Monitoring UNGASS-AIDS Goals on Sexual and Reproductive Health

Indonesia
UNGASS Declaration of Commitment on HIV & AIDS

Following the UN Millenium Summit in 2000, UN General Secretary Kofi Annan began endorsing world leaders to form a global alliance to respond to the challenges of halting and reversing the HIV epidemic that had rapidly become a global emergency. The Secretary General invited country leaders and all 189 General Assembly members to gather and discuss what concrete action could be taken in response to the epidemic of HIV/AIDS at global, regional & national levels. This was the first time that General Assembly members had gathered to discuss one specific health issue. On the last day of the Assembly, a declaration was made which is now considered to be a milestone in the history of HIV/AIDS response.

The UNGASS Declaration of Commitment (DoC) on HIV/AIDS is arguably one of the most important commitments to influence the global effort towards reversing the spread of HIV. This high level commitment stood beside international commitments such as Millenium Development Goals and CEDAW, among other influential commitments. As a matter of fact, UNGASS DoC on HIV/AIDS is considered a blueprint for meeting the Millenium Development Goals target of halting and reversing the HIV epidemic by 2015.

This declaration, made in New York – June 2001, contained targets to be fulfilled within a certain period of time. These targets were set up to cover 9 different themes encompassing all areas of the HIV & AIDS response. These themes are:

- Leadership
- Prevention
- Care, Support and Treatment
- Human Rights
- Reducing Vulnerability
- Conflict or Disaster Regions
- Resources
- Follow-up

Many parties perceive the DoC both as a platform from which to endorse various sectors related to HIV & AIDS response, at the international and national level, to collaborate and an arena in which countries responding to the epidemic can work side by side.

DoC is also known as one of the commitments that allows countries to pursue the targets already set, based on what is appropriate & fit - in terms of their culture, economical capacity, political situation and other in-country circumstances affecting the approach used in response to the spreading of the virus. In conclusion, each country could determine which route they want to take to reach the target.
Besides the benefit of flexibility in determining an appropriate approach to reach the targets contained in the declaration, UNGASS DoC on HIV/AIDS recognized sub-populations that are often marginalized such as MSM, IDU, sex workers, migrant workers, et cetera. This was another significant progression made on that particular level that should be acknowledged.

**Civil Society Involvement**

Despite all the commitments that have been made, progress made by certain countries was considered to be slow and often, at the decision making level or sometimes at other levels of the response, exclusively for the government, multilateral & bilateral agencies only. Civil society - including the community sectors, private sector, NGOs, CBOs, FBOs, and other civil society members – has often been excluded from various significant levels of the response towards AIDS within the country. Even when civil society plays an important role at grass root level, it often lacks the political or financial support necessary for involvement in higher levels of decision-making, and at times is even treated as a target group.

Although UNGASS DoC on HIV/AIDS fully endorses countries to be inclusive in the in-country process and fully support civil society involvement at the national, regional and international level, it remains that in certain countries the lack of involvement is evident from the UNGASS country reports that are submitted bi-annually.

This lack of involvement could be caused by various challenges present at several levels. In many cases, there are only a few members of civil society who are familiar with commitments such as DoC on HIV/AIDS. This makes the demand for involvement in the construction of country reports impossible to meet since civil society remains in the dark. In other cases, the governments often perceive the system used by the government as sufficient to detect all the data needed to get a clear picture of the HIV & AIDS situation within the country, so the involvement of civil society in the construction of the country report will be less effective. Furthermore, in several cases, the policies within countries have become major obstacles to increasing the involvement of civil society.

However, the progress made over the years should be acknowledged. There are significant changes that have been made, both through advocacy at the national level and through the international consultation process or simply because many parties started to realize the importance of civil society involvement. At the national level, progress is often reflected through the process of the construction of the country report, decision-making process, policy designing, construction of the National AIDS programs, and through other significant mechanisms. At the international level, the progress made in terms of civil society involvement has been reflected through the increasing number of community members that were involved in the UNGASS+5 in New York and in many other UNGASS & Universal Access
related events such as preparation meetings, technical trainings & workshops.

This progress should be sustained continuously to ensure equal partnerships between governments, multilateral & bilateral agencies, donors & civil society at the national, regional and international level.
UNGASS Declaration of Commitment in Indonesia

Indonesia was one of the 189 member states that signed the Declaration of Commitment on HIV/AIDS in New York, June 2001. Indonesia was represented by the Minister of Health, Mr. Sujudi, as a representative of the government of Indonesia in committing to targets set up by the Declaration of Commitment.

