

change



“Because this is the disease of the century”

Understanding HIV and AIDS-related Stigma and Discrimination in Vietnam

Khuat Thu Hong & Nguyen Thi Van Anh

Institute for Social Development Studies, Hanoi

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International Center for Research on Women, Washington, DC

The stigma triangle

HIV/AIDS

Social
Evils

Drug
Injection/
Prostitution

Design: Manu Badlani

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Table of Contents

| | |
|--|----|
| Acronyms | 1 |
| Executive Summary | 2 |
| 1. Introduction | 3 |
| 2. Social Context of Vietnam | 4 |
| 2.1 Overview of the HIV and AIDS epidemic in Vietnam | 5 |
| 2.2 Government efforts to combat HIV and AIDS in Vietnam | 5 |
| 2.3 HIV and AIDS-related stigma and discrimination issues in the legal framework and in the national AIDS program | 6 |
| 3. The Research Project | 8 |
| 3.1 Data collection process | 8 |
| 3.1.1 Research methods | 8 |
| 3.1.2 Site selection | 8 |
| 3.2 Study sample | 10 |
| 3.3 The research team | 11 |
| 3.4 Data processing and data analysis | 11 |
| 3.4.1 Factors determining HIV-related stigma in Vietnam | 11 |
| 3.5 Scope and limitations of the research | 12 |
| 4. Findings | 13 |
| 4.1 The causes of HIV and AIDS-related stigma in Vietnam | 13 |
| 4.1.1 Stigma related to fear of HIV and fear of casual transmission | 14 |
| 4.1.2 HIV, drug use, sex work and their impact on family: moral causes of stigma | 17 |
| 4.1.3 HIV and AIDS as “social evils”: the stigma triangle | 20 |
| 4.2 Forms and manifestations of stigma and discrimination | 22 |
| 4.2.1 Isolation and avoidance as a means of “prevention” | 23 |
| 4.2.2 Expressions of stigma relating to HIV as a sign of moral misconduct | 30 |
| 4.2.3 Self-stigma—shame and feelings of hopelessness and despair | 32 |
| 4.3 Gender issues | 34 |

| | |
|--|----|
| 4.4 Broader impact of HIV-related stigma and discrimination for people living with HIV and AIDS | 36 |
| 4.4.1 Reluctance to disclose HIV status | 36 |
| 4.4.2 Impact of HIV-related stigma on the families of people living with HIV and AIDS | 38 |
| 4.5 Reasons for hope: love, affection and good intentions | 38 |
| 5. Conclusions and Recommendations | 41 |
| References | 44 |
| Appendix A. Situation of Drug Use in Hai Phong | 45 |
| Appendix B: HIV and AIDS Intervention Projects in Hai Phong and Can Tho | 46 |
| Appendix C: Words and phrases used by the community to describe HIV and AIDS, people living with HIV and AIDS, injection drug users and sex workers | 47 |
| Appendix D: Case Study of YT, 23-year-old female sex worker living with HIV in Can Tho | 48 |

Tables, Boxes and Figures

| | |
|--|----|
| Table 1. Estimated Cumulative HIV and AIDS Cases and AIDS Deaths, 2003-2010 | 5 |
| Box 1. News on Social Evils: Prostitution and Drug Use | 7 |
| Box 2. Defining “Stigma” and “Discrimination” | 13 |
| Box 3. Basic Facts about HIV Transmission | 14 |
| Box 4. The Stigma Triangle | 20 |
| Box 5. Causes of HIV and AIDS-related Stigma and Discrimination | 41 |
| Figure 1. Conceptual Framework | 11 |

Acronyms

| | |
|---------------|--|
| AIDS | Acquired Immune Deficiency Syndrome |
| AUSAID | Australian International Development Agency |
| CSDS | Center for Social Development Studies (former name of ISDS) |
| FGD | Focus group discussions |
| GOV | Government of Vietnam |
| HIV | Human Immunodeficiency Virus |
| HIV/AIDS | The combined disease entity as described in policy and programs ¹ |
| ICRW | International Center for Research on Women |
| IDU | Injection Drug User |
| IEC | Information, Education and Communication |
| ILO | International Labor Organization |
| ISDS | Institute for Social Development Studies |
| LAG | Leadership Advisory Group |
| MOH | Ministry of Health |
| MTP | Medium-Term Plan 1996-2000 |
| MOLISA | Ministry of Labor, Invalids and Social Affairs |
| NASB | National AIDS Standing Bureau |
| NCADP | National Committee for the Prevention and Control of AIDS, Drugs and Prostitution |
| NGO | Nongovernmental Organization |
| PASB | Provincial AIDS Standing Bureau |
| PLWHA or PLHA | Person living with HIV and AIDS ² |
| PLWHA_IDU | Study participant who acquired HIV through injection drug use |
| PLWHA_SW | Study participant who acquired HIV through sex work |
| PLWHA_Other | Study participant who acquired HIV infection through means other than injection drug use or sex work |
| STD | Sexually transmitted disease |
| SIDA | French language acronym for HIV/AIDS, also used by some Vietnamese |
| SW | Sex Worker |
| USAID | United States Agency for International Development |
| UNDP | United Nations Development Program |
| UNODC | United Nations Organization for Drug Control |

¹ When used to describe the condition itself, this designation can be confusing and inaccurate, as it implies that the two entities—HIV and AIDS—are the same, which they are not. In this report, the designation HIV/AIDS is only used to describe specific policies and programs.

² This acronym is only used when quoting others or as shorthand to describe study participants as noted.

Executive Summary

From August 2002 through January 2004, the Institute for Social Development Studies and the International Center for Research on Women conducted research on HIV and AIDS-related stigma and discrimination in two Vietnamese cities: Can Tho and Hai Phong. This research set out to describe the context in which stigma occurs and to document the experiences of stigma and discrimination among people living with HIV and AIDS and their family members. The research sought to explore the ways in which HIV-related stigma and discrimination intersect with stigmas that may adhere to injection drug users and sex workers, and to understand the ways in which gender and gender roles may affect these processes.

Fieldwork for this qualitative research study was conducted in selected communes of Can Tho from 4 – 19 January, 2003 and Hai Phong from 12 – 26 February, 2003 by trained researchers from the Institute for Social Development Studies. Structured thematic analysis of qualitative data gathered from over 250 participant transcripts indicates that HIV and AIDS-related stigma in Vietnam stems largely from two issues.

First, people in the community generally understand the ways in which HIV is transmitted, but ambiguities persist, leading to fears of acquiring HIV casually through everyday contact with infected persons. This leads people to take unnecessary, often stigmatizing, actions which they perceive will prevent further transmission of the disease.

A second important cause of HIV-related stigma relates to the fact that in the minds of community members, leaders and health care workers, HIV and AIDS are inextricably linked with injection drug use and sex work, which are both regarded as “social evils.” Particular complications were observed for injection drug users, widely perceived as people

who prefer “indulging in play” rather than contributing meaningfully to society. Thus, judgments are passed against people living with HIV who are thought to have acquired the infection through behaviors that are considered to be morally, socially and economically harmful to both family and society.

Findings also show that women living with HIV and AIDS tend to be more highly stigmatized than men due to a combination of the commonly-held assumption that HIV is acquired through immoral means, and social expectations that women should uphold the moral integrity of family and society while men can be more self-indulgent. While women tend to be “blamed” for acquiring HIV and AIDS, men are often forgiven by family and society. The consequences of stigma are also more severe for women, who are more frequently sent away from their families and separated from their children than men are.

It is also clear, however, that despite the prevalence of stigma associated with the disease, most of the people living with HIV and AIDS also receive love, support and care from their families and compassion from some members of their communities.

The study has concluded that more can and must be done to confront and address the root causes of HIV and AIDS-related stigma and discrimination in society, not just their effects. Firstly, programs are needed to reduce the fear of casual transmission of HIV and AIDS by delivering unambiguous, factual information about HIV and AIDS, and how and why it is and is not transmitted. Secondly, sincere, deliberate efforts are needed to delink HIV from “social evils” in policy, legislation, programming and the public imagination. Thirdly, the media should do more to reinforce these messages through positive portrayals of people living with HIV and AIDS. In the next phase of the study, ICRW, ISDS and the CHANGE Project will be taking these recommendations forward.

1

Introduction

The Institute for Social Development Studies (formerly the Center for Social Development Studies) and the International Center for Research on Women have undertaken an 18-month study investigating the causes and consequences of HIV-related stigma in Vietnam.³ This project was funded by USAID through the CHANGE Project/AED, with additional funding from GlaxoSmithKline's Positive Action program.⁴ The research explored the context in which HIV-related stigma occurs, how it intersects with the stigmas associated with injection drug use and sex work and how gender and gender relations interact with these processes. The phase of the project reported here ran from August 2002 through January 2004 and the fieldwork was conducted in January and February 2003 in the cities of Hai Phong in the north of Vietnam, and Can Tho in the south. A second project phase, beginning in February 2004, will involve specific activities putting the findings and recommendations from this research into practice.

The overall objectives of this research were to:

- ▶ Document experiences of people living with HIV and AIDS;
- ▶ Explore how HIV-related stigma interacts with other stigmas, specifically those associated with drug use and sex work;
- ▶ Investigate the role of gender in the causes and consequences of HIV-related stigma;
- ▶ Sensitize social organizations to stigma and its impact; and
- ▶ Mobilize leaders to serve as advocates on behalf of people living with HIV and AIDS and their family members.

These objectives were explored through five key study components:

1. A workshop entitled "Understanding and Confronting HIV and AIDS," held in Hanoi in September 2002. This workshop brought together individuals working in a range of national and international NGOs as well as key grassroots social organizations, people living with HIV and AIDS and health care providers working in HIV and AIDS in Hanoi, Hai Phong and Can Tho provinces.
2. The Institute for Social Development Studies assembled a Leadership Advisory Group (LAG) for the study. The LAG consisted of 12 highly placed and respected individuals based in relevant governmental departments and national organizations. The LAG provided advice and guidance on the research process and developed action plans taking the findings of the study forward in their respective jurisdictions.
3. The field research, conducted in January and February 2003.
4. Data analysis.
5. Dissemination and publication of the research results in both Vietnamese and English.

This report provides an overview of the key insights from the fieldwork phase of the project. Section 2 provides an overview of the Vietnamese context, the nature of the HIV and AIDS epidemic in Vietnam and relevant aspects of HIV and AIDS policy and programs. Section 3 describes the research project, the study sites, the nature of the study sample and the research process. Section 4 presents the key findings of the study: the root causes of stigma, its principal manifestations and impact and the gender dimensions observed. The report concludes with recommendations for next steps.

³ The National AIDS Standing Bureau, now no longer in existence, was the governmental partner for this project.

⁴ USAID funded the substantive research. GSK/Positive Action funded the two-day mobilization workshop held in Hanoi in September 2002.

2

Social Context of Vietnam

Vietnam, with a population close to 80 million, is located in Southeast Asia, sharing a border in the north with China, in the west with Laos and in the southwest with Cambodia.

A series of important changes took place in Vietnam during the last century. Two wars lasting continuously for more than half a century seriously undermined the country's economic development. In order to keep pace with a rapidly changing global environment, in the mid-1950s Vietnam began a transition from agrarian-based, which had lasted for thousands of years, to a centrally planned economy with a socialist orientation. A second shift occurred at the end of the 1980s when Vietnam began to transform its economy to a market orientation (the "Open Policy"), although the government maintains links to the ruling Communist Party and continues to play a substantial role in economic development. This most recent evolution has brought with it important economic achievements but also challenges. For example, the Open Policy has increased Vietnam's participation in regional and global economic development and has provided new opportunities for cultural exchange with the outside world. Yet at the same time, this process has profoundly changed the value systems, traditional norms and lifestyles of the Vietnamese people.

Prostitution and the use of illegal drugs are two problems that have emerged out of this context of rapid social change. In the last two decades, prostitution has increased alongside urbanization. According to official statistics, there are over 50,000 sex workers nationwide (Associated Press 2003) although other estimates put the total closer to 300,000 (WHO 2002). The trafficking and use of illicit drugs are also on the rise: the Centre for Harm Reduction (2002) estimates that there were between 185,000 and 200,000 drug users nation-

ally in 2003. According to the National Standing Bureau for Drug Control of Vietnam, there are 142,001 registered drug users. Among these, 116,505 are living in the community and 25,453 are in detoxification centers, prisons, corrective camps and education and rehabilitation schools managed by the Ministry of Police (Bao Cong an Thanh Pho Ho Chi Minh 2002). The majority of drug users are male and nearly half are under the age of 30 (ibid.).

In Vietnam today, prostitution and the use of illicit drugs are widely considered to be "social evils" that bring negative consequences to society. This belief is, in fact, institutionalized in official government policy, as this excerpt from a decree entitled "Eradication of Drugs and Prostitution"⁵ illustrates:

"Prostitution and drugs are social evils against the moral and traditional customs and habits of the nation, which bring negative influences on the health, offspring, material and spiritual life of the people and social security, which cause serious consequences for subsequent generations. All forms of these social evils should be prevented and violating persons should be severely punished."

Indeed, there are several manifestations of the government's determination to combat these "social evils." In addition to spearheading various campaigns and initiatives and using national and local media to convey its message, the government has also established compulsory rehabilitation centers for those addicted to illicit drugs (known as "06 camps") and for female sex workers (known as "05 camps"). At the camps, habitual drug users and female sex workers receive treatment, education, job training and work for the required period, which ranges from three months to one year. With the advent of the AIDS epidemic,

⁵ From Decree No 87/CP (GOV 1993) on Enhancement of the Management of Cultural Activities and Cultural Services Article 1, Chapter 1

compulsory HIV screening has also become standard. Habitual drug users desiring to come off drugs can also voluntarily admit themselves to these centers. The 05 and 06 centers are managed by the Department for Social Evils Prevention, part of the Ministry of Labour, Invalid and Social Affairs (MOLISA).

2.1 Overview of the HIV and AIDS epidemic in Vietnam

The first case of HIV was detected in Vietnam in December 1990 and the first AIDS case was identified in 1993. Up to July 2003, the cumulative number of HIV infections in Vietnam was 69,495; of those, 10,541 became ill with AIDS, and 4,694 died (MOH 2003). The Ministry of Health (MOH) estimates the rate of HIV infection in Vietnam to be 0.25 percent, although it varies in different parts of the country, with estimated prevalence ranging from 0.2 percent in Ho Chi Minh City (234 per 100,000) to 0.5 percent in Quang Ninh Province (543 per 100,000) (MOH 2003).

The HIV epidemic in Vietnam is currently concentrated mainly among injection drug users (IDUs) and the young. Sixty percent of those infected are using or have used injection drugs; 10 percent are between 10-19 years old, and 55 percent are between 20 and 29 years (MOH 2003). However, HIV transmission through sexual intercourse is on the increase: the proportion of people living with HIV who are sex workers has increased from 0.6 percent in 1994 to 6 percent in 2002, and the proportion of sexually transmitted disease (STD) patients testing positive for HIV has increased from 0.5 percent in 1994 up to 2.9 percent in 2001. The Ministry of Health (MOH) estimates that there will be increased risks of HIV transmission to the wider

community due to the increasing rate of drug injection among female sex workers, unsafe sexual relations between IDUs and people living with HIV and the low prevalence of condom use among female sex workers. MOH warns that HIV transmission will not remain limited to the so-called “high risk groups” but will increasingly be an issue for the general population. This trend is evident in the HIV rate among new army recruits, which has increased from 0 percent in 1994 to 1.3 percent in 2001, and in pregnant women, which has increased from 0.035 percent in 1995 to 0.39 percent in 2002 (MOH 2003).

MOH estimates that in 2005 there will be 197,500 people living with HIV in Vietnam, with an average of around 12,000-18,000 new infections each year. According to this projection there will be 351,000 HIV infections in Vietnam by 2010.

2.2 Government efforts to combat HIV and AIDS in Vietnam

Before the first HIV case was detected, the Vietnamese government had already defined HIV as a disease closely related to deviant social behavior that could only be controlled through close intersectoral coordination. The National AIDS Program, established in the late 1980s as an infectious disease control program, was assigned to the AIDS Division, which is under the Ministry of Health. In 1990, the National AIDS Committee was established, with involvement from 16 different ministries and branches.

