

Report on Stigma Index Survey

Background and overall picture.

Stigma index survey is a major activity of the component on Stigma-discrimination Index under the project on AIDs Rights Advocacy and Stigma Index Development, especially the component on stigma-discrimination index survey which was designed based on the stigma index user guide and questionnaire which were introduced through regional workshops facilitated by IPPF, UNAIDS and various international NGOs. Thailand is one of the countries has participated in this initiative. With the two components on AIDS rights advocacy and stigma-discrimination index survey, the project was developed across multi-partnership with key national and international partners such as Thailand Network of People living with HIV/AIDS(TNP+), Thai NGO Coalition AIDS(TNCA), Ministry of Justice(MOJ)'s Department of Rights and Liberty Protection, FAR, Ministry of Public Health(MOPH)'s Department of Disease Control, Public Media, Academic Institution, National Human Rights Commission(NHRC) and UNAIDS as well as key UNAIDS cosponsoring agencies, namely UNDP, UNICEF, UNFPA and UNESCO. The project was implemented by the Foundation for AIDS Rights(FAR) together with TNP+ that looked after the component on the stigma-discrimination survey. The project was implemented between February 2009 – January 2010.

The stigma-discrimination survey component was implemented with three major activities: training of research assistants; field data collection; and local and national workshops or meetings to analyze the data and to disseminate the results.

The training of research assistants was conducted in April and May 2009 involving 13 research assistants who were the people living with HIV and volunteered to serve the project to assist the research principal in data collection. The training was a series of workshops conducted by the research principal from Ubobrachathani University. The workshops were organized to make the research team to understand about the project concept and background, research tools(user guide and questionnaire), research theories and methodology and data collection and analysis. Field exercise and pre-test were also included in the training process.

Data collection was undertaken by the research team composed of the research principal and 13 research assistants between June and August. In this process, 233 respondents were interviewed.

Data analysis was then undertaken in October and November by the research team, though a series of meetings were convened to allow the research assistants to participate in the initial analyzing process after field data collection, especially the stage of cleaning the raw data and defining key terminology related to the research framework.

In the meantime, the research team and FAR organized meetings in the 7 regions aiming to disseminate the initial results and seek feedback on the research finding from various groups of participants. The meetings were actually attended by key representatives from the networks/groups of the people living with HIV, MOPH officers and CSOs at local level. In this regard, each meeting was attended by about 100 participants.

In addition, FAR and key partners organized 4 additional meetings funded by UNDP(as an additional funding support for these particular meetings) in November to

involve wider audiences focusing and to build a campaigning foundation for World AIDS Day(WAD) event(In Thailand TNCA, FAR and partners organized WAD event and activities on 28-29 November) that would jointly address WAD theme on Universal Access and Human Rights at the country level. The meetings were actually attended by those who were the key actors to address the issues and cases related to stigma and discrimination as well as build networks and partnership. These included TNP+ members, lawyers, NHRC members, MOJ officers, academia, local government organizations and CSOs at local levels. The attendance was ranging between 70-200 participants.

National Launch of the Report.

As planned under the project mentioned above and as a part of national AIDS campaigning process and as an event to celebrate the International Day of Human Rights, the launch of the report on stigma-discrimination index survey was organized on 10 December. It was a national workshop to present final results of the index survey and seek final comments from key national mechanisms before the completion of the project. The launch was attended by 115 participants from various levels and types of key concerned government agencies, non-governmental organizations, public independent institutions, UN agencies, public media and academia. In this regard, high level officials at Director-General level from 3 key departments under MOJ and MOPH attended the meeting and provided very good comments. A number of government departments concerning human rights and HIV sent their technical staff to attend the meeting and made useful comments(See appendix 1). Special guests who functioned as the commentators came from prominent background and popularity including Magsaysay Awardees and member Thai PBS TV Board, Director – General, Department of Rights and Liberty Protection and Director-General of Prosecutors' Legal Assistance Division.

Key agenda were welcoming address by UNAIDS Country Coordinator, introductory remark by TNP+ representative, Opening remark by Representative of UN High Commission on Human Rights, HIV/AIDS stigma and discrimination play by research assistants and TNP+ volunteers, Presentation on survey results by research principal, comments by special guests and open discussion.

Key activities

After the official ceremony, the launch started with an HIV/AIDS stigma and discrimination play. The play consisted of a series of 10 scenes in which each scene showing a different form of HIV/AIDS stigma and discrimination was played out(Appendix 2).