The commitment was translated into a national-scale commitment when the Sentani Commitment was declared. The Sentani Commitment, which involved 8 high-prevalence provinces & 6 ministries, later became a 6 ministry & 14 province commitment and has been a useful tool to stimulate sectors within the government to work together in responding to HIV/AIDS and also to endorse the HIV/AIDS response within the provinces involved. It sets up 8 targets for AIDS response in the provincial level.

Generally speaking, UNGASS DoC is not well known in Indonesian civil society; even in the community sectors and is certainly not as popular as Millenium Development Goals itself. Similar situations are also present in other South East Asian countries and probably in some countries in other regions - that have limited resources & capacity to access this kind of information at this level.

A group of representatives from the Indonesian community sector was also involved in 2001 Special Session in New York. However, the information about the commitment was only imparted to a limited amount of civil society.

Advocacy work done by both civil society or/and by the National AIDS Commission or other government agencies seldom uses the declaration as a tool, however the advocacy work itself is often in-line with the targets contained in the declaration it self.
**HIV & AIDS in Indonesia**

The first case of HIV in Indonesia was found in 1987. Soon after the first case, more cases were found all over Indonesia and the first wave of the epidemic, when HIV cases were significantly increasing, occurred during the period of 1999 – 2003. It jumped once again over the period of 2003 – September 2007 (the latest data).

![Kasus Baru per Tahun](chart.png)

In most provinces in Indonesia, the spread of HIV is still concentrated within sub-populations; mainly IDUs who contributed almost 50% of the HIV cases. However, in Papua, the epidemic has become generalized with a prevalence of 68.86 (as indicated per 100,000 population).

The latest number of reported cases recorded by the Ministry of Health stated that, cumulatively, there are 5904 cases of HIV and 10384 cases of AIDS since the first case of HIV in Indonesia in July 1987 until the last reporting period (July – September 2007).

The data also stated that 2035 cases of AIDS are females and 8288 AIDS cases are males, while 61 other cases remain unknown.

Based on the risk of transmissions, injecting drug use still remains the main mode of transmission in Indonesia with IDUs accounting for 5140 cases of AIDS, followed by heterosexuals with 4361 cases of AIDS. Pre-natal transmissions accounted for 166 AIDS cases, while cases caused by blood transfusions numbered only 10.

The province with the highest number of AIDS cases is DKI Jakarta with 2849 cases of AIDS. Meanwhile, the province with the lowest number of cases reported is West Sulawesi where the report showed there are no reported AIDS cases within the province.
Although Papua is only the third highest province in terms of cumulative AIDS cases, according to the prevalence per 100,000 population Papua has the highest prevalence with 68.86 (September 2007). DKI Jakarta came in second place with 31.27 per 100,000 population.

The latest official estimation of cases of HIV in Indonesia gives a number between 193,000 – 246,000 cases of HIV. The highest number based on age groups is among young people aged 15 – 24 years old, which is made up of 52% of an estimated 600,000 injecting drug users, 45% of commercial sex workers and 31% of men who have sex with men.

*(data source: Directorate General CDC & EH, Ministry of Health, Indonesia)*
Methodology

Objectives:

To explore current issues related with HIV/AIDS epidemic and its impact in Indonesia

To gather additional information, especially information at the grass root level, to contribute to the official UNGASS DoC on HIV/AIDS – Indonesia country report

To initiate discussions among civil society regarding current situation related with HIV/AIDS response

Field Study

This recommendation was made based on the qualitative study conducted from August – December 2007. The study gathered data from 198 questionnaire respondents, 29 interview respondents and 45 focus group discussion participants.

Quantitative data interpretation was done on the basis of frequency of answer for every variable while qualitative data was gathered with 2 methods: respondent interviews and focus group discussions. Qualitative data was processed based on researchers’ notes and transcripts.

Interview respondents were selected based on criteria below:

- Indonesian activists working on AIDS issue, or other co-related issues, such as gender and children issues
- Has been working in the area for at least 2 years

Through those criteria, the team identified 29 respondents, mostly based in Jakarta. From 29 respondents, only 4 persons were based outside Jakarta. This was due to the limited budget for this study.

The interview sites also varied from interview to interview. Most of the interviews took place in respondents’ offices. Some took place in restaurants, malls, or other public places. 2 verbatim were seriously distorted by background noise.

