductive health. The commission was placed under the Ministry of Health, which had limited authority to coordinate the related sectors (Departemen Kesehatan RI 2005:31). Like the KPA, the commission involved government officials who usually prioritized their own work.

The Reproductive Health Service Package of 1996 consisted of two major programs: 1) the Essential Reproductive Health Package, which encompassed safe motherhood, family planning, STIs and HIV/AIDS, and adolescent reproductive health; and 2) the Comprehensive Reproductive Health Package, which included all the programs in the Essential Reproductive Health Package, plus programs for older adults.

In the footsteps of the safe motherhood program, the government launched the ‘Making Pregnancy Safer’ program in 2000 to decrease maternal and infant mortality rates. Its three aims were that: 1) every delivery should be attended by a skilled health

\textsuperscript{28}The midwives were recruited from three-year nursing academies and were given an additional year of midwifery training. Once assigned to the community, midwives were paid a salary for three to six years by the government. They were then expected to start private practice after having built up a client base in the village. They had public practice during normal working hours, and were allowed to practice privately after hours.
provider; 2) every obstetric and neonatal complication should obtain adequate aid; and 3) every woman of reproductive age should have access to unwanted pregnancy prevention and post-miscarriage complication treatment. Family planning in this period also saw a paradigm shift from fertility control towards quality of family life and reproductive health rights.

Adolescent reproductive health (ARH) is the field least addressed by Indonesian reproductive health policy. Following the ICPD, the government slowly developed a health program for adolescents in the Puskesmas and schools. A National Task Group on ARH was formed in 1998, led by the Ministry of National Education. Although educational materials were developed, their distribution has fallen far short of target. ARH in schools is addressed primarily through extracurricular activities and as part of biology, physical education, and religion. The focus is on the biology of reproduction and not on sexual practices within social contexts (Utomo 2003:17). As discussed earlier, sexual activity is only sanctioned in marriage while extramarital and premarital sex is strongly discouraged. Sex education for students in school is largely avoided.

Again, NGOs played a key role in providing reproductive health education to adolescents, though their coverage was mostly limited to urban areas. NGOs are usually more innovative and progressive in providing information to young people, whether in or out of school. The national family planning program, for example, only provides information on contraceptives to married couples and ignores issues such as unwanted pregnancy and dating violence.

As with the HIV/AIDS program, political decentralization has affected the implementation of policy as local governments have limited resources and capacities. Commitment towards the family planning program, for example, has weakened (Radar Karawang 18 November 2006; Kompas 13 December 2006). I asked about its implementation in Karawang:

Absolutely… it’s not as strong as before. Now it’s marginalized. It depends on the district head to put it under a certain institution…. In Karawang it is under the Office of Population and Civil Registration… not independent like in the past…. I liked how it was before because it really helped us. Honestly, now it’s not focused for they don’t
have capacity at the local level... (Mr. Jajang, Family Health division, Dinkes Karawang).

Generally speaking, sexual and reproductive health programs are now a lower priority for governments while budgets for health at all levels – central, provincial, and district – have stagnated.

**Integrating HIV/AIDS into maternal and child health programs**

“51 housewives in Biak infected with HIV/AIDS”

The Vice District Head of Biak, Adrianus Kafiar, appealed to all people in Biak Numfor district, Papua province, to actively participate in promoting HIV/AIDS disease prevention. As many as 51 housewives have been infected by the deadly disease.

‘I’m very concerned with the HIV and AIDS infection in this area. Till end of July 2006, it’s already 192 cases and 51 of them are housewives’, said Adrianus Kafiar, in Biak on Tuesday (8/8/2006).

As the head of Local KPA Biak Numfor, Adrianus appealed to all elements in society, religious leaders, adat (customary) leaders, women, and youth to continuously campaign on disease prevention.

Adrianus Kafiar stated the number of HIV infected housewives is higher than commercial sex workers in Biak Numfor district. Certainly, it has happened because they have no knowledge about the danger of this disease.

According to Adrianus, HIV/AIDS infection among housewives can have happened because their husbands have multiple partners. This situation is worrying, so there is a need to involve all stakeholders to disseminate information on HIV/AIDS to the community, particularly in the family.

To detect whether someone is HIV/AIDS infected needs accurate medical research. As the head of KPAD Biak Numfor, Adrianus promised to recheck these data.

As of 31 July 2006, the Health Office of Biak Numfor district reported 192 HIV/AIDS cases. The detail is 44 HIV and 148 AIDS, while 82 of them died (Media Indonesia Online, 8 August 2006).
This news piece from 2006 sends an alarming message about the HIV/AIDS epidemic in Indonesia: it is now affecting ‘low risk’ populations, including housewives and children. Papua province has the highest prevalence rate in the archipelago: 2.4% of the general population aged 15-49 in 2007, far surpassing the estimated national average of 0.22% (National AIDS Commission Republic of Indonesia 2009:2).