Presentation on search results

Objectives: This survey research aims 1)to obtain relevant data as a national set on HIV/AIDS stigma and discrimination for those who are infected in Thailand in terms of types, occurrences and impact; 2)to develop an understanding of HIV/AIDS stigma of discrimination and the rights of those who are HIV positive and those who are affected; and 3)to develop an index on HIV/AIDS stigma and discrimination, which could be used to determine the extent of the problem and what changes take place over time.

Research team: The research team was composed of one research principal from Ubonrachathani University and 13 research assistants who were the people living with HIV(PLHA) including 10 males and 3 females, but representing different sexual identities. These 13 people came from the different regions of the country.

The Questionnaire :The questionnaire was globally developed in collaboration with four organizations: GNP, ICW, IPPF and UNAIDS. The questionnaire was translated by UNAIDS Thailand and then further adapted to the Thai situation.

Target group of the research and characteristics of respondents:

In total, 233 PLHAs were interviewed. These people belong to the TNP+ network and were distributed throughout the country. The distribution by sex and gender were: 57 males, 148 females and 28 members of the ‘third sex’. In terms of age distribution, 57.5% were aged 30-39 and 26.2% were aged 40-49. Regarding the period of time infected with HIV, 35.2% believed they were infected for 10-14 years; 29.2% for 5-9 years; and 6.9% for less than one year. For the minority status of respondents, close to half of them (43.8%) belonged to a minority group – they were gay, MSM, injecting drugs, belonged to an ethnic minority group or had been or were prisoners. 11.6% had a disability. In terms of their education, 52.3% had only had primary education. 30.5% had secondary education. For the employment, the majority of the respondents lacked secure employment. Only 16.3% had a full-time employment. 20.6% were unemployed.

Findings

Stigma caused by outsiders or surrounding factors:

- Over a third (34.3%) of the respondents indicated that they are restricted from participating in community activities. Of these people, 57.8% believed this was because their HIV status was known.
- Based on the questionnaire, 94.9% of the respondents indicated that they were excluded from religious activities.

- A third of the respondents (32.2%) indicated that they had lost their jobs because of their HIV status.
- Over a quarter (26.2%) of the respondents had been rejected from taking on new employment because of their HIV status.
- A fifth of the respondents had been denied access to medical services (many other respondents indicated that they were not denied access to medical services but they had to queue up or undertake other activities in order to gain medical services, which were perceived to be different from those who are not infected with HIV).

Self stigma:

- 64% felt embarrassed being HIV positive
- 47.6% felt guilty that they were HIV positive
- 42.9% blamed themselves for being HIV positive
- 43.8% lacked a sense of belief in themselves
- 16.7% wanted to commit suicide
- 21.9% felt that they should be punished for being HIV positive
- 64.4% were afraid of gossip
- 57.5% were afraid of harassment by verbal abuse or harassment

54.5% thought that people were afraid to have sex with them, because of their HIV.

Main issues were discussed:

- Stigma and discrimination faced by children infected and affected by HIV/AIDS in school

This was a theme that was presented in the play about stigma and discrimination and was picked up by the audience as an important issue. Discussion focused on the problem of eight HIV positive children who were refused entry to study at a school. These children were living at a Christian Home for children, and thus received institutional support. But despite that they were denied access to their local school, because of their HIV status.

➤ Problems of harassment of sex workers by police

A representative from the sex workers organisation SWING complained that police officers were harassing male and transgender sex workers. They were searching the sex workers to see if they had condoms and if they did they would then accuse them of being sex workers and then would demand money from them. The sex workers did not feel they were in a position to complain, as they feel they need to maintain good relations with the police, despite what is going on.

➤ Stigma and discrimination at work

A number of participants complained about factories demanding health check ups, including a HIV test for future employees. The area around Rayong province is an industrial area, with numerous factories, employing large numbers of people. PLHA are being discriminated against as they are being denied employment opportunities.

➤ Stigma and discrimination that HIV positive people receive at hospitals

This was another issue presented in the play about stigma and discrimination. A number of government officials felt that what was presented in the play was extreme and that to some extent was past history. However, PLHA representatives at the meeting indicated that presently, medical staff were still trying to persuade HIV positive women not to have children, to get sterilized and to have abortions if they were pregnant.

➤ HIV positive migrant workers and their access to ARVs and for OI care

Reflecting the large number of migrant workers in the South of Thailand the participants expressed their concern for these people and their access to care and treatment. Migrant workers, whether registered or not, have numerous problems accessing care. Unless their health problems have become serious, many migrant workers will not want to visit a Thai government hospital. They find it difficult communicating to hospital staff because of language difficulties and because of cultural misunderstandings. Also, because of the language barriers they may not fully understand the treatment regime, and thus not fully taking their medications. Further, migrant workers often fear arrest, deportation or the need to pay bribes to reach the hospital, even for those who are registered as many employers keep their legal documents. Finally, migrant workers and their family members who are HIV positive are denied access to ARV medications. It is not clear what can be done for these people. The meeting, however, noted that the situation has improved with changing government policies in allowing these people access to these medications – for at least those who are registered migrants. For unregistered migrants, a limited number of them had access to ART only under the project funded by the Global Fund to fight against AIDS, TB and Malaria(GF-ATM).