In 2000, the government merged the National AIDS Committee with those committees on prevention and control of illicit drugs and prostitution to become the National Committee for AIDS,

Table 1. Estimated Cumulative HIV/AIDS Cases and AIDS Deaths, 2003-2010

| Year | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 |
|---------------|--------|--------|--------|--------|--------|--------|--------|--------|
| HIV | 165444 | 185757 | 197500 | 207375 | 256185 | 284277 | 315568 | 350970 |
| AIDS | 30755 | 39340 | 48864 | 59400 | 70941 | 83516 | 97175 | 112227 |
| Deaths | 27135 | 35407 | 44102 | 54132 | 65171 | 77228 | 90346 | 104701 |

Source: MOH 2003. National Strategy for HIV/AIDS Prevention and Control to the year 2010 with vision to the year 2020

Drugs and Prostitution (NCADP). This committee, which oversees the activities of the National AIDS Program, includes members from the National Drug Standing Bureau (Ministry of Police), the National AIDS Standing Bureau (Ministry of Health) and the Department for Social Evil Prevention (MOLISA). It was this last incarnation that most firmly established the link—both in official policy and, at least partly as a result, in people’s minds—between the “social evils” of illegal drug use and prostitution with HIV and AIDS. Although this structure changed yet again in 2003, the AIDS program still remains within the purview of the NCADP.

These developments have occurred alongside the release of documents which define a legal framework to support the control of HIV and AIDS in Vietnam. The first of these, issued in March 1995, provides guidelines for the development and enhancement of the National Program for HIV/AIDS Prevention and Control. The Ordinance on Prevention and Fight against HIV/AIDS (GOV 1995) was promulgated two months later by the Standing Committee of the National Assembly. In 1996, the government issued the Decree No 34/CP (GOV 1996) to guide the implementation of HIV/AIDS Prevention and Control activities.

The government’s Information, Education and Communications (IEC) programs have been among the more effective NAP interventions, successfully mobilizing active participation of mass media and organizations, which contributed to 70 percent of the population of reproductive age having basic knowledge on HIV and AIDS modes of transmission and prevention measures (UNDP-MOH- AUSAID 2002). However, these IEC activities have not been fully evaluated, and they target only specific groups such as youth, men who have sex with men, people living with HIV and AIDS, sex workers and injection drug users. In addition, IEC activities have not resulted in behavior change that would prevent the spread of HIV. According to the Evaluation Report of National AIDS Program 1996-2001, many of the images used in the messages were fear based—leading, as we show below, to increasing discrimination against people living with HIV and AIDS (UNDP- MOH- AUSAID

2002). Other interventions have included condom distribution, provision of HIV testing and anti-stigma and discrimination measures, which will be discussed further below.

2.3. HIV and AIDS-related stigma and discrimination issues in the legal framework and in the national AIDS program

Government interventions to combat AIDS in Vietnam have a number of key characteristics that distinguish them from efforts in many other countries. One of these is the development of legislative language to support its activities. In this report, we highlight only those pieces of legislation most pertinent to HIV and AIDS-related stigma and discrimination, as they are crucial aspects of the context in which stigma occurs and efforts to redress it.

The Ordinance on the Prevention and Fight against HIV/AIDS (GOV 1995) and the Decree No 34/CP (GOV 1996) are the two most important legal documents regarding activities to reduce HIV and AIDS-related stigma and discrimination. The Ordinance devotes one entire chapter to the issue. Article 4 of this chapter clearly states that people living with HIV and AIDS are subject to protection against stigma and discrimination. Article 9, Item C emphasizes that government bodies, social organizations and the armed forces have the responsibility to provide services and emotional support to people living with HIV and AIDS. Article 11, Item 2 defines the responsibility of family members of people living with HIV and AIDS to provide care and emotional support. Article 20 defines the responsibility of health staff to provide care for AIDS patients and to prevent HIV transmission to their family members. AIDS patients who acquire opportunistic infections are entitled under the Ordinance to get treatment in appropriate specialized health facilities. The refusal to examine or treat people living with HIV and AIDS is strictly forbidden.

The Decree No 34/CP (GOV 1996) also endeavors to reduce HIV and AIDS-related stigma and discrimination, for example, by prohibiting the mass media from providing personal information

about people living with HIV and AIDS without their consent. The Decree also clearly states that the community should provide support and should not stigmatize against people living with HIV and AIDS. However, the Decree does permit health facility leaders and employers to request HIV screening for those “suspected of being at a high risk for HIV infection.”

The National AIDS Program has also made some efforts to tackle AIDS-related stigma and discrimination. For example, one of the targets of the program’s IEC campaign, defined in the Medium-Term Plan 1996-2000, was to raise community understanding about HIV and AIDS in order to reduce fear and stigma. However, no clear guidelines for how to do this have been provided, and while messages, such as the slogan “living together with AIDS,” have been introduced, the content is sometimes obscure and tends to be alarmist and sensationalizing rather than grounded in fact (UNDP-NASB, 2002).

Ironically, the government may unintentionally be undermining its own salutary efforts to combat stigma and discrimination by linking HIV and AIDS to drug use and sex work in both policy and programming. For example, the media—an arm of the government—perpetuates this linkage in its reportage about HIV and AIDS, as can be seen in Box 1, drawn verbatim (although translated into English) from one of the main newspapers of the Communist Party, the Labour Newspaper.

Box 1

News on Social Evils: Prostitution and Drug Use

In the report disseminated in the Summary Conference addressing activities on prevention and control of drug and prostitution...MOLISA reports that the number of sex workers in the whole country has reached 51,255, of whom 16,801 have been documented. Sex workers who are adolescent are on the increase (4.5 percent of sex workers in Hanoi are under 17 years old). Sex workers who are drug addicted and HIV-infected have rapidly increased also (with proportion of HIV infection among those in treatment facilities over 50 percent). The occurrence of the social evil of prostitution has become complicated, especially in big cities, in tourist areas, and resorts, and it has a tendency to spread to suburban areas, and industrialized zones.

The social evil of drug use is also an important problem. In the whole country, there are about 140,000 recorded drug users with 28,000 new cases this year. It is worrying that there are still more than 100,000 drug-addicted persons who are living in the society, and yet only a small number in rehabilitation or education centers.

The fight against drug use and prostitution in Vietnam has for many years been strongly promoted, with a number of policies and strong measures implemented from central to local levels. In the year 2002, 1,351 points of prostitution have been destroyed, 14,167 criminal violations of drug laws have been uncovered, and thousands of related cases have been arrested. However, after each year, statistical data of cases related to these two social evils continuously increased.

Source: Lao Dong 2003. “Prevention and control of drug and prostitution in Vietnam”. Labour Newspaper, No 66, dated 7th, March, 2003

3

The Research Project

This report highlights results from the data collection undertaken in Hai Phong and Can Tho cities in January and February 2003. This section provides an overview of the structure of the project, its methods, details on the sites selected, the study sample, and the data collection and analysis processes.

3.1. Data collection process

3.1.1. Research methods

Due to the sensitivity of the topic, it was decided that a qualitative approach would be most appropriate. The primary methods used to collect data were in-depth interview and focus group discussions (FGDs). Other methods used included observation, photography and the use of participatory techniques during FGDs such as matrix mapping and brainstorming. Before conducting interviews or FGDs, researchers obtained the consent of respondents to participate and their permission to record the discussion.

Secondary sources were also consulted widely. Academic journals, research reports, books, newspapers and TV broadcasts on HIV and AIDS were explored, and further information was obtained from LAG members.

Focus group and interview guidelines were developed by the team, based on findings from the NGO workshop and discussions with experts from ICRW and the LAG. These guidelines were refined and eventually finalized and compared with tools developed for Africa HIV-related stigma and discrimination studies conducted by ICRW with their partners in Ethiopia, Zambia and Tanzania.⁶ Data collection instruments were pre-tested and further refined during the fieldwork process.

3.1.2 Site selection

Through discussion with ICRW and the National AIDS Standing Bureau, two areas were selected for the research: Hai Phong city in the north, and Can Tho city in the south. These two cities were selected on the basis of the following considerations:

- i. These two provinces represent the two largest river delta areas in the country and they have relatively equal levels of socio-economic development;
- ii. Both provinces are experiencing an expanding HIV and AIDS epidemic;
- iii. Many intervention activities have been implemented in these provinces; and
- iv. The research in these provinces could be facilitated by pre-existing relationships between ISDS and the two Provincial AIDS Standing Bureaus (PASB)

Based on the advice of the LAG and partners at the Provincial AIDS Standing Bureaus, it was decided that the research sites should be peri-urban with a fairly high density of people living with AIDS. The peri-urban location was considered important as these areas are undergoing rapid socio-economic development and change, including rising rates of drug use and sex work. They are wards in which the newly urbanizing populations mix with longer-standing rural populations, and are socially and economically diverse. The two wards ultimately selected were Lam Son in Hai Phong and Xuan Khanh in Can Tho city. Prior to conducting the research, the PASB sent an official letter to the area selected to inform the local officials about the research and to request their permission to undertake the work.

⁶The project reported here is part of a larger program of work on HIV and AIDS-related stigma and discrimination being undertaken by ICRW with its in-country partners in a number of settings, including this three-country study in Africa. See Nyblade et al. 2003 for more details, or visit www.icrw.org.

Hai Phong

Hai Phong, a coastal port city, is the third largest city in Vietnam, covering 1,507 square kilometers with a population of 1.7 million people. It is one of the main sea, waterway and road transportation hubs of the North.

Hai Phong is known to have a serious problem with illicit drug use. In 2001, the Hai Phong police identified, arrested and brought to court 442 drug-related cases, in which 722 people were found to have participated in drug trafficking and use. Currently, Hai Phong has 5,200 recorded drug users, but the actual number is likely much higher. Like other areas in the country, drug addiction in Hai Phong occurs mainly among men, with women making up only 1.2 percent of the total. Drug addiction is also a phenomenon of youth: most drug users are 18-35 years old. Injectable heroin is the most commonly used drug in the area. See Appendix A for a discussion of the issue of drug use in Hai Phong.

Hai Phong currently has the second highest HIV infection rate in Vietnam. The total number of HIV cases in Hai Phong is currently 4,986, among whom 807 have developed AIDS and 372 have died (Hai Phong Health Department 2003). According to the Summary Report on HIV/AIDS Prevention and Control Activities 2002 and the Hai Phong Health Department's Working Plan for the Year 2003, the HIV and AIDS epidemic in Hai Phong is closely linked to increases in drug use and sex work. Statistical data indicates that 71.2 percent of those living with HIV and AIDS were infected through injection drug use and 2.5 percent were infected through sex work. Over 80 percent of the total number of those living with HIV and AIDS in the city are between the ages of 19-40.

HIV and AIDS intervention projects have been in place in Hai Phong since the early 1990s. Many of these projects are supported by international organizations, such as Family Health International, Save the Children Fund and World Vision. Projects include peer education and support efforts such as the Seagull (*Hai Au*) Club (see Appendix B) and Friends to Help Friends groups.

As noted earlier, Lam Son ward was selected as the site for this research. This ward contains 3,000 households with a total population of about 13,000. Lam Son ward also contains some of the most notorious gathering places for drug use in the city: the railway area, the city canal and the river port. There is a small residential area in the railway and canal districts known as the "daring village" (*xom lieu*) because it is home to a high number of drug users, sex workers and others involved in illegal activities. According to officials at the Le Chan District Health Center, Lam Son has the highest number of people living with HIV and AIDS in the district, with 99 people living with HIV and AIDS as of February 2003.

According to the Lam Son ward health report (2003), the first case of HIV was detected in 1998. Drug use and HIV and AIDS are currently considered to be the most pressing problems in the ward. The ward's authorities report that there are currently about 60-70 drug addicted persons living in the ward area.

The ward authorities and police have been actively involved in attempting to put a stop to the area's drug trafficking and drug injection activities. However, these authorities informed us that their efforts have merely driven these activities further underground, and dispersed them into other areas of the city—the market area in particular.

Because of its notoriety as a location for drug use and sex work, a number of HIV and AIDS intervention projects have been carried out in Lam Son, including a World Vision project known as "support and care for PLWHA in community" (see Appendix B). For this reason, it is likely that people living here have had relatively good exposure to information and education concerning HIV and AIDS.

Can Tho

Can Tho province is located in the middle of the Mekong river delta, about 170 km west of Ho Chi Minh city. Can Tho city is the main urban area in the province and has long been the socio-economic and cultural center of the Mekong river delta. Can Tho city itself covers 141 square kilometers and has a total population of about 400,000.

The first case of HIV in Can Tho was detected in 1992. By the end of 2002, 2,068 HIV cases had been recorded (Can Tho Health Department 2003). As elsewhere in Vietnam, those affected most by AIDS are the young: more than 90 percent of those living with HIV and AIDS in Can Tho are between the ages of 15 and 39. An important distinguishing characteristic of the HIV epidemic in Can Tho is that, unlike other parts of the country where the disease is transmitted primarily through injection drug use, here it is thought that in the early stages of the epidemic nearly 80 percent of infections were acquired through heterosexual intercourse (Can Tho Health Department 2001). Since 2000, however, there has been a notable increase in HIV infections among young drug users, and this population now accounts for 41.5 percent of all HIV cases in the province (People’s Council of Can Tho province 2002).

There are likely considerable numbers of sex workers who also inject drugs, as well as increasing numbers of young women who sell sex in order to fund a drug habit. According to a Population Council report (Population Council 1999), Xuan Khanh ward is a “hot spot” of drug use and sex work. In 1998, 63 percent of those living with HIV and AIDS were 20-29, mostly female sex workers (nearly 40 percent). Drug injection was the cause of only 4.1 percent of all HIV infections—only two or three cases (Population Council 1999). However, local authorities in Xuan Khanh report that the number of IDUs sharply increased in 2000 and 2001, and by 2002 there were 48 people living with HIV in the ward who had become infected through injection drug use (Can Tho Health Department 2003).

Various HIV and AIDS prevention activities have been implemented in Can Tho. These have included the provision of health examinations and HIV testing for waitresses, bar girls, barbers, masseurs, sailors and long-distance truck drivers. HIV testing is also conducted among those joining the army. Can Tho was among the first provinces to conduct behavior change programs for “high risk groups” in all residential clusters and IEC cam-

paigns directly in restaurants, bars and hotels. The province has also implemented the “100 percent Condom Use Program” in some key areas known for sex work. Other HIV and AIDS programs in the area include the “Women’s Health Club” project (see Appendix B) and a project on STD prevention supported by Family Health International.

Because of its well-known problems with drug use and sex work, the Xuan Khanh ward within Can Tho city was selected for the fieldwork. This ward has a population of 26,948 (in 3,528 households) and is experiencing rapid urbanization. The population is relatively poor, principally earning income through petty trade and daily wage labor.

3.2 Study sample

The research sample included people living with HIV and AIDS, their family members and people living in their communities. In selecting participants living with HIV and AIDS, we sought to interview those who were infected through injection drug use, those infected through sex work, and those who acquired HIV through other means.⁷

The fieldwork for this study was carried out with close and active collaboration of the two PASBs, staff of district and wards’ health centers, and the wards’ People’s Committees (a local governance structure that includes elected representatives at the provincial, district and community level). People living with HIV and AIDS were selected mainly through introduction via the district health center and PASBs. Snowball sampling techniques were also employed to identify people living with HIV and AIDS, particularly sex workers, in Hai Phong. Community members were selected with assistance from local collaborators.

In each site, the research sample included:

- ▶ Fifteen people living with HIV and AIDS (male and female): five who were reported to be infected due to sex work, five infected through drug injection use and five infected by other means (mainly the sex partners or spouses of IDUs and clients of sex workers).

⁷ Although we agree that the use of acronyms to refer to these particular groups of people is objectionable, for ease of reading, we have used the following designations when attributing quotes: **PLWHA_IDU** refers to participants who acquired HIV through injection drug use; **PLWHA_SW** refers to participants who acquired the infection through sex work; **PLWHA_Other** refers to those participants who acquired HIV infection through other means.