Focus Group Discussions took place in 4 cities outside Jakarta. Data from FGD was processed and analyzed through the transcripts, although recording was not clear and used local language most of the time.
Challenges in the study

There are 3 main challenges in this study, which are:

• **Not every member of the Indonesian UNGASS Forum played an active role in this study.** Out of 15 people from 14 organizations that joined the 1st UNGASS Forum in Ciawi, Bogor August 2007, the group ended up with 7 active members. Therefore, the group lacked representation from MSM group, LGBT group and a representative from the women’s network.

• **Most of the data collectors were lacking in interview skills.** As a result of the limited time and budget, we were not able to do pre-assignment training. Therefore, lack of probing and reformulation of questions were the most common errors in the interview process.

• **Lack of data, mostly secondary data from civil society organizations.** Most of the NGOs or organizations do not document most of their work. Therefore, the study often relied on individual rough estimation.
Study Results
Goal 37 - Government leadership in facing the HIV/AIDS epidemic

"By 2003, ensure the development and implementation of multi-sector national strategies and financing plans for combating HIV/AIDS that address the epidemic in forthright terms; confront stigma, silence and denial; address gender and age-based dimensions of the epidemic; eliminate discrimination and marginalizing; involve partnerships with civil society and the business sector, and the full participation of people living with HIV/AIDS, those in most vulnerable groups and people at risk, particularly women and young people(...)"

Indicators:

• Effective participation by representatives of women and youth living with HIV in the HIV/AIDS Programs, including the room of participation at the decision-making level and in the UNGASS monitoring actions

• Participation of groups of women assisted by the design, implementation, and evaluation of the programs directed towards them

Study result(s):

In general, civil society participation in Indonesia is still in its early stages, in which the participation really depends on individual capacity, network and relationship rather than on the equality between government agencies and community groups or civil society organizations - or in a broader context, the general population.

Abdullah Denovan, a member of the founding board of the national network of PLHIV, stated that several improvements made for the last 2 years regarding participation of people living with HIV in the decision-making level are:

• According to the Presidential Regulation number 75/2006 regarding National AIDS Commission, one of the National AIDS Commission members should be the Head/Coordinator/Chief of National PLHIV Organization. Although this regulation has yet to be implemented, mainly because currently in Indonesia, national network of PLHIV is undergoing a major reconstruction, the policy needed for PLHIV involvement in national level decision-making process is already in place

• People living with HIV are also involved in several working groups established by National AIDS Commission, such as the Harm Reduction and Media working group
• Involvement in the National AIDS Commission is also reflected through Provincial/District AIDS Commissions. Several PLHIV have taken up significant positions managing programs in local AIDS Commissions

• The participation of people living with HIV in the Country Coordination Mechanism (CCM) for Global Fund for TB, AIDS and Malaria. Main challenges for PLHIV regarding their involvement in this level are mostly due to the language barrier, since the CCM meeting is often conducted in English rather than the local language.

These are only some examples of improvements in terms of PLHIV involvement. Other improvements have been made at the organizational level, where people living with HIV are involved in many NGOs, bilateral agencies, UN agencies, and other international organizations in a more meaningful way.

Other groups such as drug users' groups also noticed these improvements in the involvement of civil society. IDU groups were able to organize their movements and participate in the amendment of Drugs bill number 22 – 1997, which stated that the response towards drug use in the country should also be concerned about the health of drug users, especially in relation to HIV and access to health service.

However, these progresses left some room for improvement. In several provinces, districts, and even in some processes in big cities, the involvement of civil society still seemed symbolic or tokenistic in many senses. In some processes, civil society was only involved in the last phase of the process so the civil society or community activists were not able to fully contribute to the process itself.

Although it is possible to measure the quantity of participation, it is almost impossible to measure the quality of the involvement itself. The bulk of participation and involvement of civil society & community activists is at implementation level with some in the program designing and decision making process. However, it is hard to find involvement in the monitoring & evaluation process, in particular PLHIV involvement.

One of the obstacles to endorsing civil society participation is that, geographically, Indonesia is a big country. This has caused “representative” issues also for the civil society. Often, civil society participation becomes very Jakarta-centric even though the grass root level issues in Jakarta may differ greatly to what civil society faces in Situbondo, for example. The same is true for Makassar, or Merauke, or Padang and there is no mechanism to collect information on what is faced by civil society in each area.
Women Participation

When the respondents of this study were asked; “Do women and young women participate in decision-making process for the national AIDS programs?”, the majority of respondents expressed their concern over the lack of involvement, especially at the level of decision making. One of the respondents stated that most of the involvement and participation of women and young women representatives is limited to some extent, such as implementers of programs.

“…..there is none in the decision making level. IPPI only involved in the implementation level...”