➤ Fishermen

Accessing fishermen with health messages and care is difficult. The fishermen may appear at a port for a short while, before going back out for a long period of time. At times the fishermen are away from a Thai port for up to a year or more. During that time the fishermen are known to undertake risk behaviours such as piecing their penises, tattooing and visiting sex workers whenever they arrive ashore.

- Lack of ID Cards

This theme was related to the migrant workers; however government officials at the meeting indicated that they were coming across a small number of Thais who did not have ID cards, for one reason or the other. Without this card it was very difficult to provide any services for them.

- Lack of awareness among government officials of their duties

The meeting noted that at times government officials were unaware of their duties in relation to providing services to PLHAs. This was often resulting in forms of HIV/AIDS stigma and discrimination. Examples of this included government officials announcing the HIV status of PLHA, without seeking the approval of the persons in question.

- Forced blood testing

A discussion took place about applicants for a hotel position being forced to take a HIV blood test. This resulted in the organisers of the meeting providing information about the ASO project that is being led by TBCA.

- Statement that created this debate concerned PLHAs having children.

A participant felt that PLHAs who were having children were not being responsible to their children or to the society as a whole. She argued that future parents should think seriously about having children, that they should only have children if they had the economic means to do so and also were able to physically look after them. She claimed that she and her non-governmental organisation were looking after too many children, as a result of PLHA having children and not being able to look after them due to economic factors, health issues or because of the death of one or both of the parents.

- Another statement that created a debate was about the ‘criminalization’ of HIV/AIDS

A lawyer in the meeting stated that laws about HIV/AIDS would imply that there are the guilty and the innocent in relation to HIV/AIDS. This led to statements indicating that HIV positive people should not have sex or that they should have only sex with an informed partner.

Others in the audience indicating that such an approach would only lead to greater HIV/AIDS stigma and discrimination and that people would not disclose their HIV status, or would not want to be tested for HIV. It was also pointed out that the logical conclusion of such an approach was that it should be illegal for anyone with any sexually transmitted infection to have sex.

- A further statement that created debate was the use of the phrase of PLHA infecting those who were pure.

For many people in the meeting this statement indicated that PLHA were guilty and those who were not infected were pure and innocent. It implied that PLHA had HIV because of their bad behaviour; they had been drug users, sex workers or homosexuals or had done something else which they had been punished for.

- Another statement during the meeting indicated that some participants felt that PLHA had more rights than those who were HIV negative

Some participants believed that PLHA were getting more rights than other people. They were getting their medications and other medical expenses free while others in the community with other medical problems were not getting the same conditions.

Key conclusions and recommendations

1. The meeting found the report reflected that there were still stigma and discrimination against the people living with HIV in Thai society, though responses to HIV and AIDS have been implemented for more than 25 years.
2. The occurrences found in the findings of the report pointed out that stigma and discrimination against various groups of population still remain no matter how difference they are: health, race, religion, culture, education etc.

Those who are part of the HIV network (PLHA) and those working on issue of HIV and AIDS in Thailand should be involved in a process of ensuring that there is a better understanding of 'rights'. This understanding should be of all dimensions of rights, whether it is legal, political, or cultural.

3. The meeting found that stigma and discrimination against PLHAs is a structural problem in association with other problems such as migration and drug.

4. The important root of problem is attitude toward HIV/AIDS leading to attitude against PLHAs. It has become an illusion resulting in actions that have to control and restrict. If service providers are trapped into this attitude, it would make their services come out with stigma and discrimination.
5. Knowledge and understanding about human rights for those who are responsible at policy and in their mechanisms and working level, especially in government agencies are not sufficient. There is a need for building understanding and awareness raising.
6. This report is just a start up and not able to solve all problems. There is a need for further study to gain more knowledge, identify measures and develop more tools to solve problems more seriously.
7. The groups that are facing more serious stigma and discrimination are prisoners as after they are released from the prisons, they are hardly offered a job. Or, drug users who do not have access or tools to prevent them from HIV infection such as needle and syringe.
8. This survey and the findings assisted the TNP+ in moving forward the human rights works within their networks. With FAR, TNP+ team on human rights in 7 regions have been developed. Key milestones are developing outreach team and setting up hot line centers.
9. The National Human Rights Commission, Office of Supreme Attorney and Department of Rights and Liberty Protection are willing to collaborate with TNP+ and concerned organizations to solve the problems related to stigma and discrimination.
10. The cabinet has recently approved the second National Human Rights Plan for 2009-2013. Stigma and discrimination are included in this plan and the Department of Rights and Liberty Protection is fully responsible for its implementation.