- ▶ Fifteen male and female family members of people living with HIV and AIDS. After obtaining the permission of the interviewee living with HIV or AIDS, a close family member was asked to provide an interview. These participants included parents, spouses, siblings, lovers, other relatives and caregivers.
- ▶ In each ward, 64 community members participated in one of eight FGDs (4 FGDs of men and 4 FGDs of the following age groups 15-24; 25-34; 35-49; and over 50).
- ▶ Sixteen people were selected for participation in two FGDs: one consisting of local authorities, and the other representatives of grassroots organizations.
- ▶ Several in-depth interviews were conducted with local leaders, including the Chairperson or Vice Chairperson of the ward; the Secretary or Vice Secretary of the Communist Party; representatives of different Party branches; representatives of groups such as the Fatherland Front, Women's Union, Youth Union, Red Cross, Veteran's Association; and various religious groups.
- ▶ Additional key informant in-depth interviews were conducted with local health workers, teachers, and other members of the community.

The total number of participants in the study—271—exceeded original expectations of 188 participants.

3.3 The research team

The fieldwork was carried out by the research team at ISDS, which included researchers with particular experience conducting qualitative research on sensitive topics with hard-to-reach groups. Before conducting the fieldwork, members of the research team were trained on the conceptual framework of the study, interview guidelines and the other data collection techniques.

Each FGD was tape recorded and facilitated by a senior researcher. A note-taker recorded the proceedings and documented observations. In-depth interviews were conducted directly be-

tween the researcher and a study participant in his or her home.

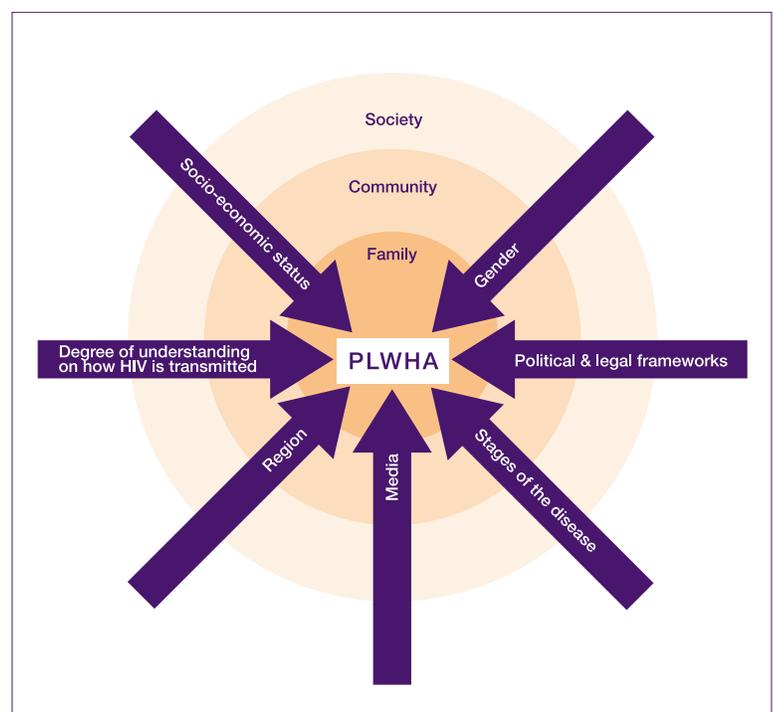
3.4 Data processing and data analysis

Following data collection, all taped interviews and FGDs were transcribed, with around 20 percent translated into English for review by the ICRW team. The ISDS team was subsequently trained in the use of NVIVO 2.0 qualitative data management and analysis software by an ICRW consultant. The software was selected because it enables researchers to organize and assess complex qualitative data, and can also work using Vietnamese language script. Through the training process, key domains for analysis were identified, data was coded, and a codebook and preliminary analytical framework were developed. These tools were further refined in consultation with the Project Director from ICRW.

3.4.1. Factors determining HIV-related stigma in Vietnam

The conceptual framework below illustrates that HIV-related stigma occurring within society, within communities and within individual families and households will all combine to influence the nature and degree of stigma experienced by an

Figure 1: Conceptual Framework



individual person living with HIV and AIDS. Self-stigma, or stigma internalized by people living with HIV and AIDS, is also evident. Through the data analysis process, it was discerned that stigma is caused by factors in the social, cultural, political and economic environment. Key factors affecting the nature and degree of stigma also include the stage of the disease (those in more advanced stages experiencing greater stigma) and gender (on the whole women were more adversely affected by the experience of stigma than men). And finally, we found that the media is having a negative impact by reinforcing, rather than challenging, the prevailing fears, misapprehensions and stereotypes that fuel and exacerbate HIV-related stigma. These findings resonate strongly with findings from studies on stigma conducted elsewhere (e.g. Nyblade et al. 2003; Bond et al. 2003).

3.5 Scope and limitations of the research

The scope and focus of this research was to observe, document and attempt to describe the nature of stigma experienced by people living with HIV and AIDS, its root causes and principal manifestations in specified areas of Vietnam. We were

particularly interested in whether, and to what extent, HIV-related stigma overlapped with and was affected by other social stigmas affecting those at risk, specifically injection drug users and sex workers. Our aim was not to *quantify* this stigma or to *measure* its impact, but to document and describe experiences and to determine underlying causes of stigma. Because so little is known about HIV-related stigma in the Vietnamese context, we felt it appropriate to focus our efforts in those geographical areas in which HIV is already present and making an impact. Although our sample was not quantitatively representative of the country as a whole (focused as it was in two urban areas only), our findings do enable us to generate *generalizable principles*, on the basis of which meaningful interventions can be developed (see Mitchell 1983). It is important to note, however, that in our sampling we omitted one important group: men who have sex with men, a population likely to be at risk of HIV infection in Vietnam. Although we recognize the special vulnerabilities of these men and feel it would be appropriate to document their experiences, the timeframe of the project did not allow us to include them in our study.

4 Findings

This section outlines and describes the main findings of this research study. We first discuss and describe what we found to be the principal underlying causes of HIV and AIDS-related stigma and discrimination, which derive from practical, moral, economic, cultural and political dimensions of people's lives. We then explore the principal forms that stigma takes, including the use of demeaning and hurtful language when referring to or speaking with a person living with HIV and AIDS; the isolation, marginalization and avoidance of people living with HIV and AIDS; and self-stigma, or the internalization of stigma due to experience or fear of the above behaviors. We highlight the main places in which stigma takes place and discuss the role of the media in perpetuating stigma. We conclude this section with an overview of the principal impact that stigma is having on people living with HIV and AIDS, their families, communities and the nation as a whole.

4.1. The causes of HIV and AIDS-related stigma in Vietnam

Stigma is a complex social phenomenon involving interplay between social and economic factors in the environment and psycho-social issues of affected individuals. Erving Goffman (1963) describes three types of stigma: "abominations of the body," or stigma related to physical deformities; stigma related to "blemishes of individual character," for example those who are considered weak willed, to have unnatural passions, or to be dishonest; and "tribal stigma," or stigma relating to race, nation or religion, or membership of a despised social group. Because one typically inherits membership to this type of group, "tribal" stigma can equally adhere to and affect all members of a family.

While Goffman focuses on the individual aspects of stigma, Parker and Aggleton (2003) offer a

framework that emphasizes stigma as a social process that produces and reproduces relations of power and control and examines how stigma is used to turn difference into inequity—including inequity based on gender, age, sexual orientation, class, race or ethnicity—thus allowing some groups to devalue others on the basis of these differences. According to this analysis, stigma and discrimination are used by dominant groups to produce, legitimize and perpetuate social inequities and to exert social control through the exclusion of stigmatized groups, thus limiting ability of the stigmatized groups and individuals to resist or fight back against the stigma.

Box 2: Defining "Stigma" and "Discrimination"

In December 2003, UNAIDS posted a Fact Sheet on stigma and discrimination on their web site (www.unaids.org) which provides a useful summary definition of both stigma and discrimination. The following is taken from this Fact Sheet:

- ▶ HIV/AIDS-related **stigma** can be described as a "process of devaluation" of people either living with or associated with HIV and AIDS. This stigma often stems from the underlying stigmatization of sex and intravenous drug use—two of the primary routes of HIV infection.
- ▶ **Discrimination** follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination occurs when a distinction is made against a person that results in being treated unfairly and unjustly on the basis of belonging, or being perceived to belong, to a particular group.

In this report we tend to refer to "discrimination" as the "forms" and "manifestations" of stigma.

The findings from this study resonate well with these explanations. In the communities of our study, we found that stigma stems largely from practical, moral, economic, cultural and political factors. The practical dimension of stigma relates to the stigma that adheres to all infectious diseases to greater or lesser degrees. Because HIV is considered to be a serious, communicable and incurable illness, it is greatly feared. This fear is exacerbated by the vague and sometimes conflicting messages conveyed by the media and through everyday gossip and talk about the mechanisms by which HIV is transmitted. Even when people seem to understand, or at least are able to repeat, the three main modes of transmission, they do not trust this knowledge. Rather, they fear that HIV can be transmitted through casual everyday contact, in

the way that other viral or bacterial infections can be (see Box 3, Basic Facts about HIV Transmission).

The moral dimension of stigma relates to the fact that up until the present time, HIV and AIDS have been strongly linked in policy, programs and in peoples’ minds with injection drug use and sex work—which in turn are considered to be “social evils.” Both drug use and sex work have long been reviled in Vietnam (and elsewhere) because they are regarded as behaviors that deviate from traditional moral norms and values. Moreover, it is generally believed in the community that drug use and prostitution *inevitably* lead to AIDS, and that those with AIDS likely contracted it from one of these two means. Thus, people living with HIV and AIDS, injection drug users and sex workers are all multiply stigmatized, as all are considered to either be “socially evil” (drug users and prostitutes), or ill as a result of their “socially evil” behavior (people with HIV and AIDS). This situation appears to be further exacerbated by the current government programs combating drug use and sex work, which capitalize on the notion of “social evils” to encourage people to give up these practices, or for others to turn those engaging in them into the police.

Box 3: Basic Facts about HIV Transmission

AIDS (Acquired Immune Deficiency Syndrome) is caused by a virus, HIV (Human Immunodeficiency Virus). HIV is *not* transmitted easily. In fact HIV is a very fragile organism that is easily killed on contact with air and water. HIV can only be transmitted directly by having sexual intercourse with an infected partner without using a condom; through the direct exchange of blood or body fluids; or from an infected mother to her child during pregnancy, delivery or through breast milk (<http://www.who.int/hiv/about/hiv/en/>). Unlike some bacteria and fungi, HIV is unable to reproduce outside its living host. Therefore, it does not spread or maintain infectiousness outside its host (<http://www.cdc.gov/hiv/pubs/facts/transmission.htm>).

In this research we found that the mode of transmission described as “through the direct exchange of blood or body fluids”—commonly referred to in Vietnam as “through blood”—is the most commonly misunderstood mode of transmission in Vietnam. According to the US Centers for Diseases Control, what “through blood” actually means is that HIV can be transmitted “by sharing needles and/or syringes (primarily for drug injection) with someone who is infected, or, less commonly (and now very rarely in countries where blood is screened for HIV antibodies), through transfusions of infected blood or blood clotting factors.” CDC goes on to explain that “some people fear that HIV might be transmitted in other ways; however, no scientific evidence to support any of these fears has been found. If HIV were being transmitted through other routes (such as through air, water, or insects), the pattern of reported AIDS cases would be much different from what has been observed. For example, if mosquitoes could transmit HIV infection, many more young children and preadolescents would have been diagnosed with AIDS” (see <http://www.cdc.gov/hiv/pubs/facts/transmission.htm>).

We argue below that in order to effectively combat HIV and AIDS-related stigma in Vietnam, it will be necessary to delink the illness from “social evils” in social policy and in the minds of the general public. Similar results have been reported in a number of recent studies conducted elsewhere in the country. A recent ILO survey on 200 workers in Hanoi and Ho Chi Minh city revealed the same link between HIV and AIDS and social evils in surveyed workers (Le Bach Duong 2003).

The following sections will deal with each of these root causes of stigma—fear of casual transmission and moral causes—in turn.

4.1.1 Stigma related to fear of HIV and fear of casual transmission

Almost without exception, study participants voiced concern about the risks posed to the wider community by the presence of HIV-positive individuals living in the community. This is due in

part to the fear of HIV as an incurable and fatal infectious disease, and in part to the fact that people have inaccurate and incomplete information about the ways in which HIV can be transmitted. Both issues stem from *fear*, and both can be positively influenced by appropriate and well considered interventions.

Fear of HIV and AIDS: “The disease of the century”

Results of the research indicate that fear of HIV and AIDS is one of the principal causes of stigma against people living with HIV and AIDS and their families. This is related in part to fear that accompanies other infectious diseases, such as leprosy or tuberculosis, and also to the fact that people are uncertain about the ways in which HIV can be transmitted or do not fully trust the knowledge they have acquired. We found that some of the messages about HIV transmission are both terrifying and vague—a combination that seems to have led to greater confusion and fear than to solid understanding and awareness. And out of this confusion and fear arises stigma.

HIV as a dreaded disease

There is a common saying in northern Vietnam that “one should not be associated with a leper,” implying that a person with leprosy is dangerous so it is better not to have any connection with him or her. One of our participants living with HIV and AIDS invokes this old saying to explain people’s stigmatizing attitudes toward him:

People do not understand well so they fear it [HIV] like the leprosy of the past. Whenever talking about HIV, they imagine the word “leprosy.” To them the two diseases are equivalent, so they keep away. (Hai Phong, male PLWHA_Other)

Others feel that HIV and AIDS are even more frightening than feared and disfiguring diseases:

It’s also awful, for example, to see someone with scabies, but people are not afraid. Comparing cancer and AIDS, AIDS is more frightening because AIDS has a scarier outside appearance, can be transmitted to others and

makes it more easy to get other diseases. Now hearing about AIDS people would fear in the way they feared leprosy in the past. Now leprosy is curable, but AIDS is not. That’s why people fear it. (Hai Phong, female health worker)

In part this fear relates to the fact that HIV is a terminal illness that currently has no cure. This type of fear is aptly summed up by the following remarks:

To get HIV is to carry the death sentence. (Hai Phong, FGD of local grassroots organizations)

Cancer may be cured in the future, but for AIDS it is only death. (Can Tho, housewife)

If in the family there is a child or husband or wife who gets HIV, honestly, the family considers those as dead already. Even though that person could live five years longer, that person is regarded as not living in this world. (Hai Phong, participant in FGD of women over 50 years old)

This pervasive fear of HIV and AIDS can even overwhelm affection toward those who are sick and intentions not to stigmatize or avoid them, as one community member admits:

Seeing that he is so very sick and rough looking, to tell the truth, even though I esteem him very much, I am afraid. If I want to sit with him I would sit far away—I could not dare to sit next to him. (Hai Phong, participant in FGD of women 35-54 years old)

The community shows readiness to assist people living with HIV and AIDS, but most community members could not hide their concerns about having physical contact with people living with HIV and AIDS:

Regarding help, everyone is willing to do so, but...getting close—hugging or even burying—that’s what they are reluctant to do. People are even reluctant to hold hands [of

people living with HIV and AIDS]. Everyone is in the spirit of helping, but many times they do not dare to visit the house or to get physically close. (Can Tho, participant in FGD of men over 50 years old)

Fear and uncertainty about modes of HIV transmission:

As the previous discussion indicates, many people fear that close contact with someone living with HIV and AIDS could result in disease transmission. This fear persists, even though most people have been exposed to some information about HIV transmission. For example, the majority of respondents list (as if by rote) three main mechanisms for HIV transmission: through blood, through "promiscuous" or "unprotected" sex (sometimes referred to as "whoring") and from mother to child through breast milk or during childbirth. However, many respondents added incorrect modes of transmission or information to this list, including the following:

- ▶ Cuts on the body from a razor, hair cut, nail trimming, washing hair, pulling teeth
- ▶ Sharing personal belongings such as towels, toothbrush or comb
- ▶ Massage, sitting on toilet basin
- ▶ Mosquito bites
- ▶ HIV can live in the environment outside the body for seven days
- ▶ HIV is not killed in boiling water
- ▶ HIV-infected blood can be transmitted by food to the stomach and can remain viable even when food is cooked
- ▶ HIV is in sweat and can be transmitted through sweat
- ▶ HIV can be transmitted through the air
- ▶ When a person with AIDS dies, the microbes "fly" from his or her body; a toxic gas rises from the body of someone who has just died of AIDS
- ▶ Smoke rising from the cremation of a person with AIDS can transmit HIV to people standing nearby

Although there are clearly many concerns and misunderstandings about modes of HIV transmis-

sion, it appears that the "through blood" mode concerns people the most, is the least well-defined and raises the most fear and uncertainty in people's minds. It is widely believed, for example, that HIV can be transmitted "easily" through the use of commonly shared implements such as nail clippers. The following quote from a woman in Can Tho is typical of this prevalent view: "It is easy to be infected when trimming nails together with an HIV infected person.... To prevent catching the disease it is important to bring a clean nail trimmer when trimming the nails—or we do it at home only." But far more worrying for most people is the nearly universal belief that "through blood" includes even minimal exposure, such as passing contact with even a minor cut or graze. As one woman in a focus group in Can Tho notes: "... In some cases an infected person might have a cut finger—we can get his disease through this kind of injury." A 21-year-old woman from Hai Phong expresses this understanding of transmission—and the fears it raises—quite clearly:

... [HIV] is transmitted through blood and unsafe sexual relationships only... but in case we are grazed, it can be transmitted through blood—even if it is a small scratch only... Cutting hair may also cause the disease. For example, if we hold the scissors that makes our skin grazed, another person who holds it later could be infected, too.