_Santy, IPPI – Ikatan Perempuan Positif Indonesia_

Ikatan Perempuan Positif Indonesia – IPPI (Indonesian Positive Women Association) was found in 2005. The network was established to amplify the voice of positive women in Indonesia and to organize the HIV positive movement in the AIDS response. However, based on the interview with the coordinator of the network, participation of women and young girls, especially those who are living with HIV, needs to be improved at every level. Often, people living with HIV only take part in AIDS response as testimonial speakers or are invited to meetings without knowing what they can contribute to those meetings.
Goal 52 – Prevention

“By 2005, guarantee that all countries, particularly the most affected, have a broad range of prevention programs that take into consideration the circumstances, the ethical and local cultural values, that include information and communication activities in the idioms they understand better, and respect their cultures, with the objective of reducing risky behavior and promote a responsible sexual conduct, including abstinence and faithfulness; more access to essential articles such as male and female condoms, and sterilized syringes; activities to reduce the harm of drugs consumption; more access to psychological support services as well as voluntary and confidential testing services; access to non contaminated blood, and quick and efficient treatment of sexually transmitted diseases;”

Goal 53 – Prevention

“By 2005, guarantee that at least 90% of youth of both genders, 15 to 24 years old, and by 2010, that at least 95% of them, have access to information, education, including peer education and specific education for youth about HIV, as well as the necessary services to develop the required abilities to reduce their vulnerability to the HIV infection; all of this in collaboration with young people, mothers and fathers, families, educators and health care professionals;”

Indicators:

- Reach, adequateness and effectiveness of prevention educational programs for women and girls
- Reach, adequateness and efficacy of sexual health programs for youth
- Female and male condom availability in the health services, schools and associations
- Easy access to condoms and proper guidance on how to use them

Study Result(s):

Most of the educational programs on HIV for women and young women were done by the NGO/CBO/FBO. The National Strategy for Sexual and Reproductive Health is already in place however, some NGO activists have stated that the implementation of that strategy has yet to fulfill what the youth need in term of sexual and reproductive health information. The strategy itself has already been “translated” into youth context, however, the challenges are in the implementation level.
“...we already have a National Strategy on Sexual Reproductive Health launched by the MoH, however the implementation has not yet reached what the youth groups need...”

Husein, Yayasan Pelita Ilmu

Currently, the House of Representatives is proposing a Pornography Bill (24 August 2007), which is still in draft and currently in the evaluation process. The definition of pornography in this bill is:

"Pornography is human created materials that contain sexuality in form of pictures, sketch, illustration, photos, writings, sounds, noises, moving pictures, animations, cartoons, lyrics, conversations, or other communication message and/or through media that perform in front of the public and/or could stimulate sexual desire also endorse action against society’s values and/or caused the development of porno-action in the society”

As with the Anti Pornography and Porno-Action bill proposed & rejected sometime ago, the definition of pornography in this draft bill could be easily misunderstood, lead to abuse and cause a major challenge for the implementation of National Strategy of Sexual Reproductive health, National Plan of AIDS, and other strategies & policies that endorse sexual reproductive health education for young people & the general population. Although this bill allows the use of materials described as pornography for education purposes, there are however, some concerns regarding the implementation of this bill since the definition could lead to confusion & abuse and especially when what distinguishes “actions against the law” and “not against the law” in this bill is only the motivation behind & purpose of the use, which is always hard to prove.

Educational Programs for Young People

Often, educational programs for young people (15 – 24 years old) would mean NGOs coming to schools and giving 2 – 3 hour sessions on HIV, drugs and co-related issues. Based on the data from Yayasan Harapan Permata Hati Kita, out of around 550 outreached schools (in Jakarta & greater Jakarta area only), only 1 school expressed their commitment and continued to strengthen their capacity in terms of HIV, drug use and co-related issues. This commitment became real when the school allocated budget for regular trainings for their teachers, began building school HIV policy and setting up a referral system & link with NGOs working with HIV & drug use.

PKBI, one of the non-governmental organizations, does a lot of work with young people and also educates young people with information regarding sexual reproductive health. Their current program geographical scope is
reaching ....provinces. PKBI programs also reached to street children and female youth.

Yayasan Harapan Permata Hati Kita also conducted programs working with youth, the program called the Youth Empowerment program, where 75 – 100 young people in an area are trained, supported and assisted to pass on information on HIV, drugs, sexual and reproductive health and other co-related issues to other young people. After having undergone a month long training, the young people form their own Youth Empowerment group and start to work with other young people. This program has been replicated in 13 provinces in Indonesia with support from various donor agencies such as UNICEF, CORDAID and others.