Appendices:

Appendix 1: List of participants and commentators

Participants:

(1) 18 participants from government ministries and agencies.

Ministry of Public Health: Department of Health; Department of Disease Control; Office of Permanent Secretary's Bureau of Policy and Planning; Department of Health Service Support; Disease Control Center No. 1, 4, 6 and 10; and National Health Security Office No. 4(Saraburi).

Ministry of Justice: Department of Probation; Department of Child Observation and Protection; Department of Rights and Liberty Protection; Department of Corrections; and Office of Supreme Attorney.

Ministry of Social Development and Human Security: Department of Social Development and Welfare.

Ministry of Education: Office of the National Committee on Basic Education

(2) 35 NGO workers

(3) 42 project staff and PLHAs involved in ground works on Human Rights and HIV from 7 regions.

(4) 5 Media: 4 from newspapers(The Nation, Daily News, KomChadLuek, Kaosod/Fresh News) and 1 from TV channel 9

(5) 7 from UN agencies: UNAIDS/UNDP/UNICEF/UNFPA

(6) 5 from academic institutions, including Mahidol University and Khonkaen University

(7) 3 from Public Independent Body(National Human Rights Commission)

Commentators:

1. Wisa Benjano, Member, National Human Rights Commission

2. Suwana Suwanjutha, Director-General, Department of Rights and Liberty Protection, MOJ

3. Nunthasak Phoonsuk, Director-General, legal Assistance, Office of Supreme Attorney, MOJ

4. Jon Ungpakorn, Thai PBS TV and Magsaysay Awardee

5. Somchai Hormla-aw, Human rights activist and lawyer

6. Anan Muangmunchai, Member, TNP+ Committee

Appendix 2: Scenes of the stigma-discrimination play

Scene 1

A teacher arriving early to school before the school year starts. He is concerned about one particular student, who he knows is HIV positive. When he finally meets her, he informs her that she has to sit in back of the class, not to play with other students, and that she had to eat her lunch separately from the other students.

Scene 2

The student (Ratana) is awoken by her mother so to get ready for school. Ratana indicated that she does not want to go to school anymore because of the way the teacher treated her. She does not understand why he behaved in such a way. The mother does not take the opportunity to explain to her daughter that both of them are HIV positive. Instead the mother indicated that she is busy and will be home late.

Scene 3

A public announcement is made in Ratana's community by the local administration office indicating who can receive social security payments. Ratana's mother's name is included, indicating that she can receive money for being HIV positive. Ratana approaches her mother and says that others at her school are saying that she and her mother are both HIV positive. Her mother denies this and says that Ratana does not have to believe what others are saying, but to believe her mother.

Scene 4

Ratana's mother is with a group of PLHA all of whom are at a hospital waiting to get their ARV medications. They are complaining about how their blood test results are been shown publicly, enabling all the villagers to see who is HIV positive. Further, they are requesting medical certificates that do not indicate their HIV positive status. They are healthy and can undertake work, so why should their medical certificates indicate that they are HIV positive.

Scene 5

A nurse arrives complaining that working with PLHA is the most tiring work that she has had to undertake in her 20 years of working experience. She tells off a woman for thinking about having a child, and demands a man has to decide if he is going to take his

ARV medications or whether he is going to continue to take drugs. She claims that PLHA should never have children and then indicates that she has to leave work early, as she has to pick her child up from school.

Scene 6

After the meeting, a couple announces that they are expecting a child. The wife is five months pregnant. On hearing this, the nurse is furious attacking them for their stupidity for thinking that they could have children.

Scene 7

On returning home the father to be, seeks advice from a friend, who happens to be injecting drugs at the time his friend arrives. He decides to also shoot up, using the same needle.

Scene 8

The school teacher, who now indicates that he is gay, along with another gay friend decides to try to pick up some men. They come across the two men who are injecting drugs and pick them up.

Scene 9 – which takes place 7 years in the future

The gay teacher's friend accuses the teacher of being HIV positive. The friend is scared to be with the teacher and refuses to share any water with him.

Scene 10

The gay teacher is left alone and he shouts out in angst that he is gay, that he is HIV positive and that he wants to die!