In fact, many people are concerned about the risks posed to their health merely by co-existing with community members who are living with HIV, as the following quote illustrates:

...in terms of theory, we should not discriminate, but in our minds fears remain. As my colleague here said, I will not sit by those infected people if I meet them in a café because I also worry whether it is transmitted by any other way... For example my neighbor who is a teacher has an infected son. Whenever meeting him by chance we only greet him summarily. We don't want to touch him. (Can Tho, participant in FGD of community leaders)

It is notable that health professionals as well as community members fear becoming infected, despite “knowing” the mechanisms of transmission. One such health worker was extremely candid during a group discussion in Hai Phong:

I am a health professional. I know that HIV is transmitted only in three main ways. But when I come into contact with them [people living with HIV and AIDS] I still worry and feel nervous... In my case it is my duty, my responsibility to work with them, to go to them. But in fact I am fearful.

Teachers also express concerns. Despite understanding the modes of HIV transmission, these two teachers both feel uncomfortable, even fearful, when having contact with people living with HIV and AIDS:

When I see those persons, I really do not dare to be open or to have contact with them, honestly. I understand though, but I still feel it is not OK. I don't dare to get close because I fear infection. (Hai Phong, male teacher)

Frankly, it's frightening, even when I know that sitting and drinking water cannot lead to infection. To be sincere, I know clearly that it is not infectious, but I don't even drink water with them [people with HIV and AIDS] as normal. That's what I say truly from my heart. (Hai Phong, female teacher)

The vast majority of people do not really know the extent or manner of the risks they are exposed to by the presence of people living with HIV and AIDS, and they generally fear the worst is possible, if not probable. This creates panic and results in the isolation and rejection of people living with HIV and AIDS, avoidance of their goods and services, and secondary stigma against their family members and children. These expressions of stigma will be discussed further in Section 4.2.

A further finding is that the fear of HIV and AIDS relates to the stage of the disease, and so changes over time. When a person living with HIV and AIDS

is in the later stages of infection, with very visible and very upsetting symptoms, heightened fear combines with physical revulsion, as one study participant who is living with HIV explains:

Everyone is frightened during the AIDS stage. When I get pimples coming out or spots on my face, people fear and they avoid me right away. They fear infection. Surely the community has compassion, but they do not dare to have contact with a person in the AIDS stage. When they know a person is dying, they just come and give gifts but they do not dare to get close. But when you first get HIV and there are still no symptoms, people have less fear. (Hai Phong, male PLWHA_IDU)

Therefore, evidence from this research indicates that despite having some information about routes of HIV transmission, people in the community, including health workers, teachers and family members of people living with HIV and AIDS, continue to be fearful and uncertain about the illness and its transmission, which can lead to stigma and discrimination against those living with it. In the next section, we discuss how fears of transmission interact with moral judgments, cultural values, and existing stigmas against drug users and sex workers.

4.1.2 HIV, drug use, sex work and their impact on family: moral causes of stigma

“In my opinion... HIV is caused by prostitutes and intravenous drug users.” (Hai Phong, female, 21 years old)

“At the present time, people are generally aware of this problem [HIV and AIDS]. They are aware that this is a social evil, it is not a disease.” (Hai Phong, participant in FGD of community leaders)

One of the core concerns of this study was to explore whether drug users and sex workers with HIV experience stigma differently than those who contracted HIV through other means, and if so, to describe these differences. When we approached

this issue with many of our respondents from these categories, we learned that they knew of and had experienced stigma long before they ever obtained an HIV diagnosis. Vietnamese society strongly opposes drug use and sex work, and those involved in these activities are generally considered to be criminals and thieves. Drug use and prostitution are referred to in common parlance as “social evils”⁸

A variety of issues underlie these attitudes, but at their core are Vietnamese values about family. The family is at the center of Vietnamese society. Building, strengthening and protecting one’s family are among each person’s most sacred responsibilities and duties. Behaviors that are seen as potentially damaging to the family are simply not tolerated. Using drugs and getting involved in prostitution are strongly condemned because these behaviors are regarded as threatening the stability of families: using drugs because this can damage family finances, and sex work because it is considered degrading and licentious; it “breaks the family’s happiness” because it causes men to be unfaithful to their wives. Therefore, drug users and sex workers have been stigmatized well before the presence of HIV in Vietnam. As one study participant says:

Since I am a “scag” [drug user], whenever I go to see my friend and ask for him, his family just hates me. They do not let their child to go with me. (Can Tho, male PLWHA_IDU)

Those drug users we spoke with say that they are being ostracized and kept away from community interactions, and they feel that there is no hope for support and assistance from the community:

The fact that they call me a scag shows that there is some discrimination already. Scag persons often do things wrongly, such as stealing their things. They are afraid of me, and avoid me so that I cannot infect them. They are not my blood ties so why should they care for me? (Can Tho, male PLWHA_IDU)

Many think that being drug addicted means losing [humanity], and that such people have no need for relationships. (Hai Phong, wife of PLWHA_IDU)

If drug users are hated and feared, sex workers often generate scorn. They are also isolated from social relationships:

People told me that I should stop spending time with her. They said things like “I know you have been close with her from childhood, but now she goes on that track [sex work] so don’t play with her. If you play with her people will say that you are also a cave [bar girl].” Since then I stopped having any contact with her. I am such a decent person I should not have anything to do with her anymore. (Hai Phong, female, 21 years old)

Now I see prostitution and AIDS as the good-for-nothing ones. It is clear that this girl is cave so she is good for nothing, she is too lazy to work. She puts on makeup, then no one knows what she is. If people know they would despise her. (Hai Phong, participant in FGD of local authorities)

The close epidemiological and sociological associations that are made between HIV, drug use and sex work have greatly enhanced these pre-existing stigmas because today it is almost assumed that if you inject drugs or become involved in sex work, you will sooner or later become infected with and die from HIV and AIDS. As one interview respondent says: “To be drug addicted is to be HIV infected.” (Hai Phong, female, 21 years old)

Even when people did not mention these behaviors directly, when discussing modes of HIV infection, many participants report that one gets HIV through “indulging in play,” “acting like a vagabond,” or living in a “snobbish” way—all proxies for drug use and sex work. Many seem to consider people living with HIV and AIDS as “unhealthy types of persons” to have around in the community.

⁸ The Vietnamese dictionary defines the word “evil” as “degenerate,” which in turn is defined as “crumpled, decayed, or bad.” The examples given to describe “degenerate” are “gambling, boozing... and social evils” (Vietnamese dictionary, Social Science Publishing House, Hanoi, 1977).

Talking about HIV, people think it is probably due to drug injection—or secondly, to prostitution. They seldom think it happens by accident. (Can Tho, female student, 24 years old)

Here the majority of them [people living with HIV and AIDS] are infected due to indulging in play or drug injection. It has never been discovered among normal people who live in a healthy way. (Can Tho, participant in FGD of women 19-24 years old)

The assumptions made about the inevitable linkages between drug use, sex work and HIV are reflected clearly in people's comments throughout the course of the fieldwork:

When you do such a job [sex work] you cannot get away with it. Everyone who does such job will get HIV-infected. (Hai Phong, female, 21 years old)

If someone goes to have sex with a prostitute, or someone injects drugs, sooner or later that person would be caught with this HIV/AIDS. (Can Tho, participant in FGD of local authorities)

Degrees of stigma

Not all HIV infected persons bear the same level of stigma. A number of participants feel that moral judgments against people living with HIV and AIDS should be based on how that person acquired HIV and on their lifestyle. According to some community members, people living with HIV and AIDS can be classified into two different groups according to reasons of infection. The first are those who are “degraded” and become infected due to deviant behaviors such as drug injection and prostitution. This group deserves blame and social opprobrium. The second are those who are simply “unlucky” and become infected by their wives or husbands, through contact with the blood of an HIV-infected person, through a blood transfusion or from a mother to her child. This group often receives sympathy, compassion and support.

In the case of women who unfortunately get infected, we should give them support and educate them so that they can avoid transmitting to others. Regarding the case of drug injectors, the damage is already done and they cannot be educated. We should definitely put them in a separate place because we cannot educate those people. The other group—they deserve our pity and we should protect them. (Hai Phong, participant in FGD of women over 50 years old)

If someone unfortunately gets infected, then people show sympathy and concern, even help. But they would despise those persons, who are for instance, sex worker, or IDUs, or indulging in play. (Hai Phong, participant in FGD of men 15-24 years old)

Some participants spoke candidly about their discriminating attitudes toward different groups of people living with HIV and AIDS according to how they acquired their infection:

If she is infected because she herself goes for prostitution... even when she is dying no one would care, but in the case of infection through her husband, then we have pity for her. We would say the husband should be damned for letting his wife become infected. (Hai Phong, participant in FGD of men over 50 years old)

Those who are expected to uphold the moral laws and the moral fabric of society are most harshly criticized should they become infected with HIV, as this infection is a *de facto* indication that they have “indulged in play.” This is generally true for women, who are expected to uphold customary Vietnamese values, as well as Communist Party members, as the following quote indicates:

I see there are two cases: if one is infected accidentally, that's another story. Now, if you sell out your morality to buy the disease, that's different. If you are a Party member, for example, and you go and do an indecent

thing and you get infected, the Party should definitely expel you. (Can Tho, participant in FGD of grassroots organizations)

Culpability of the family

As indicated by Goffman (1963), stigma adheres not only to the person or persons with the discrediting characteristic, but sometimes to their families as well. In Vietnam, the families of IDUs or sex workers who become HIV infected are also criticized heavily. It is felt that the family has neglected the education of its children, causing them to become "degraded." Many use traditional sayings such as "strike while the iron is hot" (one must educate children when they are still small) or "a child becomes spoiled because of the mother, a grandchild becomes spoiled because of the grandmother"—to emphasize the family's responsibility (and particularly the mother and grandmother's responsibility) for ensuring that their children do not get involved in "bad behaviors" that make them vulnerable to acquiring HIV infection.

People tend to think that children get this disease when they become spoiled. It's clear that the family does not know how to educate their children. People say that the family is to blame, not the infected one. (Hai Phong, male PLWHA_IDU)

In reality, many families, knowing that their child is using drugs, try to educate and encourage him or her to give up. If these children later become infected with HIV, the parents despair of what happened to their family. They often feel helpless, as the following quotes indicate:

I regret for him, he is young and not married but follows that track of drug addiction and... harms the family and... society. I also do not like that. Many times I encouraged him to go for detoxification, but what could I do if he did not follow my advice? It's not as if I knew he was addicted and just let him alone. (Hai Phong, mother of PLHA_IDU)

Now I am asking you, he is my child, what should I do to him? If I do not allow him to inject [drugs] inside the house, he goes outside in the street to inject. What would you do? (Can Tho, father of PLWHA_IDU)

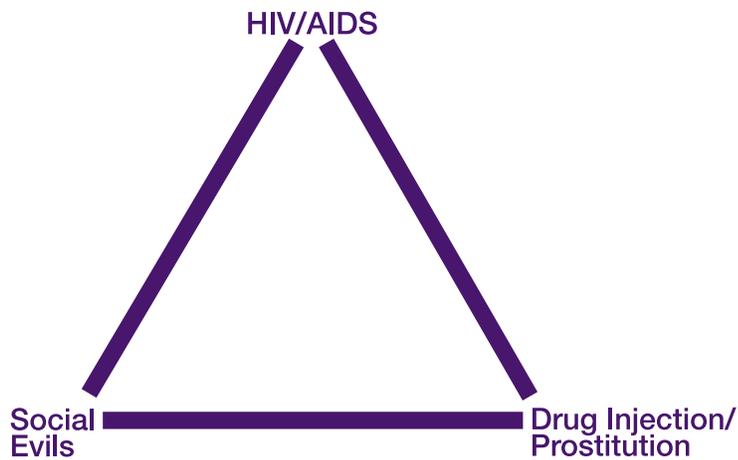
4.1.3 HIV and AIDS as "social evils": The stigma triangle

The previous sections highlighted the links between moral judgments about IDUs and sex workers, and how these judgments are an underlying cause of HIV-related stigma.

As discussed in the introduction, drug use and prostitution are not only described as social evils and linked with HIV and AIDS by the lay public, but also in the law. Even as recently as February 2003, the government issued a policy stating that prostitution and drug use are the primary causes for the escalating HIV and AIDS epidemic.

Results from our study suggest that linking prostitution, drug use and HIV and AIDS is exacerbating the stigma experienced by people living with HIV and AIDS. Our research indicates that in the public mind, HIV and AIDS have become equivalent to a social evil, as indicated in the simple "triangle" diagram in Box 4. In the eyes of society, people living with HIV and AIDS often are suspected of

Box 4: The stigma triangle showing perceived equivalence between HIV/AIDS, drug use and prostitution, and social evils



having evil behaviors, and they are then seen as “deserving” their fate. At the same time, they are reviled as a source of disease transmission.

The comments of some of our respondents clearly illustrate this phenomenon:

At present time, people are generally aware of this problem [HIV and AIDS]. They are aware that this is a social evil, it is not a disease. (Hai Phong, participant in FGD of local authorities)

In fact, PLWHA [infected from sex work or intravenous drug use] are social evil persons, they are not like normal people who get infected accidentally. (Hai Phong, female, teacher)

Family members of people living with HIV and AIDS are bitter about the blame their children receive for the increase in “social evils”:

Among that group, they talked to each other, they called him as “SIDA guy.” In the hamlet some kids said that. I glared at them and said, “Please do not say that. I do not want to hear that saying in front of me.” The word “SIDA” is not just a normal word, it indicates the bad person of the society nowadays, only that kind get such disease. If a person is decent and honest, how could that person go on that track? I do not know what this disease is, but hearing the sound HIV, I hear a wicked word of the society. (Can Tho, mother of PLWHA)

Although our research did not seek specifically to examine the concept of “social evils” in depth, such a study would be useful. More knowledge is needed on people’s perceptions of and belief about “social evils,” and the ways in which official discourse and legal and policy documents may contribute to the confusions that are significantly exacerbating HIV-related stigma and discrimination for people living with HIV and AIDS and their family members.

The government’s “Liquidate Social Evils” campaign has brought unexpected consequences, negatively

affecting attitudes toward people living with HIV and AIDS. The messages of the campaign are delivered through various channels, including high-impact Information, Education and Communication activities. In the following section we take a brief, but critical, look at the impact of the campaign on HIV-related stigma and discrimination.

Role of IEC in creating and perpetuating HIV-related stigma and discrimination

The government Information, Education and Communication (IEC) campaign around HIV and AIDS was discussed briefly in Section 2.2. This campaign has achieved much in terms of raising awareness and understanding about HIV and AIDS (UNDP_MOH_AUSAID 2002). IEC programs on “social evils” have also been widely implemented with the objective of increasing awareness and vigilance concerning the dangers of substance abuse and the consequences of prostitution for families and society as a whole.