However, currently there is no mechanism at the national level to measure the impact of prevention approaches & method of information disseminations. It is almost impossible to get information on which method could be considered best practice – once again, this is because there is no comparison study or quality assessment done to measure these important issues.

Sexual and Reproductive health has already been integrated into the school curriculum. Usually, it is the school counselors are in-charge of delivering this subject. Similar topics are also addressed during biology and religion classes although they often fail to address the information needed by young people. There is no monitoring and evaluation mechanism for the implementation of the curriculum, making it impossible to measure effectiveness and quality.

**Condom use**

Condom use is one of the means of prevention popularized in Indonesia since before it was even offered as one of the HIV transmission prevention instruments. Indonesia is one of the countries considered to be successful in their implementation of a Family Planning program where condoms were offered as a mean of contraception.

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**Condom use among female IDUs (during their last sex)**

<table>
<thead>
<tr>
<th>Method</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coitus Interuptus</td>
<td>21%</td>
</tr>
<tr>
<td>Condoms</td>
<td>11%</td>
</tr>
<tr>
<td>Not using anything</td>
<td>68%</td>
</tr>
</tbody>
</table>

*Source: Perempuan dibalik Tirai Dunia Narkoba – Joyce Djaelani Gordon – Ford Foundation*
The Sentani commitment also endorsed the implementation of “100% Condom Use” in provinces within Indonesia. Some provinces and districts translated the Sentani Commitment into provincial or district regulation, where not using condoms in a “high risk” area would be considered an action against the law. Jayapura is one of the districts to implement the “100% condom” district regulation. However, this regulation alone seemed unable to ensure condom use. In Tanjung Elmo, the most popular brothel complex in Jayapura, 2 outreach workers that worked in that area were interviewed. They stated that the regulations actually influenced the “pimps” to endorse the sex workers to wear condoms during sex transactions with clients, the sex workers even have to show the used condoms to their pimps after the sex transaction is over. This good intention to protect their workers is not supported by the client’s sufficient understanding on how to protect them self although often information only would not protect them. Clients regularly refuse to use condoms and the sex workers are not in the best position to negotiate. In this situation it is common for the sex worker to fill the condom with saliva, so that they can show it to their pimp and pretend that it has been used.

Bali and East Java have already advanced and provided District Regulation for their own province. These district regulations contain a comprehensive set of laws that regulate HIV prevention in their provinces, covering all aspects of HIV prevention from the basic principles such as considering humanity, gender, togetherness and justice as the foundation of the regulation, regulations about VCT, and endorsing condom use. Although these regulations only slightly touch the surface of care, support and treatment, they could be considered to be models for other provinces to replicate.

**Goal 54 – Prevention**

“By 2005, reduce the amount of HIV infected breast fed babies in about 20%, and by 2010 in about 50%, offering to 80% of all pregnant women prenatal services with information, psychological support, and other HIV prevention services, growing the availability of efficient treatment to reduce the transmission of the virus from mother to child and giving access to treatment for HIV infected women and babies, and offering access to treatment for HIV infected women that are breast feeding, as well as efficient interventions for HIV infected women that should include psychological support and the voluntary and confidential testing services, access to treatment, particularly the antiretroviral therapy and, when appropriate, to the substitute of breast milk, and a continuous series of attention services;”

**Proposed Indicators**

- Reach, quality and care of services for HIV infected pregnant women
• Access to adequate treatment for pregnant women

• Availability of appropriate detection testing

• Quality of counseling for HIV detection testing in pre-natal services

• Nutritional support for HIV infected pregnancy; anti-HIV prophylaxis during delivery

• Reach, adequateness and efficacy of programs that guarantee breast milk substitutes

**Study Result(s):**

“Tik, a 17 year old girl from Jakarta, is now a widow with a baby son. She got HIV from her late husband, an ex IDU. Her baby boy was also infected.

She lives in small rented room in a slum area in Jakarta where drug abuse and premarital sex are common. In an interview she said; “I guess it’s about 75% of teenage boys, mostly aged 15 – 17. For girls, its usually free sex with their boyfriend or ‘uncles’. There’s a small house in the neighborhood where young people, mostly boys, use injected drugs and bring girls”

Tik got married when she was 15 and had just graduated from Junior High School. Sadly, her marriage lasted for only 5 months. In the second month, her husband’s condition deteriorated badly, and he had to be hospitalized for about 4 weeks. She had to struggle very hard to take care of her husband in the hospital with her six months pregnancy; and also had to deal with kampong and upper level administration, so that she could claim the hospital fee reduction available to poor people, and get money from her neighborhood to cover her expenses. At this point she was HIV tested (with no pre and post test counseling) just after her husband began medical treatment. She said “They said I was positive...and I didn’t know what that was exactly. The doctor just gave me a referral letter for me to go to POKDIKSUS in the central hospital to prevent my baby from getting HIV too..” ...........