The second National AIDS Strategy for 2003-2007 prioritized preventing the mother-to-child transmission (PMTCT) of HIV. The National Guidelines for PMTCT clearly stated that PMTCT services should be integrated into existing mother and child health and family planning (MCH-FP) services at all levels (Departemen Kesehatan RI 2006:3). As most elements of the PMTCT program – antenatal care, normal labor and delivery, prevention and management of emergency obstetric complications, postpartum care, family planning, and infant feeding – ran parallel to the safe motherhood program, the idea was that with some additional resources and training, existing personnel could implement an expanded program in existing facilities. All women visiting MCH-FP sites were to obtain information on HIV/AIDS and be offered voluntary counseling and testing.

The WHO initially promoted a three pronged strategy to reduce the mother-to-child transmission of HIV: 1) prevention of new infections among parents-to-be; 2) prevention of unwanted pregnancies among HIV infected women; and 3) prevention of transmission from infected mothers to their infants. More specifically, the PMTCT program consists of the voluntary counseling and testing of pregnant women, antiretroviral therapy for HIV-positive pregnant women to protect their unborn children, and provision of breast milk substitutes after delivery. These programs prioritized preventing transmission to the unborn child; they often disregarded the mother’s right to be informed and to choose what is best for her and her child (WHO 2003:13). Realizing that a more comprehensive strategy was necessary, the WHO and UNAIDS have since added a fourth objective: care and support for HIV-positive mothers and their children and families. While PMTCT has improved in recent years, care and support services for HIV-infected women have lagged behind. In addition, PMTCT programs generally do not encourage male involvement or responsibility.
HIV/AIDS and MCH programs are structurally separate in Indonesia though both are under the Ministry of Health. The integration of PMTCT into MCH programs requires effective coordination between the Directorate of Family Health and the Sub-Directorate of HIV/AIDS. But experience shows that coordination, whether within or between institutions, is a weakness of Indonesian bureaucracy. While NGOs and local staff complain about this lack of coordination, officials tend to speak as if all is going according to plan.

Another challenge in integrating PMTCT into routine maternal and child health programs is the social stigma surrounding HIV/AIDS and the need to ensure confidentiality in testing, counseling, and care. The social stigma surrounding AIDS has proven to be one of the most formidable barriers to slowing the spread of the disease. MCH health providers may themselves be hesitant to work with PLWHA, while their other clients may not want to be associated with a facility that provides HIV/AIDS services. Health providers’ knowledge of HIV/AIDS also often remains limited. In the PMTCT campaign for village midwives in Rawamerta sub-district, Karawang, which I observed in 2006, it was obvious that their knowledge about mother-to-child transmission was almost non-existent: their questions concerned how health workers can avoid infection and the kinds of symptoms exhibited by HIV-positive persons.

**Conclusion**

Influenced by NGOs in the field, President Soeharto’s government embraced a rights-based approach to combat HIV/AIDS. But this was only on paper. The downfall of the New Order regime and subsequent decentralization did little to improve policy implementation. While decentralization gave NGOs more space to advocate and collaborate with local governments (some provinces and districts issued local regulations on preventing HIV/AIDS), local political commitment to tackle the epidemic has often been weak.

A key constraint facing HIV/AIDS programs in Indonesia is the taboo on the public discussion of sexuality. Sex in Indonesian society has its legitimate place in marriage – and with the assumption of fidelity, marriage has been seen as a safe haven to avoid HIV infection. Nevertheless, the more recent increase in the
number of HIV-positive pregnant women has forced PMTCT onto the agenda. Implemented through existing programs of antenatal care, PMTCT services in theory are now available to all women. But again, implementation lags behind, in part due to the socio-cultural resistance of policy-makers to admit that marriage is no longer a safe haven.

Integrating HIV/AIDS within Indonesia’s reproductive health services poses new challenges for policy and programming. But as the epidemic advances, blame, stigma, and denial are still coloring the responses of both government and society. The dominant approach to controlling HIV/AIDS – which focuses on ‘high risk’ groups such as sex workers and their clients, injecting drug users, and men who have sex with men – has been unable to stem the epidemic. The focus on ‘high risk’ groups furthermore overlooks the role of men, despite men being the obvious bridge between ‘high’ and ‘low risk’ populations. While governments and NGOs often unconsciously and uncritically employ Western notions of disease and risk, there remains a need to translate scientific terms into more readily understandable, culturally and socially appropriate concepts.