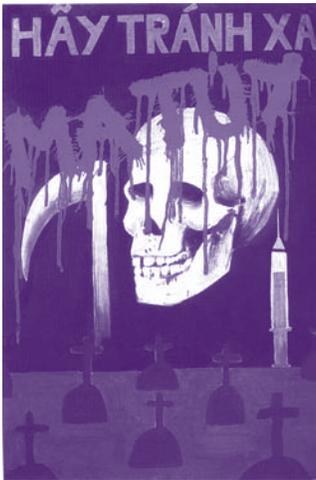
These achievements, however, need to be viewed alongside the campaign’s unintended perpetuation of stigma against people living with HIV and AIDS and their families. We found two key problems with the materials observed in the study sites. Firstly, the posters and news stories being disseminated about HIV and AIDS tend to emphasize negative images and employ fear-tactics in order to “warn” people of the dangers of “social evils” and HIV and AIDS. Secondly, the posters and news



Drug-AIDS, scourge of the century.



Let's stop prostitution and drug abuse, the nation's scourge.



Stay away from drugs

stories tend to conflate HIV and AIDS with social evils—underpinning the public perception that these phenomena are equivalent and that HIV and AIDS are themselves social evils. Many posters use highly emotive symbols such as human skulls, bleeding syringes and coffins, or contrast images of sick and dying drug users with images of robust, healthy people. The former images create feelings of fear and disgust and evoke negative thoughts about drug users. In many posters, the words

“drug abuse” and “prostitution” appear together with “HIV/AIDS,” implying that these are all equivalent “evils.”

Reports published in newspapers and on television were similarly problematic. The vast majority of stories on HIV and AIDS reported sensational cases that profoundly affected public perceptions. For example, HIV-related stigma has been heightened by a series of press stories in recent years

about instances when someone living with HIV has deliberately infected others for revenge or used supposedly HIV-infected syringes as weapons in muggings. A typical example is a case reported in December 2001 about a 5-year-old child who was deliberately injected with blood contaminated with HIV by someone seeking revenge against his father (middle photo). This case inflamed public anger and



panic that has extended beyond these isolated incidents to affect all those assumed to be drug users and others assumed to be living with HIV and AIDS. The following remark is typical:

We take preventive measures but if [he or she] becomes daring to stab us with a needle then we would die! The truth is, we live in a place where there are many chances to meet drug addicted people—so we are very afraid. Most people are afraid. (Hai Phong, participant of FGD of women over 50 years old)

Another inflammatory story was story broadcast on Hai Phong TV about drug users, using the alarming title, “A corner of the death market” (bottom photo is from this report). These stories shocked the public, creating panic, fear and confusion rather than greater clarity or a conducive environment for prevention and care.

During the research, community members recalled their feelings of fear when watching or reading these and other reports on “social evils.” This fear clearly contributed to stigmatizing attitudes and the belief that it is necessary to isolate “infected” people from the community at large. One woman living with HIV and AIDS in Can Tho told us about her fears of the public reaction to news reports being broadcast:

I also watch the Can Tho TV which broadcasts programs on Monday and Thursday showing many SIDA persons. They looked disgusting. Only getting SIDA such as shown on TV is frightening, but if you are [HIV] positive and healthy like me, there is nothing to be afraid of. They said that persons who get SIDA should be sent to something like a concentration camp to live together, they should not [be] let outside. (Can Tho, female PLWHA_SW)

4.2 Forms and manifestations of stigma and discrimination

The previous section discussed what our research suggests are the principal causes of HIV and AIDS-related stigma in the two study sites. These are 1)

fears of casual transmission that stem from the nature of the disease and misunderstandings or lack of understanding about the nature of the virus and modes of transmission; and 2) the association of HIV with “socially evil” groups—particularly sex workers and injection drug users—who are already stigmatized by Vietnamese society at large.

In this section, we discuss the ways in which this stigma is expressed. Sometimes it was quite clear when stigmatizing behaviors stemmed directly from fear of casual transmission—as when people told us they maintained physical distance from people living with HIV and AIDS, although they were generally sympathetic with their plight. Just as often, however, such fears combined with beliefs that those with HIV acquired their infection through moral misconduct, and so should be avoided or excluded from society.

Although there are many ways in which stigma is manifested, in this report we will highlight only those that we observed to be the most prevalent: stigma expressed through avoidance of those living with HIV and AIDS due to fear of infection, and stigma related to moral causes, expressed through the use of demeaning and hurtful language and intentional social marginalization. The third form of stigma discussed is “self-stigma”—also sometimes referred to as “internalized stigma,” or the ways in which people living with HIV and AIDS may turn the negative behaviors, attitudes and expressions of those around them inwards, manifesting in depression, hopelessness, despair and sometimes self-isolation and withdrawal from contact with loved ones and the community.

4.2.1 Isolation and avoidance as a means of “prevention”

One expression of stigma found in the research is the isolation and avoidance of people living with HIV and AIDS and sometimes their close family members. As noted earlier, this stigma sometimes stems directly from people’s fears of becoming infected with HIV through “casual” or everyday contact with people living with the disease, and is thus generally perceived as a form of “prevention.”

Knowing that HIV is transmitted “through blood” should allay these fears but does not because this mode is so vague and poorly understood, and because it is at odds with other information people have about disease transmission more generally. There is widespread confusion, for example, about the difference between the transmission of HIV and the transmission of other infections, such as the common cold, the flu, hepatitis or tuberculosis, all of which people know through experience can be acquired simply by being in close proximity or sharing utensils and dishes with those who are sick. This leads to some confusion—even among those in the medical profession—between stigmatizing behavior and legitimate prevention.

Thus, the pervasive perception that HIV can be relatively easily transmitted leads to behaviors that may be *experienced* as stigmatizing, although not necessarily intended to be so. This can include the isolation of HIV patients in hospitals, isolation within families and avoidance by neighbors and the community more generally. The last is sometimes expressed as “watchfulness” or “cautiousness.”

For self-prevention of the disease, I think I should keep far from PLWHA because those persons [can infect me]. As we know for prevention of disease, to keep away is best. (Hai Phong, participant in FGD of women 15-24 years old)

Even those who want to show compassion to avoid hurting the feelings of people living with HIV and AIDS often are cautious and distant:

Our people have compassion, but despite compassion, we should be watchful. (Hai Phong, participant in FGD of grassroots organizations)

I can sit together [with a person living with HIV and AIDS] but there would be no sharing of things...Sharing a cup cannot transmit [HIV infection], but just to be sure I would not share a cup. If they invite me [for tea] I would find a

way to refuse politely. I would not let them know that I know they have the disease. I would contact normally but keep a little bit distant. For example I would say "Oh, no thank you, I just had a cup of tea." (Can Tho, participant in FGD of women 35-49 years old)

"Cautiousness" from fear of infection also leads people to prevent their children from having contact with those known to be living with HIV and AIDS:

I certainly do not allow my child to play together with him [a person living with HIV and AIDS]. (Can Tho, participant in FGD of men, 35-49 years old)

If neighbors know, they are also fearful, they do not dare to visit the house anymore. If small children come close to my door the neighbors insist they go home. They do not dare to go the house of PLWHA. (Hai Phong, female, PLWHA_SW)

This avoidance extends more broadly as well. Many participants report that if they know that a neighbor or friend has HIV or AIDS, they will visit the house less often or will not drink tea when visiting, or will try not to sit near or to touch the person. Sometimes they will just exchange greetings rather than visit. Those who were once good friends may become colder and more courteous (less familiar) than before, or may end the relationship altogether.

They do not dare to get close to me really, compared to before when they would visit my house. For example, before children often came to my house for play but now they do not, so I feel that people mind their manners with me. Before, when my mother was a babysitter, many left their children but now they do not bring their children, so I guess there's something wrong. It's possible they behave like that because I am infected. (Hai Phong, male, PLWHA_IDU)

Some people living with HIV and AIDS told us that before they became infected, they, too, held such beliefs and acted in such ways:

Surrounding people think this disease is terrifying. Even me! Before when I did not know the disease, if I knew that an HIV-infected person sat here to eat breakfast, I would not eat breakfast here. I would not dare to go to that shop anymore. (Hai Phong, male PLWHA_Other)

A mother of a young man living with HIV and AIDS told us in tears about her neighbors' attitudes toward her son when they learned of his condition:

They keep away from him now. When they see him coming up the stairs, they act as though he has leprosy. (Hai Phong, mother of PLWHA_IDU)

Sometimes the actions taken are subtle but very powerful. This mother explains her experience when she and her daughter, who has HIV, went to watch television at a neighbor's home:

When we watched TV with them they put mosquito-killing incense beside them. Do you see? Nothing happened when others were sitting there but when we came they took the incense and put it beside them. This made us feel ashamed. (Can Tho, mother of PLWHA)

This type of avoidance by the community, while not necessarily intended to be stigmatizing, can have a devastating impact on people living with HIV and AIDS. In the communities where we conducted the fieldwork, social relations and communication are relatively close and adhesive. This is usually expressed in a neighborly concern and willingness to help each other in times of crisis, as indicated in the well-known Vietnamese proverb, "neighbors are together when lights are out," or "we sell remote relatives to buy close neighbors." Moreover, the narrow living spaces of the alleys, and the fact that many neighbors share a common place of employment or occupation, also nurture close relationships between neighbors.

On the positive side, these features of daily life in urban Vietnam foster the development of close relationships and a readiness to provide mutual assistance. However, the high value placed on cohesive community relationships, and the importance of these relationships, intensifies the impact of the social isolation that can result when one's HIV status becomes public knowledge. This social isolation has implications for a family's economic and social status as well as their emotional well-being:

Now she [the person living with HIV] cannot do anything. When they know she is in such state they keep far from her, they do not dare to be close to her. If they really understood about this disease, they would not be so afraid. Because they do not understand, they even do not allow her to carry their grandchild.... This made my daughter feel so inferior. (Can Tho, mother of PLWHA)

Avoidance in public places

In addition to its expressions and impact among neighbors, the fear of acquiring HIV through casual contact can affect life in the community more generally. When ranking public places where people living with HIV and AIDS are most likely to be stigmatized, the majority of community members listed food and tea shops—where members of the community typically gather and socialize—at the top. Many of those selling food, for example, will refuse to serve a person living with HIV, or will refuse to serve him or her in the shop itself. Some food vendors were said to have scolded people living with HIV and AIDS in front of a crowd, saying hurtful phrases, directly or indirectly insulting them. Due to their fear of losing customers as well as the fear of infection, many vendors clearly discriminate against people living with HIV and AIDS, particularly those who were thought to have acquired their infection through injecting drugs. As one respondent living with HIV and AIDS recounts:

I asked, "Please give me a cup of sugar cane drink" and the vendor said: "If you drink in the

cup, other persons will see you drink from that cup and they won't dare to use it. So take the drink in a bag [disposable nylon bag]." See? They spoke straight to me. I myself also know it's better to keep away so they can sell their goods. (Hai Phong, male PLWHA_IDU)

Clearly, the vendors are responding both to their own fears and feelings as well as to the assumed or known feelings and fears of their customers. Although some interviewees reported that there is significantly less stigma in food shops and tea houses today compared to previous years because people's understanding has improved, their own stories and attitudes suggest that stigma and discrimination toward people living with HIV and AIDS persist. A majority of community members state, for example, that they would not eat or drink in a shop frequented by someone known to be living with HIV and AIDS:

I can only eat there if I don't happen to know he or she is infected, but if I knew I would not eat there. (Hai Phong, participant in FGD of women 18-24 years old)

Although fear of infection can be one factor in their refusal to eat in these shops, respondents also cite negative reaction to the physical appearance of people living with HIV and AIDS—which in turn relates to stereotypes and assumptions about the nature of the disease and those with it.

To go out to eat or drink but sit beside some guys who got SIDA? It's worrying and unhygienic. In general, many people think so. It is awful to see them [people living with HIV and AIDS] scratching while eating. (Hai Phong, participant in FGD of men 18-24 years old)

Many in the community are aware that people living with HIV and AIDS and their families need sympathy and assistance, and most feel that these members of their communities should not be stigmatized. Nevertheless, many also express that people living with HIV and AIDS should not be allowed to live in the community, but should be

sent away to live in separate areas to protect the community from infection. They feel this is about prevention, not stigma or hate:

In newspapers, it is written that people [with HIV] still can have a normal life. That is what's documented in papers, but in practice, people in the community do not accept this is possible. People will keep away and fear anyway. Therefore, it is best to have separate areas for people with HIV and AIDS... if they live in the society, everyone would be afraid. It's difficult to treat [PLWHA] normally. (Hai Phong, male teacher)

In order to avoid further transmission, in our opinion if someone is HIV infected, the government should create a separate area in order to limit them.... If there is no separate place and we let them [intermingle] like now, people will be afraid. (Hai Phong, participant in FGD of women over 50 years old)

Similarly, some participants agree that job creation for people living with HIV and AIDS is necessary, but feel that they should work in segregated areas:

Everyone is afraid to hear about HIV/AIDS, so if the government could find an island for them [people living with HIV and AIDS] where they can live and work, they should work. Now, knowing that they are infected but still let them wander around? I do not agree with that. The government should not let PLWHA wander in the community and in the society. They should be split off. I say this not because I hate them but because I am thinking of the protection of the community. (Can Tho, father of PLWHA_IDU, 65 years old)

Isolation and marginalization within the family for “prevention”

Avoidance, isolation and marginalization due to an HIV-positive status was in some ways most striking within the family setting, perhaps because the expectation is generally that families will provide unconditional love, support and care. Indeed, we found that the family setting is a place of many contradictions for people living with HIV and AIDS.

Attitudes and behaviors of family members toward people living with HIV and AIDS range (sometime in the same household) from love, pity, care and support to scolding, hatred and isolation, or a mix of all of these. Attitudes or behaviors also tend to change over the course of the illness and can be very different at different stages of the disease. Family members frequently fluctuate between love and anger, especially the parents and spouses of the person living with HIV and AIDS.

The quote below illustrates a family member's struggle with conflicted feelings between fear and sense of duty to the family:

Since I found out about his infection, I never touch his body.... The family has to provide care; the family cannot abandon him, cannot neglect him. Despite anger, the family has to strive hard, but it is so frightening. If the disease becomes more serious, I cannot give care anymore because it is too scary. I don't know very much about how to provide care—I know only to wear gloves. So when his illness becomes more severe, I cannot care for him any more, I will have to withdraw, I cannot care for him. (Hai Phong, sister of PLWHA)

Some families abandoned the person living with HIV and AIDS and refused to give him or her care:

Near... my work, there was a girl who got the disease. She was abandoned, lying alone until death. No one visited or brought food or drink for her. Her parents left rice there for her but would not come close to her, brought no change of clothes or had any contact with her. (Can Tho, female PLWHA_SW)

Generally, when I got this disease no one would like to be close to me. My family has to keep away from me, let alone outsiders. (Can Tho, male PLWHA)

However, this was not the norm we observed during fieldwork. In fact, the research results indicate that the majority of close relatives do not believe they stigmatize against the person living with HIV in their family. (See Section 4.9 for more

on love, care and support in the home.) Nonetheless, care occurs alongside actions that can be and often are experienced as stigmatizing by people living with HIV and AIDS. Although many of these actions are taken in order to “make prevention,” they are in fact neither necessary nor appropriate for this purpose, and in fact add needlessly to the already significant emotional, economic and time-related burdens these families must bear.

The types of actions that are taken to “protect” the wider family and “make prevention” of HIV include minimizing contact between the person living with HIV and AIDS and other family members, particularly (but not only) small children; separating the belongings of the person living with HIV and AIDS; and designating specific eating utensils, towels and bed linens for the sole use of that family member.