The hardest challenge she has to overcome now is how to earn money to pay her room rent, buy formula milk, pay for ARV and other medicines for tuberculosis; and for her son, whose condition improved after ARV. Now she is a volunteer in YPI (Yayasan Pelita Ilmu), as a peer supporter for other people living with HIV & AIDS”

*Individual interview*

Source: Save The Children – Vulnerabilities and Impacts of HIV & AIDS on Children’s Life
This interview was conducted in 2005. There have been significant improvements related with care, support and treatment for mothers living with HIV in Indonesia – however, the coverage of these improvements may still be limited to big cities such as Jakarta and other municipalities in Indonesia. First line and second line of ARV drugs are subsidized by the government and some PMTCT programs already include nutritional support and support for formula milk as substitution for breastfeeding. Some high prevalence remote sites remain untouched by these programs, this is principally due to geographical difficulties (mainly in Papua) and lack of awareness from the local governments, community based organizations and donor/funding agencies.

Yayasan Pelita Ilmu (YPI) is one good example of this improvement in the community-based organization. Since 2003, YPI has provided comprehensive programs for HIV positive pregnant women and support for mothers living with HIV, including safe motherhood programs, VCT counseling, nutritional support for mothers and babies, assistance for mothers through home visits and facilitation of support groups for women and mothers.

Starting from October 2006, with the support from GFATM, Yayasan Pelita Ilmu increased the coverage of PMTCT programs to 6 provinces in Indonesia, working in partnership with local NGOs and hospitals. However, since there was an unfortunate internal “management” problem with GF funds in Indonesia, the program was stopped in April 2007 and hasn’t been able to move forward since that time.

**Anti Retroviral Treatment for Pregnant Women**

Though the first and second line of ARV drugs in Indonesia is already subsidized by the government of Indonesia, some people living with HIV still find some challenges in accessing the drugs. Especially when PLHIV encounter “additional costs” for laboratory tests, hospital administration fees, and transport expenses that they have to consider when accessing the free ARV.

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**Obstacles in Accessing ARVs**

![Obstacles in Accessing ARVs](image)

*Source: PLHIV and Health Service Access – A Participatory Research - 2006*
For women living with HIV, accessing public health service often generates greater challenges compared to those usually faced by other groups. This is especially caused by financial dependency, – in this case to their spouse/partner. Many women in Indonesia live in a marriage where the husband is the one responsible for financial income of the family. Most of the time this means the husband works while the wife cares for the family & children, cooking, household chores. If the relationship with the husband is disrupted for any reason, often that would also mean interruption to the wife’s access to information, health care services, healthy lifestyles and nutrition support, and many other aspects of their life.

It is also undeniable, that women living with HIV have more personal constraints in accessing ARV than male PLHIV, as is described in the table below:

![Personal constraints in Accessing ARVs](image)

*Source: PLHIV and Health Service Access – A Participatory Research - 2006*

Yayasan Pelita Ilmu is one of the community-based organizations that provides VCT & PMTCT services to pregnant women since 2003 – 2006, from the 2470 pregnant women who accessed their service (in Jakarta), 11 women turned out to be HIV (0.5%). Yayasan Pelita Ilmu stated that the main challenge in assisting HIV positive pregnant women is the stigma and discrimination often faced when accessing health care services in hospitals, clinics and other centers for health care. There are some documented cases where health service providers refused to conduct caesarian section for HIV positive pregnant women, usually justified by reasons such as the hospital not having sufficient medical equipment to proceed with caesarian section or stating that there is no formal permission from the head of the hospital.

Based on our interviews, it seems apparent that most of the PMTCT programs are provided by NGOs such as YPI and other NGOs. We did
identify one hospital that currently provides PMTCT services, however from the data we gathered it is evident that there is a great need to expand the coverage of PMTCT programs in Indonesia, especially to cover other areas outside municipalities.
**Goal 61 Human Rights**

"By 2005, ensure development and accelerated implementation of national strategies for women’s empowerment, the promotion and protection of women’s full enjoyment of all human rights and reduction of their vulnerability to HIV/AIDS through the elimination of all forms of discrimination, as well as all forms of violence against women and girls, including harmful traditional customary practices, abuse, rape and other forms of sexual violence, battering and trafficking of women and girls."