For example, one mother of a person living with HIV and AIDS told us that the family takes good care of her son and pays special attention to make him feel nothing is different than before he became infected. He still shares food, bowls and chopsticks with other family members. However, the family has designated a thermos cup for his use only in order to “protect the small child and visiting guests.” When visiting this family, the field workers were warmly received by the young man’s mother, and inviting the interviewer to drink tea she said, as if to reassure, “please feel free to drink from our cups. He [the son] does not use them, he has his own cup over there.” (Hai Phong, mother of PLWHA_IDU)

Many families state that their knowledge and understanding about HIV and AIDS has improved, and so they are not afraid or worried anymore. However, they continue to take unnecessary “preventive” measures, as the following quotes suggest:

I keep on eating separately. I am very careful in eating and drinking... I rinse all his goods with boiling water. (Can Tho, mother of PLWHA_IDU)

A wife candidly states:

[I treat him] differently now, why not? But secretly. To say openly, after he has eaten his food, I throw away the portion leftover in his dishes. (Can Tho, wife of PLWHA)

Due to the fear of infection, some family members of those living with HIV and AIDS try to prevent them from doing casual housework, such as preparing food for the family:

People are also afraid whenever he [a person living with HIV and AIDS] cooks or cleans the rice... During meals, they also fear sharing things. The family is so fearful. Of course, the family does love him, but... (Hai Phong, wife of PLWHA)

An even more hurtful form of stigma resulting from fear and uncertainty about transmission routes is the separation of people living with HIV and AIDS from their own children. One respondent, the father of a young man who died of AIDS and whose daughter-in-law is infected with HIV, considers himself a learned person generally, and particularly well-informed about HIV and AIDS since he had studied the subject when he discovered his son was infected. He states his view, which is in fact not an uncommon one:

In the countryside, people are frightened to be infected through eating [with an infected person] because they do not understand. I understand clearly because I have read documents. So I know that swimming in the same tub or using the toilet together does not cause the disease at all.

However, later in the same interview this respondent reported that his grandchild is not permitted to live with his mother for fear he may become infected. His words express both the fears and the consequences of these fears:

The child is living here to avoid being infected. I let him live with us because I am frightened

[that he may become infected]. It is better to make disease prevention. Supposing a mosquito stings his mother? That mosquito will continue to sting my grandchild [and so infect him]. What if there are some marks or traces of scabies and itches on my grandchild's body and his mother scratches for him? He can be infected when the place bleeds. It cannot be clean... So I let him live here with us to avoid these bad consequences.

Stigma in schools related to fear of casual transmission

Teachers participating in the research show relatively positive attitudes toward people living with HIV and AIDS in general and their students specifically. Teachers often note that according to the law and school policy, children living with HIV and AIDS should attend school just like other pupils. They also feel that these children should get extra support and encouragement. Thus far in Vietnam there are no recorded cases of children not being admitted to school because their parent has HIV.

However, stigmatizing attitudes were evident through the way teachers express their concerns or worries about the risks of HIV being transmitted to other pupils:

We should adopt measures to prevent transmission to other pupils. We could, for example, arrange appropriate [separate] seating for them [child with HIV or whose parent has HIV] to make it safe for the rest of the class... We should try to find a way to assist that pupil while also preventing transmission to other pupils. (Hai Phong, teacher, female, 35 years old)

Kindergarten teachers are especially concerned about transmission risks and have adopted certain precautionary measures. For example, since knowing that there are children of people living with HIV and AIDS in the school, instead of conducting the weekly nail cutting for children in the

class, the teachers have requested parents cut their children's nails at home before going to class.

In addition, results of the study indicate that because of these fears, some teachers are delivering negative, fearful messages and showing horrifying pictures of people living with HIV and AIDS to pupils, making them feel afraid and disgusted. This may be strengthening HIV-related stigma among these children.

Students and parents also expressed concerns about the presence of children with HIV and AIDS, or the children of people of living with HIV and AIDS attending classes alongside other children. For example, one student states:

If seated next to someone with HIV, I would move to another seat because although I understand [about transmission] I am still afraid—what if I get infected accidentally? (Hai Phong, participant in FGD of men 15-24 years old)

Impact of fear of infection on care and support

Although the majority of families provide care for those living with HIV and AIDS at home, the fear of infection can have a profound impact on the type of care they receive. Some families are too fearful of infection to provide care when their family member becomes very sick with AIDS-related infections. They may choose to hire others—sometimes other people living with HIV and AIDS—to provide care, as in the following example:

Many families, although they love the child, still keep away, they are so afraid. So they hire the group of Friends Help Friends⁹ and peer groups to provide care for him at the last stage, but they do not dare to provide care directly by themselves. They hire those persons, let them inject drugs and feed them so that they care for their child. (Hai Phong, participant in FGD of grassroots organizations)

⁹ “Friends Help Friends” are informal groups established in some communities to help those with HIV and AIDS and their families. Sometimes these groups are organized through NGOs, though they can also emerge organically.

One mother of an IDU living with HIV says she will send him to a health facility when he develops AIDS because the living space of the family is too small, and there is no separate place to care for him.

Stigma and fear of transmission at health care facilities

As noted earlier, health care workers are also concerned about the risks of HIV transmission through casual contact. This fear leads to the adoption of excessive and unnecessary measures that are experienced as stigmatizing by those living with the disease.

The perspectives and experiences of people living with HIV and AIDS and their families:

Many of the study participants living with HIV and AIDS feel that health workers' attitudes toward them are negative. These negative attitudes are expressed through avoidance and sometimes through rudeness. Some people living with HIV and AIDS feel that health professionals they deal with, though providing care, only do so reluctantly. Two participants recall their experiences in the hospital with some bitterness:

Now talking about staying in hospital I would definitely not stay there again. Even if someone gave the money I would not, because I do not like the way they treat me there... doctors examine patients but fear infection. (Can Tho, male PLWHA_IDU)

The doctor and nurse who gave me injection and medicines take overt measures to protect themselves that make me feel that they despise me. (Hai Phong, male PLWHA_Other)

Some health workers have applied preventive measures too excessively, making people living with HIV and AIDS in their care feel ashamed:

They wear two or three pairs of gloves at one time; cover their mouths with two masks... Each time the nurse came in she became pale with fear. And others [people caring for patients] just gathered outside the door and

did not dare to come to the place where I was lying. (Can Tho, female PLWHA_SW)

Health workers' attitudes often make people living with HIV and AIDS and their families feel reluctant to approach them when they need information:

I was hesitant to ask. Doctors who understand—they would sympathize with me, they would answer my questions. Many people do not even answer me, making me feel ashamed. So in the end, I do not dare [to ask questions]. (Can Tho, mother of PLWHA)

Women living with HIV and AIDS met difficulties when giving birth at health facilities because the providers were fearful of contracting the virus. This led some to hide their sero-status. Some women living with HIV and AIDS in Can Tho report that health workers in some health facilities tried to send them elsewhere when learning that they were HIV-positive. Thus, many simply avoided the public health services altogether, instead seeking out a private or other health facility to give birth; and many tried to hide information about their HIV infection status. (See Case Study, Appendix D.)

Health workers' perspectives:

Health staff admit there is still a significant reluctance among their colleagues to provide care for AIDS patients:

Normally, doctors who are not specialized as us still worry. They are fearful that HIV can be transmitted to them and to other patients, and they are afraid that if other patients know a person lying beside them is HIV infected, they would have a bad reaction. (Hai Phong, health staff member at the Department for Infectious Diseases)

One health worker argues that there is no stigma and discrimination at health facilities, but also reports that the ward's health center does not provide some health services for those living with HIV and AIDS, such as injections, explaining that this precaution is taken to protect others using the facility—especially small children.

When they [people living with HIV and AIDS] come here, we treat them normally, but we do not give them injections. We absolutely never inject infected persons. We just give them medicines... we also treat small children here, so we give PLWHA no injections at all. (Hai Phong, female health worker of the ward)

A doctor working in the department providing treatment for AIDS patients recognizes that in order to lessen worries of other patients, his department has to maintain separate medical devices for AIDS patients. However, as the department cannot afford expensive specialized equipment, these sometimes have to be borrowed from other departments, creating a range of problems that ultimately result in many HIV and AIDS patients receiving less than ideal treatment:

If I would like to borrow an endoscope to examine the respiratory system of a PLWHA, I will definitely be refused. Even though they know very well that HIV is killed by common sterilizing techniques they still worry for their clients and their new patients who are not HIV infected. (Hai Phong, male health provider)

Perspectives of community members:

Many participants report that HIV-related stigma is most profound in hospitals because this is where the risks are highest. As one focus group participant says, “[In the hospital] there is a high possibility of infection because there are so many chances to come into contact with blood” (Hai Phong, participant in FGD of women 18-24 years old). The fear of infection creates concern among those going to health facilities, especially where AIDS patients are received. One participant in Hai Phong tells about a recent trip to the emergency room: everyone there that day went for HIV testing because they discovered that one of the patients who had come in that day had HIV. Despite knowing that all medical devices are sterilized, the fear of infection made those people extremely cautious. In-patients and their family members at health facilities often ask to be moved if they are sharing a room with someone living with HIV and AIDS, or ask to be tested for HIV. Naturally, AIDS

patients detect those attitudes. One person living with HIV and AIDS told us about his hospital experience:

If people saw me sitting at this table to eat [in the cafeteria], they would move away to another table. They never sat with me... The only patients who came to eat with me were those who didn't know. If they knew they would have kept away too. (Hai Phong, male PLWHA_IDU)

This section has discussed the manifestation of stigma resulting from peoples’ fears of becoming HIV infected through casual, everyday contact with those living with HIV and AIDS, and gave some indication of how these behaviors are experienced by them. In the next section, we outline some of the manifestations of stigma resulting from associations made between HIV and “social evils”—or the moral roots of stigma.

4.2.2 Expressions of stigma relating to HIV as a sign of moral misconduct

The forms and manifestations of stigma relating to fears of infection discussed above are applied generally to *all* of those living with HIV, regardless of how they have, or are thought to have, acquired the illness. Stigma also stems, however, from the perception that the virus is acquired through behaviors that contravene important social norms of morality and conduct. These expressions of stigma include the use of demeaning and hurtful language and the way people often conflate HIV with drug use and sex work. In addition, the discriminatory actions taken by family and community members are sometimes justified on the basis that HIV was acquired through “indulging in play” and through behaviors that caused hardship to others. Health care providers also refer to the presumed immorality of those living with HIV and AIDS to explain actions that are both stigmatizing and discriminatory. In this section, the forms of stigma that emerge from these explanations are discussed and illustrated.

“Labeling” and the use of demeaning language

One of the ways in which stigma stemming from

moral causes is expressed is in the way people refer to those living with HIV and AIDS. Sometimes people are unaware that the language they use is unkind—the stigma is unintentional, but nonetheless hurtful. Study participants often made such comments as: “that person (with HIV or AIDS) deserves to die”; “he got his just desserts”; “it serves him right”; “those people are the scum of the society”; “they are social evils”; “they should die to free the alley from people like that” and “they should die to make the society clean.”

The comments of one police officer in a focus group discussion in Hai Phong illustrate how those using hurtful and demeaning language to describe and discuss drug users sometimes do so unconsciously:

Do people have negative feelings towards drug users? Well, it is uncomfortable to sit next to the drug addicted guys that we have caught. They are really too fetid to stand. They are too dirty, terrible. Therefore, here it is not the problem of antipathy—it could just be because they are very fetid.

People living with HIV and AIDS described to us how the language and actions of those around them made them feel “despised” and “hated”:

They dislike [people living with HIV and AIDS] very much, of course. They do not know that I am also [HIV] infected so they talk to me as to normal people. They hate people living with HIV and AIDS very much. They curse them, saying “Let all such persons die.” (Hai Phong, female, PLWHA_SW)

I have seen that people despise PLWHA; they would not even like to talk to them. They despise drug addicted persons, and those who get the disease [HIV and AIDS]. (Hai Phong, female, PLWHA_SW)

Indeed the linkage between drug use and HIV and AIDS that is assumed in the previous quote is a key source of stigmatizing language. In Vietnam, those who use illicit drugs, as well as sex workers, are

often labeled by society as “deviant” or “bad.” Through FGDs and interviews, common terms used to refer to these individuals or groups included “thằng nghiện” (the junkies), “thằng xi ke” (scag), and “con pho” (whore). Over the course of the research, it became clear that the language used to describe or discuss drug users and sex workers was also being applied to those living with HIV and AIDS, and that often no distinction was made between these groups. People would often interchangeably use terminology describing physical appearance, such as: “being skinny” and “lurching like a junkie,” “look like a scag,” “sort of SIDA” and “thằng SIDA”¹⁰ to describe those living with HIV and AIDS and IDUs. This language expresses the belief that all of those living with HIV are or were drug users and vice versa, that all drug users have HIV. Clearly, this language is both hurtful and demeaning, and makes people living with HIV and AIDS feel “despised” and “hated.”

The close association between HIV and “social evils” was also evident in the opinions of some students. The following quote illustrates the common conflation between fear of infection and belief that people living with HIV are morally “evil”:

I think school is a cultural environment. If there are students with HIV, they should voluntarily quit class in order not to affect other persons. In school, if there are pupils who are at risk of HIV infection, they should send these pupils to detoxification, and not let them study in the class so to avoid their influence on other pupils. (Hai Phong, participant in FGD of men 15-24 years old)

Moral and economic issues and stigma in the family

As indicated above, there are many families in which people living with HIV and AIDS are helped and cared for, but there are also those families that ignore and isolate their members living with HIV—particularly if those family members are also injection drug users who have already created economic problems, for example by stealing family assets to sell for drugs. In fact, the research indicates that those people living with HIV experi-

¹⁰ See Appendix C for a full listing of the words and phrases used to describe injection drug users, sex workers and their perceived effects on society and their families.

encing the most blame and abandonment by their families are mainly those who were drug users or sex workers. This father of man who is a drug user, now living with HIV and AIDS, expresses his feelings as follows:

Now I say to you that if he dies I will bury him, but now he makes me too miserable—I cannot accept him anymore. It’s definitely like that. I can’t stand his stealing. (Can Tho, father of PLWHA_IDU)

The negative attitudes of family members are much more painful for people living with HIV and AIDS than the negative attitudes of other community members. The reproaches and criticisms enhance and exacerbate the shame felt by many.

Moral issues and stigma in health care settings

Stigma toward injection drug users who are also living with HIV and AIDS extends to the health care setting. Some health workers in charge of providing treatment for AIDS patients in the local area state that they do not fear the disease, but they are uncomfortable working with patients who inject drugs:

Health workers are reluctant to work with PLWHA not because of stigmatizing attitudes about the disease of the infected person, but because those persons have immoral ways of living, that’s the point. This is the psychological aspect of the issue, but not stigma to AIDS, that’s different. Because they [people living with HIV and AIDS] come here to inject and inhale drugs right in their room, they throw syringes and needles everywhere, it’s full of dirty rubbish, they speak rudely and are unmannered. They bring all the scum of society—the social evils of the society—here to the Infectious Department and they make other patients frightened. HIV patients steal all [the belongings] of other patients—thermos, cup, sandals, shoes—to sell for money to use for drugs. (Hai Phong, participant in FGD of health workers)

Impact of moral stigma on care and support in community

Organizations such as the Youth Union, the Women’s Union, and others actively and effectively conduct many activities assisting disadvantaged groups (for example the poor and the disabled). However, according to study participants, those organizations are not yet providing adequate assistance to people living with HIV and AIDS and their families. The justifications given are that, firstly, there are too many other (more “deserving”) groups that need help and support; and secondly, respondents explain that people with HIV and AIDS mainly belong to “social evil” groups, such as drug addicts and prostitutes. The community protests against efforts to help them, saying that such assistance is wasted, useless and unreasonable, and even that it enables the continuation of “social evils”:

Oh God, if we give them benefits or subsidize them, they would only go out and buy lottery tickets. If money is given to them, they would just use it to buy drugs—so why should we provide benefits to them? (Hai Phong, participant in FGD of grassroots organizations)

He got infection [HIV] because of injecting drugs, so people don’t want to help him. If he is poor I would like to help, but since he is a scag and due to that he got SIDA, he needs to try and bear it by himself. Why should I help him? (Can Tho, participant in FGD of women over 50 years old)

4.2.3 Self-stigma—shame and feelings of hopelessness and despair

The terms self-stigma and internalized stigma frequently are used to describe the almost universal tendency of those living with HIV and AIDS to turn the expressions of stigma inward. The intensity of self-stigma varies according to the individual, depending on factors such as support from family and friends, the family’s relationship to the wider community, the stage of the illness, overall understanding about the disease and the presence of public discourse about HIV and AIDS.

However, almost all people who receive an HIV diagnosis experience, at some point, feelings of self-hatred, guilt and shame that can be expressed as depression and despair and can lead them to withdraw from family and social life to simply await their death. Some make drastic changes to their living style, relationships and other necessary social communications.