**Proposed Indicators**

- Reach, adequateness, and effectiveness of specific laws to prevent, punish, and repair the damage caused by violence against women
- Reach, adequateness, and effectiveness of specific actions against the sexual exploitation of girls
- Coverage, quality, and care of the attention services for women and girls victims of violence or sexual violence, with anti-HIV and anti-STD prophylaxis, emergency contraceptives, and abortion
- Existence of a public system for collecting and publicizing data about violence against women and girls

**Study result(s):**

In 2004, the government released Bill number 23 – 2004 regarding “The Elimination of Domestic Violence”. Prior to that, Government of Indonesia also launched Bill number 7 – 1984 as a ratification of CEDAW (Convention on The Elimination of all Forms of Discrimination Against Women).

Related with violence against children, in 2002, the government also produced Bill number 23 – 2002, where all forms of violence against children would be considered action against the law, including sexual exploitation and violation of human rights of children.

On October 15th 1998, National Commission on Violence Against Women was founded. It was built on Presidential Decree number 181/1998 as a national mechanism to eliminate violence against women in Indonesia.

A society in which social structures as well as patterns of relations and behavior are conducive to the creation of peaceful life, in which there exists respect for diversity, as well as freedom from fear and from threats and acts of violence and discrimination, so that each woman can enjoy her basic rights as a human being

*Vision Statement – National Commission on Violence Against Women*
Through this National Commission, violence against women is documented and publicized through various media, including their website (www.komnasperempuan.or.id) and often used for advocacy purposes.

According to an interview with Ida Wulan, staff of the Ministry of Women Empowerment, the gender-mainstreaming program has already been done in 32 provinces of Indonesia and already covers 75% of the districts, although the result & impact of this gender-mainstreaming program remains unclear.

**HIV Prophylaxis**

Currently in Indonesia, there is no use of Anti HIV Prophylaxis for HIV exposures allowed except for profession-related exposure (such as nurses, doctors, etc).

**Abortion Law in Indonesia**

*In verse 15 (1) Health Bill number 23/1992, it was mentioned that in emergency situation, as an effort to save mother’s life and/or the fetus, there are certain medical action that could be done. However, in verse 2, there is no mentioning about what kind of medical action should be taken in such situation. It only mentioned the requirement to give the medical attention. Therefore, the definition of abortion as part of certain medical attention to save mother’s life or the fetus’s is very unclear and causes confusion for general society and medical professionals.*

*KUHP strictly forbids abortion, regardless of the reason for doing it, as written in verse 283, 299 and also 346 – 349. As a matter of fact, verse 299 states that giving hope of abortion to a woman could result in a sentence of up to 4 years in prison.*

**Source: LBH APIK (Indonesian Women Association for Justice)**

From the analysis of LBH APIK about laws in Indonesia regarding abortion, it is clear that the law regarding abortion in Indonesia remains unclear. It is not uncommon for this confusion to cost people’s lives as a result of unsafe abortion.
Goal 65 Orphans

"By 2003, develop, and by 2005, implement national policies and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans girls and boys infected and affected by hiv/aids, including the provision of appropriate counseling and psychosocial support, ensuring their enrolment in school and access to shelter, good nutrition and health and social services on an equal basis with other children; and protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance;”

Indicators:

• Reach, adequateness, and effectiveness of specific support programs for orphans and children infected and affected by HIV

• Quality of shelters

• Reach, adequateness, and effectiveness of educative programs for orphans and children in vulnerable situation because of AIDS

Study result(s):

Dina, 28 years old, a young HIV positive mother in Bogor, has shed a lot of tears recently. Several years ago, she often disclosed her status in the media, with a spirit that “put a face to the epidemic” and to help to eliminate stigma and discrimination towards people living with HIV & AIDS. However, the incidents that have happened to her lately made her feel that it’s been a wasted effort and she may as well have tried to catch the wind.

Two months ago, she received a call from her 4 year old son’s school; they insisted that Dina and her husband come to the school in order to have a discussion with the school principal immediately. As Dina was in another city doing an AIDS project, she had to postpone the invitation for several days.

When she and her husband finally came to the school, the principal explained to her that several parents saw them giving testimony on one of the national television stations and had read articles in a magazine about their HIV status. The principal also explained that the parents had become afraid and angered by the fact that Dina’s son goes to the same school as their children, plays alongside their children.
Possibly the most shocking fact for Dina was that when she postponed the invitation, the angry and scared parents decided to open her son’s shirt to check his body, did not allow him to play with other kids during school break time, and also did not allow him to drink from the same water dispenser. The parents also decided to move their children to other classes. Before these incidents, the class was filled with 30 students. By the time this interview was done, the class size was reduced to 15 students only.