The following quotes illustrate consequences of self-stigma for two of our study participants, the first a 21-year-old male injection drug user and the second a 20-year-old former sex worker—both from Can Tho:

I am afraid of giving my disease to my family members—especially my youngest brother who is so small. It would be so pitiful if he got the disease. I am aware that I have the disease so I do not touch him—I talk with him only. I don't hold him in my arms now.

I did not tell anyone of my disease, but I still made disease prevention for the others. For example, I did not share clothes with anyone and I put my personal things in a separate place for myself. I also suggested to others that they shouldn't touch my things. I don't want anyone to touch my personal things because I am infected person—I don't want to bring this disease to others.

Interviews with people living with HIV and AIDS and their family members indicate the shame that people living with HIV and AIDS feel when their family shuns them, one of the most important factors in shaping self-stigma:

Even when living with the family, I see they keep away from me—often I feel shame. Even my close aunty and uncles, when I visit them, I would not like to enter their house, I force myself to go... When I visit I feel they do not like me, so I myself do not want to be close to them, I would like to keep away from them.
(Hai Phong, male, PLWHA_Other)

Since my family knows about my disease, my older brother also is afraid of my coming home, afraid of my carrying his child, or afraid that due to my resentment, I would revenge his children, revenge other people [i.e. deliberately attempt to infect them with HIV]. So they keep away from me, they do not allow me to come to their house anymore. If I go there, they show sullen faces. So I don't go there anymore. (Hai Phong, female PLWHA_SW)

Some injection drug users living with HIV and AIDS state that their self-esteem is lower when they are in the community than when they were living in the rehabilitation camp. In addition, they worry about being seen with their close relatives, because they fear that their relatives could also be stigmatized:

I wasn't afraid when living in the camp. Guys there are good, they are not like outside here where this person talks to that person, buzzing and gossiping. I do not even dare to accompany my mother... they would fear my mother who has this sick child. They would keep away from her and fear her, too. (Can Tho, male PLWHA_IDU)

Many of those with HIV consider this as the “end of life” and that they have no viable future. This leads to a feeling of despair and an unwillingness to try and improve one's life. This is especially difficult for those who are still young and unmarried, who feel their chances for marriage and a family are over.

As I have an [HIV] infection I feel like there's no future, no happiness for me anymore. Now, for example, if I was not HIV infected I could give birth. Everyone dreams of having a happy marriage, a family that gathers together for Tet.¹¹ And yet I am alone—it's very sad. Because I've got it, I do not want to marry because if I get married I would make my spouse unhappy and I don't want that. (Hai Phong, female PLWHA_SW)

¹¹ Tet is the Vietnamese New Year, the most widely celebrated holiday of the year.

I am in such state—how could I get married? If I could begin my life again, nothing would make me happier. As it is, I cannot marry a wife, my economic situation cannot be regained and my body is not healthy. So, as far as I can afford to, I just play [take drugs]. (Hai Phong, male PLWHA_IDU)

While having no marriage prospect is difficult for all, it is especially hard for those who are the only son in the family. Fear of ending the family line deepens their feelings of low self-esteem, hopelessness, withdrawal from life and any thoughts of the future.

More generally, self-stigma results in feeling despondent and giving up on plans and hopes for the future.

I have no plan, I just live, that's all. You see, I am addicted already—what should I care about? Now I live knowing about passing days and I don't know how much longer it will be. I also cannot imagine how my life will be in the future. (Hai Phong, female PLWHA_SW)

4.3 Gender issues

Findings from this research indicate that gender also plays a role in the ways HIV-related stigma is expressed, and the intensity with which it is experienced. As discussed earlier, the family is at the center of Vietnamese culture, and one is meant to act in ways that support and reinforce the well-being of one's family. Those who violate this norm are often harshly criticized. However, these norms do not apply to men and women equally. Women are expected to devote themselves to their families, and while men are praised for doing so, it is not considered to be the norm. This is reflected in many Vietnamese proverbs, such as: “no matter how wise, she is still a woman; no matter how silly, he is still a man.”

Gender stereotypes are evident in people's attitudes and behaviors toward people living with HIV and AIDS: men who are living with HIV and AIDS seem to be more easily accepted than

women. This is mainly because “social evils” committed by women are simply not tolerated:

I think it is no problem for a man to get HIV/AIDS and he could be talked with, but people hate a woman who gets infected. I say the truth. Why is that so? Because work is available for women—they should have good employment. So if a woman indulges in play too much, people would hate it. For example, people do not hate a drug addicted man nearly as much as a drug addicted woman. (Hai Phong, participant in FGD of women 18-24 years old)

If a man becomes infected with HIV through drug use or “indulging in play,” he is often regarded as a “victim of social evils.” If a woman gets infected, she will be criticized because she will be regarded as having violated a core moral norm of the society:

To say frankly, if men are still young and they indulge in play and get [HIV] infected, that's the general story of the society. If a girl gets this disease, no one would like to get close to her, because it is a problem of her conduct and her morality. It is not tolerated in females compared to males. (Hai Phong, female, community counselor)

In Vietnamese society, it is regarded as normal for men to “like indulging in pleasures” or to “prefer rare and new things,” so when they become HIV infected people are not always surprised or angry. On the other hand, if women, who are always expected to be careful and virtuous, get HIV, it would be a shock for their families and it would be hard to expect sympathy:

If a man is infected, people would consider it natural, because men indulge in play and are greedy with new things. But a girl who lives in a normal family to get infected? Now, that's a surprise. That's why people treat them [men and women living with HIV and AIDS] differently. (Hai Phong, participant in FGD of men 15-24 years old)

Many rated sex work as a greater “evil” than drug use by men:

If men get infection that’s due to injection, but if women get infection, it’s certainly that they do that [sex] work and get infection, so they are judged more. Anyway, as women we cannot do the same as men do. (Hai Phong, participant in FGD of women 25-34 years old)

Data collected in the study sites reveals that gender stereotypes are reflected in the fact that however they have become infected, women with HIV will be tolerated by the community less than men:

An infected man is different to an infected woman. Because of course men will indulge in play and get infected. But if a woman gets infected, people wonder: did she get it from her husband or is she a sex worker, or does she do this or that to get infected? People talk idly about women more than men, I think. There are so many things that make it different. (Hai Phong, female PLWHA_Other)

Men living with HIV and AIDS generally feel there is no difference in the ways women and men are treated; that once infected, men and women are the same targets of stigma and discrimination. According to these men, the ways in which you are treated by the community has to do with whether you have “evil behaviors,” not gender:

Men and women are treated the same. Even a doctor or engineer who gets infected is stigmatized. Man or woman, I think they are the same. (Hai Phong, male PLWHA_IDU)

If it is an accident [i.e. not infected through sex work or drug use], people would treat you one way. If you are drug addicted, people treat you another way. To men or to women, they treat the same. If a woman is drug addicted and gets SIDA, people would drive her away as they would a man. (Hai Phong, male, PLWHA_IDU)

Women living with HIV and AIDS, however, recognize that women who are drug addicted and HIV infected are stigmatized more than men:

People still have more antipathy and stigma to an infected woman. It is said that it could be OK if a man is drug addicted but being a woman but addicted, it is not acceptable. You can see, looking at a woman holding a cigarette people already dislike her—let alone if she is addicted [to illicit drugs]. (Hai Phong, female, PLWHA_SW_IDU)

In a focus group discussion, one man echoed the sentiment of many other study participants, that “it [drug use] is not suitable for a woman! Why would she get involved with it?” (Can Tho, FGD of men over 50 years old). Many are also unforgiving of women who contract HIV. A participant in an FGD of grassroots organizations in Can Tho bluntly states that a woman who becomes infected with HIV “is degraded and rotten.”

Gender differences in the expression and experience of HIV-related stigma come sharply into focus when one considers the experience of married couples. In general it is believed that women should offer forgiveness and accept her husband’s mistakes, while husbands are almost expected to abandon their wives should they find that their wives have HIV:

I see that if a woman gets it [HIV], her husband would strongly despise her because she could get infection only if she engages in adultery somewhere else. I say truly that a husband would despise his wife first thinking that the wife is unfaithful. But if the husband gets infected, his wife would forgive. (Hai Phong, participant in FGD of women over 50 years old)

We also observed disparities in terms of the care received by men and women. Men living with HIV and AIDS are almost always cared for by their mothers or wives, but if a woman becomes HIV-infected, her in-laws may neglect or abandon her, or force her to remain isolated from her children:

If a woman gets infection, then her family in-law drives her away, but if children are not infected, they would keep children. Surrounding people would say: “Let her die and let’s bring the children home to foster them, as they are pitiful.” (Can Tho, participant in FGD of grassroots organizations)

4.4 Broader impact of HIV-related stigma and discrimination for people living with HIV and AIDS

Some people living with HIV and AIDS express their desire to be useful in society, and they do not want to become a burden for their families. They would like to earn money because they are aware of economic and emotional damage they have caused to their families. Most of the people living with HIV and AIDS that we interviewed are earning in some way because they are still healthy.

In my conscience, I would like to say that for as long as I live I would like to do some good things for the community and for society. Truly I do not want to be a burden. I myself want to do some work to earn so I don’t have to rely on the family and the society. Secondly, I do not want to transmit [HIV] to the community. (Hai Phong, male PLWHA_IDU)

However, it is clear that the stigma against them in the broader society seriously constrains their options and life opportunities. All study participants, including those living with HIV and AIDS, believe that those living with HIV and AIDS should not marry or have children:

[People living with HIV and AIDS] who get married only put more burdens on society. (Hai Phong, participant in FGD of women over 50 years old)

Many people living with HIV and AIDS also report difficulties finding work, or that they have been dismissed from their jobs. Many people refuse to hire people living with HIV and AIDS:

Now they are afraid of me so they do not hire me [to wash clothes]. People like me cannot

ask for any job. Now I do only do some agricultural laboring—that is all I am doing for my living now. (Can Tho, female PLWHA_SW)

It is very difficult for people living with HIV and AIDS to find a job that gives them a stable income:

This girl now does work such as catching shellfish and snails or drying rice, but she cannot apply to work in factories, as they will not accept her. They don’t say it is because of HIV, they say that they do not accept, that’s all. They may feel disgusted when they see her. So she lives such a lonely life. She catches snails for three to five thousand dong [US25 cents] per day when she can, probably to buy rice. If she cannot work, she stays at home, so we eat whatever we, her parents, can afford. (Can Tho, mother of PLWHA)

The children of those living with HIV and AIDS are also affected by HIV-related stigma and discrimination:

If people know that I am infected, people would despise my daughter, so I hide it from them. (Can Tho, female PLWHA_SW)

When her child went to school, her friends in the alley called her “SIDA child.” She cried then and did not want to go to school. I just heard that they said “do not play with a SIDA child. If you play with her you will get infected.” She cried again and ran home to tell me, her grandmother. I said to her, “Don’t mind them. Your mother has SIDA, not you. Do not mind what they say to you.” (Hai Phong, mother of PLWHA, 69 years old)

4.4.1 Reluctance to disclose HIV status

Many of the people living with HIV and AIDS who participated in our study report that they have tried—some successfully, some not—to keep their sero-status a secret from neighbors, friends and sometimes family. The reason reported is the fear of how they will be treated by these close contacts should their situation be known:

Because our community does not have good feelings towards infected persons, they keep away from them. This makes me feel inferior. That's why I would like to hide [my status]. (Hai Phong, male PLWHA_IDU)

If they knew [about my HIV infection] everyone would keep away from me. They are afraid that if they are friendly with me they would get infected. They do not know that it is transmitted only through some routes such as blood or sex. They think they could get infected just by sitting and talking, eating or drinking. They disgust me. (Can Tho, male, PLWHA_IDU)

The fact that people living with HIV and AIDS hide their sero-status could also stem from the fear of being blamed by the community that they acquired HIV by engaging in “bad behaviors” such as drug use, prostitution or “promiscuous” sex—that is, through “social evils.”

They hide because they think if they speak out about this disease people would criticize. They are afraid if they say the truth the surrounding people would misunderstand that they are drug addicted or too licentious. That's why they do not dare to say the truth. (Hai Phong, participant in FGD of men 35 and over)

This is social evil, so they are afraid that people would think badly about them, like they were involved in drug injection or with playgirls and got infected that way. (Hai Phong, female health worker)

In some cases, people would rather turn down services for people with HIV and AIDS rather than risk disclosing their status:

The ward invited me [for counseling] several times but I did not go because I am reluctant to meet people there. I think, for example, today it's the turn of our residential area to be invited, so there will surely be many people there who know me. It's normal for a drug addict to be infected. But for me, people tell each other “look, such a girl but yet infected.”

So I feel reluctant, I do not want to go [to ward's activities for PLWHA]. (Hai Phong, female, PLWHA_Other)

However much they may wish to keep information about their health status private, it is clear that this information does become public. In principle, information about one's HIV sero-status is maintained only by organizations such as the local Centre for Preventive Medicine or the AIDS Division, and they are only meant to share this information with health workers or family members with the consent of the person living with HIV and AIDS. However, many community members report that sooner or later, the word gets out. They report that this information might mistakenly be disclosed by a health worker, or deduced from observations of the changing appearance of individual people living with HIV and AIDS as they become symptomatic. Disclosure can even occur through well-intentioned efforts of intervention programs aiming to provide support, as the following quotes indicate:

Generally speaking, this information is not shared. But I am invited to attend meetings...I received counseling, have been given a set of guideline books [on care and support for people living with HIV and AIDS], and I am often invited to participate in the Friend Help Friend group. So it's understandable that my family is known to be affected. (Hai Phong, mother of PLWHA_IDU)

On that day, Ms. H [a health professional from PASB] invited me to receive medicine—that's how people know. People saw me go there. Neighbors saw and then they gossiped to each other. And on another day I was interviewed and filmed for TV. (Can Tho, mother of PLWHA)

Whatever the manner in which information about someone's sero-status becomes public knowledge, participants generally agree that the information spreads through communities with alarming speed by word of mouth (gossip). Some participants are of the opinion that health workers and others should share this information in order to

enable others to “protect” themselves from becoming infected:

When hearing there is a [HIV] infected person, the first thing they should do is inform others, especially the family members, telling them “that guy is already HIV-infected, so you should be careful.” Some persons quickly break the news to other places in order to avoid accidental cases of infection. (Hai Phong, male, member of the ward’s Executive board of the Youth union)

4.4.2 Impact of HIV-related stigma on the families of people living with HIV and AIDS

HIV and AIDS-related stigma was found to be having profound effects on the families of people living with HIV and AIDS, limiting their opportunities and constraining their options as well. Most of the families that participated in this study were experiencing economic difficulties. Only some families have a stable income; most earn their living in the informal sector. Research conducted by UNODC (2002) on consequences of drug use on women in Hai Phong discusses the serious economic damage that drug users impose on their families. The research also points out that due to stigma, those families have little opportunities for economic recovery. It is hard for them to borrow, or to get a credit loan. The mother of a drug user now living with HIV and AIDS expresses her worry about the family’s opportunities to do their business:

I am just worried about economic problems. To say frankly to you, because this is the family of a junkie, no one wants to lend us money. (Hai Phong, mother of PLWHA)

Families already struggling with such financial burdens are then even further constrained by health-related costs for caring with someone with HIV and AIDS. Some families cannot provide the level of support they would like to, but do what they can within their means:

If I had money I would give him adequate food, so he could recover his health quickly and increase his resistance. But in my circum-

stance, I cannot afford, so what we have for meals we give him the same. (Can Tho, mother of PLWHA)

4.5 Reasons for hope: love, affection and good intentions

This report has highlighted the principal underlying causes and manifestations of HIV-related stigma in the two study sites and has discussed some of the impact of this stigma on the social and emotional functioning and well-being of people living with HIV and AIDS and their families. While it is vital to understand and address the presence and impact of HIV-related stigma, it is also vital to acknowledge that this stigma is occurring alongside sympathy, support and the provision of care to people living with HIV and AIDS. Our research indicates that the majority of family and community members have good intentions toward people living with HIV and AIDS. Sometimes these good intentions are tempered by fears and moral concerns, but as a whole they benefit those living with the disease and striving to continue to have meaning and purpose in their lives.