According to Dina this incident changed her son from an active boy, to a quieter one. “He always wanted to play with many of his friends, and now he only wants to play with his teacher” said Dina.

“And what really broke my heart was when I heard from one of the parents (there is one supportive parent that supports Dina and her son) that one day my son asked her ‘Aunty, do you love me? Why do my friends run from me when I want to play with them?’ and it just broke my heart…”

*Individual Interview*

*Dina, 28 years old*

In Dina’s case, the school actually acted very supportively in response to the incident. Soon after the incident, the school facilitated a small seminar for parents regarding HIV and other co-related issues. Unfortunately, it seems that the seminar did not have a significant impact as Dina’s son continues to experience discrimination from other students and parents, the most recent example of this occurred at the time of this report being written. Dina reported another incident at the school in which the parents insisted that Dina’s son should not go to the school medical unit should there be anything wrong with his health.

Several similar cases have been reported to the national mailing lists (AIDS-INA & WartaAIDS mailing list), although there is no known valid documentation of these cases either by the government agencies, international agencies, or non-governmental organizations. Currently there is no official program launched by the government that specifically deals with orphaned and vulnerable children of AIDS.

Most of the programs on this issue are done by the community-based organizations. Yayasan Citra Ushada in Bali is one of the NGOs focusing on this issues through building a playgroup for children that can be accessed by children with HIV and also provide support groups for children with HIV. According to their data, there are currently 20 children living with HIV in Bali.

Rachel’s House is also one of the NGOs that facilitate a hospice providing palliative care for children with AIDS and Cancer. Although the program...
not yet officially commenced, staff at Rachel’s House are preparing themselves to provide comfort and space for children living with HIV and also Cancer – working in partnership with several private sector organizations.

Despite the lack of a mechanism to measure or to predict the number of children living with or affected by HIV at the moment, it is logical to assume, just by looking at how the number of people living with HIV keeps increasing from year to year that there will be or already has been an increase in the number of children living with or affected by HIV.

The Child Protection Law number 23/2002, should be one of the law that could be use to prevent and/or used to respond in these kind of case, however due to the level of public knowledge regarding these policies, the public still practicing stigma and discrimination and often, integrate that into schools system.

The bottom line is that orphans and vulnerable children (OVC) is one of the issues that are, currently, lacking attention, commitment and action from both government and non-governmental organizations. This issue should be revisited & included in the national AIDS strategy as a priority area.
Recommendations

- National AIDS Strategy & Plan should contain strategy to endorse participation of civil society. This strategy should be supported by commitment that reflected through allocation of budget for community empowerment, in the true sense of the word “empowerment”

- National AIDS Commission should set up indicators for civil society participation in AIDS response and integrate these indicators in National AIDS Strategy, allocate specific budget to monitor & evaluate these indicators, since measuring participation often is more to art than to science

- National AIDS Commission along with Ministry of Coordination and People’s Welfare, and Ministry of Health, should ensure that the existing policy should be brought into reality, therefore it would be fulfilling it’s true purposes: to ensure the people of Indonesia would benefit from the existing policies & fulfilling needs at the grass root level

- As mentioned repeatedly by community, health & academic expert, there are possibilities of second wave of HIV epidemic that would be driven by mode of transmission that is different than what drove the first wave of HIV epidemic in Indonesia; as the first wave was driven by injecting drug using, the second wave is predicted to be driven by unprotected sex, it is reasonable to recommend the government to revisit all possible issues and take all measures needed to prevent second wave of HIV epidemic.

- The government should change the basic perspectives in dealing with health & social issues. So far, actions and measures were taken after the issues grew and create impact for the society. It is urgent to change the actions to be more preventive, rather than reactive. It is also necessary to conduct economical analysis to study the comparison of cost to prevent, cost to treat and the cost of not doing anything significant.

- Considering the lack of coordination among the community & community-based organizations in Indonesia, there is an urgent need to establish a national level platform where community and community-based organizations could plan and coordinate among themselves

- Community and community-based organizations should reflect the movement of AIDS response in the country, conduct community-based studies on assessing what things are working and what are not working; focusing on fulfilling needs at the grass root level
• Most of community-based organizations in Indonesia took role as direct service provider for the population. However, there are several role that often left out; such as advocacy role, policy & implementation monitoring role, research role, et cetera. There is a need for community to revisit these roles and determine the balance of the roles we take as community
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