When a person living with HIV and AIDS becomes sick with AIDS, the family will usually endeavor to find ways to make him or her comfortable. The principal family care provider is normally the mother or wife of the person living with HIV and AIDS, and she will seek medicine, wash his or her clothes, prepare and serve food (sometimes actually by hand-feeding) and will try to meet his or her particular nutritional demands. Some family caregivers have received training in the care of people living with HIV and AIDS by the district health center and are following the advice and guidance received. Unfortunately, the health center staff may not always be giving the best advice, as the quote below indicates:

Regarding care, that’s feeding of food and drink. If the child [with HIV and AIDS] is too sick, I also sit by him and feed him three meals a day. I put everything in nylon bags. I was trained on everything by the district [health center]. As the district has trained I have to follow. (Hai Phong, mother of PLWHA)

Although they may disapprove of the behaviors leading to the infection, once a family member has acquired HIV most families will do what they can to provide emotional encouragement:

He [interviewee's son] already has a negative attitude; if we are also negative, then we will have failed him. So we have to encourage, and help him so he can feel peace inside and try hard to live on. When he is sick... I myself provide treatment. Only when I have no other choice do I carry him to hospital. (Hai Phong, mother of PLWHA)

Community relations also play an important role in the lives of Vietnamese people. Close relationships of mutual assistance are maintained and nurtured, and people take great interest in the affairs of the surrounding households. Therefore, although HIV and AIDS-related stigma and discrimination exist, most participants feel that people living with HIV and AIDS and their families need sympathy and support of the community—that they should not be kept away and stigmatized, but supported and encouraged:

In general, everyone here is good. Neighbors visit frequently. They also encourage me, now that he is sick and drug addicted, so I can try hard to overcome. (Hai Phong, wife of PLWHA)

Here, we uphold the Vietnamese spirit: "The healthy leaf covers the torn one." When seeing the family's difficult condition, of course, people provide help—effort, money or what have you. People do not just leave them alone. (Can Tho, participant in FGD of men over 50 years old)

Some people living with HIV and AIDS explain that while some people show stigmatizing attitudes, many neighbors, friends and family members are friendly and cheerful to them, despite knowing they are living with HIV:

Some persons, a few, keep away and do not want to be friends with me. But the majority of

them still talk to me. Many even ask me to go to drink coffee with them. (Can Tho, male PLWHA_Other)

Now that I am HIV-infected, people are closer to me. Before when I was drug addicted only, no one was close to me. (Can Tho, male PLWHA_IDU)

Everyone is still the same, showing love but no fear. We still give her consolation, support and do nothing that could make her feel self-pity. Her sisters still love her very much. They share a bed, baths and meals as usual. (Can Tho, mother of PLWHA)

This caring spirit has been cultivated in recent years by government campaigns encouraging "Living together with HIV/AIDS." In addition, a number of nongovernmental organizations have been working to encourage stigma reduction, such as World Vision's program in Hai Phong, "Supporting PLWHA." These governmental and non-governmental efforts appear to be having some success in encouraging provision of care and support to people living with HIV and AIDS and their families:

These days, PLWHA receive more care. They can attend all activities, even the ward's activities. Before, there was no playing area for PLWHA; now many sport games are available. (Hai Phong, female health worker)

At first, probably they are also afraid, but the government has mobilized the movement of living closely with PLWHA, and they have become less fearful. (Can Tho, father-in-law of PLWHA)

There is also the sense that these campaigns have worked over time to improve understanding about routes of transmission, and therefore reduce fear and stigma toward people living with HIV and AIDS:

Four years ago, I did not understand so I was afraid of infection. But now many people

understand it can be transmitted only through blood and sex but not through talking to each other, so AIDS disease is not as frightening as before. (Can Tho, participant in FGD of men over 50 years old)

Before, people were afraid to hear of someone who is infected. But now we listen to radio, read newspapers and watch TV where they talk all the time about support and care [for people living with HIV and AIDS]. So now people are not so afraid. People seem normal now. For example, they will sit together [with people living with HIV and AIDS]. They still

won't touch them, but people do not drive them away or run away due to fear anymore. (Hai Phong, female, ward's health worker)

I think people are keeping away less now. There is so much information about prevention, so people know more, they do not keep away as before. Before, people are afraid of infection, they want to avoid, and are afraid when seeing a PLWHA. Nowadays people know how to prevent and control [HIV] so they are less afraid. (Can Tho, participant in FGD of men 15-24 years old)

5

Conclusions and Recommendations

This report has discussed the root causes of stigma, its manifestations and its impact on the lives and well-being of people living with HIV and AIDS and their family members. Findings suggest that the most important causes of stigma are people's fear of casual transmission and moral judgments and assumptions made about the lives and lifestyles of those affected. These underlying causes appear to be reinforced by some media portrayals and IEC campaigns about HIV and people living with HIV that promote negative and fearful images—heightening people's fears and uncertainties, rather than exposing them for consideration and debate.

The main forms of stigma—its manifestations—range from social isolation due to fear of infection, to the use of demeaning and hurtful language, to more drastic forms of discrimination and social marginalization of people living with HIV and AIDS and their family members.

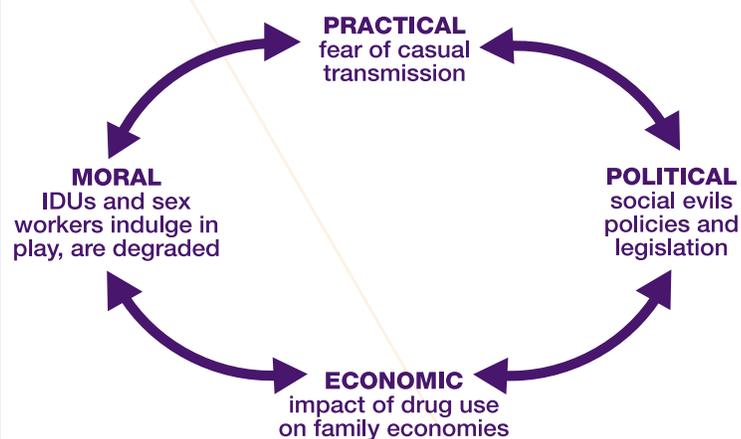
It is clear that stigma prevents people from disclosing their HIV status to others and stands in the way of access to care and support. This can have a profound impact on the epidemic. It may mean that transmission occurs that could otherwise have been prevented; it means that individuals and families suffer unnecessarily; and it means that the community is deprived of the important contributions of people living with HIV and AIDS and their family members.

However, our findings indicate that there are reasons to hope that the situation will improve. On the whole, people have very good intentions—they do not mean to hurt others and want to be seen as caring and supportive to neighbors and friends. This is true of community members as well as the media and others with influence. The information provided by this study can assist in

developing a process for building on these good intentions to find effective and appropriate solutions to the problem of HIV-related stigma. In addition to improving the lives of individuals living with HIV and AIDS and their families, tackling stigma *now* may in fact ultimately result in stemming the further spread of the epidemic.

The government's current anti-stigma campaign has made important initial inroads in tackling stigma, instilling the notion that it is important to support those living with HIV and AIDS and their families. However, we found that despite these efforts, many—if not most—people remain afraid and uncertain. Many are aware of, but hesitate to act according to, the anti-stigma messages because their knowledge about HIV transmission is clouded in myth, fear and ambiguity, and their feelings about people living with HIV and AIDS and their families are grounded in negative moral judgments. People have become confused by the contradictions between the anti-stigma campaign (“Living with HIV”) and what they hear in the anti-“social evils” campaign (IDU/sex work = social evils

Box 5: Causes of HIV and AIDS-related Stigma and Discrimination



= HIV). They are asking themselves, “How can we support those living with HIV when they are the same people we are meant to be criminalizing for social evils?” We need to help them resolve this dilemma, and the results from this study can help make a start.

The data from this project indicates that anti-stigma efforts need to do more to address those factors that currently underpin stigma: people’s fear of casual transmission and the moral judgments against people living with HIV and AIDS and their families. Effectively addressing these root causes of stigma will enable and encourage those infected and those at risk to take necessary and appropriate measures to prevent further transmission and to live healthy, productive lives.

Specific Recommendations:

1. Reduce fear of casual transmission

Evidence from this study clearly indicates that most people have internalized some information about HIV transmission—that HIV is transmitted “through blood,” from mothers to their children and through unprotected sexual intercourse. However, it is equally clear that very few people actually trust what they have learned. Much of the information is vague and ambiguous. The ways in which HIV is different from other types of infection are not clear in people’s minds. Consequently, fears and uncertainties remain that lead directly to stigmatizing behavior and the imposition of unnecessary and inappropriate “prevention” measures. It is therefore vital that programs deepen people’s knowledge about HIV and AIDS by:

- ▶ Delivering unambiguous information about how HIV is and is *not* transmitted and why;
- ▶ Highlighting *real* and discussing *imagined* risks that people are exposed to in the community, in the household and in intimate relationships;
- ▶ Providing opportunities for direct questions to be asked and direct factual answers to be given;
- ▶ Ensuring that universal precautions are taken; and
- ▶ Training health staff, teachers, social workers

and others in HIV transmission, and providing them with the necessary equipment for universal precautions as appropriate.

2. De-link HIV and people living with HIV and AIDS from “social evils”

The second set of recommendations from this study stems from the need to tackle the “moral” roots of HIV and AIDS-related stigma. Moral judgments about people living with HIV and AIDS and their families inhibit people from disclosing their HIV status. As people acquire better and deeper knowledge about HIV and AIDS, policies and programs can reinforce this knowledge to promote appropriate care, support and prevention by:

- ▶ Delivering positive images of respected people having direct contact with people living with HIV and AIDS; and
- ▶ Involving leaders and respected people in activities combating HIV and AIDS-related stigma.

Injection drug use and sex work are important problems in Vietnam—we do not mean to downplay or underestimate their importance, or the importance of finding a way to reduce the prevalence of these activities and their impact on the community. And there is an important epidemiological association between these behaviors and HIV transmission. But the facts presented in this study clearly indicate that great thought needs to be given on how to ensure that the disease (HIV) can be delinked from injection drug use and sex work in the minds of the community, health care providers, teachers and leaders. On the basis of the findings from this research, we recommend the following:

- ▶ Remove the term “social evils” from legal documents and programs on HIV and AIDS;
- ▶ Disassociate HIV and AIDS from “social evils” in the media;
- ▶ Disassociate HIV and AIDS from “social evils” in IEC programs and campaigns; and
- ▶ Deal with HIV and AIDS separately from behaviors such as injection drug use and sex work in policies and programs.

3. Promote positive messages on HIV and people living with HIV and AIDS

Much of the current approach to HIV and AIDS education and information in the media and in programs is based on prevention through fear. Efforts tend to focus on the negative and sensational and do not provide a factual picture of what it really is like to live with HIV and AIDS. This research found that these messages create fear, panic and stigma, thus impeding care and support efforts. We recommend that the media revise its programming around HIV and AIDS to include a more realistic perspective, including discussions about new treatment and prevention technologies. Using positive images of healthy people with HIV will encourage greater understanding about HIV and AIDS, that HIV is not a death sentence; that people living with HIV and AIDS can lead productive lives and make valuable contributions; and that care and support make a difference. In addition, messages about treatment and new technologies can inspire hope, and programs that discuss best practices can show how other countries have tried to move forward in the face of their own HIV and AIDS situations.

In the next phase of this study, ISDS, ICRW and the CHANGE project, with funding from USAID, will be working together with partners in the Commission for Ideology and Culture, the media, people living with HIV and AIDS and others to begin a process of moving the findings from this research and its recommendations into practice. In an ambitious

three phase project, we will devise a set of “HIV and AIDS Fact Sheets” specifically designed to address the fears and uncertainties that emerged from this study as key causes of HIV-related stigma and discrimination. In a second phase, we will be adapting the “Anti-Stigma Toolkit” developed by the CHANGE Project, ICRW and their partners in three African countries¹² to the Vietnamese context, and later implementing the toolkit in workshops with members of the Commissions for Ideology and Culture in all of Vietnam’s provinces. The final phase of the project will involve working to develop a strategy for HIV and AIDS programming.

In conclusion, we take inspiration from the words spoken at a focus group discussion of community leaders in Can Tho, which clearly express the underlying basis of caring and concern that exist among the people of Vietnam toward people living with HIV and AIDS. Future policy and programs that build on this sentiment will help ensure that HIV-related stigma and discrimination become a thing of the past in this country:

“Concerning the community, we clearly define that we should not avoid those persons [with HIV and AIDS] but be close to them and console them. We know that they have to die sooner or later, so the more we are close to them and we show our consolation, their lives will be longer, because they are also human beings.”

¹² See <http://www.changeproject.org/technical/hiv aids/stigma.html> to access the Africa “toolkit.”

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Appendix A

Situation of Drug Use in Hai Phong

Hai Phong currently is a hot spot of the drug evil and AIDS. It is estimated that drug evil has been largely spreading to residential areas and in every social strata. The hottest spots for drug use are in the railway areas passing through the Cat Dai, Tran Nguyen Han, and An Duong [adjacent to the Lam Son] wards, where many drug selling spots are located. These areas are characterized by a concentration of many severely drug addicted persons, and the only means to go there is to walk. Therefore, it is very difficult to penetrate this area to find and arrest [drug sellers and drug users]. Drug selling in this area has nearly become open, especially at nightfall. This area is now called the “drug market” by drug users. Many sophisticated tricks are used by drug users to evade the city’s officials. Although the police in the city have conducted many attacks in this area, it is still thought to be the hottest spot of the drug evil in the city.

In 2001, the police of Hai Phong uncovered, arrested and put to court 442 cases, with 722 persons who participated in drug trafficking and use. Currently, Hai Phong has 5,200 drug addicted persons on record, but it is likely that this number is much higher. According to current estimates, up to 80 percent of HIV/AIDS infected persons have acquired HIV due to drug injection.

In the implementation of the Decree No 24/NQ of the City’s People Council and the National Program on Prevention and Fight against HIV/AIDS, Drugs and Prostitution, the mass media, different branches and organizations have been actively involved in the prevention and control of AIDS, drug and prostitution. Besides IEC propaganda for HIV/AIDS and drug prevention and control, the local authority of Hai Phong also pays special attention to detoxification activities. The Centre for Educating Labour and Health Rehabilitation of Hai Phong provides treatment for drug addicted people (350 person in the year 2002). After being detoxified, drug users learn some occupation and work that are considered as detoxification therapy and educational for them. According to current estimates, the return rate to drug addiction after finishing detoxification in Hai Phong is still very high. The main reasons cited are that the drugs remain in the social environment, so that when they return home after giving up drugs, they still experience the community’s avoidance. They are unable to obtain stable employment, and eventually they are led to return to drug use. Therefore, providing employment to former users in the post-detoxification period remains an important problem in Hai Phong now.

Source: Vietnam TV Channel 1, transcript from program aired April 2002

Appendix B

HIV and AIDS Intervention Projects in Hai Phong and Can Tho

1. The Seagull (or Hai Au) Club in Hai Phong

The target of the Club's activities is to minimize self-stigmatization among patients, to help them better integrate into their communities and to help them become active advocates for the prevention and control of HIV and AIDS among drug users.

Club activities include support to people living with HIV and AIDS, counseling, education and advocacy to improve knowledge about HIV and AIDS among drug injectors and their families, provision of free medical care to club members once a week, provision of clean syringes and needles and free condoms. Up to the present time, 2,000 people have directly participated in the club's activities.

Source: Vietnam TV Channel 1, transcript from program entitled *Prevention and Control of Social Evils and Drug* in Hai Phong city, aired January 4, 2002

2. Project on capacity-building in care for PLWHA in the Le Chan district, Hai Phong

Le Chan district (Hai Phong) was the first location selected by World Vision in Vietnam and AUSAID to implement the model of "Care and Support PLWHA at home," which seeks to improve care and support for PLWHA at home and in the community. The project was implemented from June 2000 to July 2002 in three wards: Lam Son, An Duong and Hang Kenh. This is a pilot project to implement a new model in caring for PLWHA.

The project's main activities involve work to improve the capacity of health workers providing care for PLWHA in the local areas, providing equipment and essential drugs for AIDS patients and conducting health examinations for AIDS patients and their family members. "Friends Help Friends," also known as "action groups," have been established for people living with HIV and AIDS to help them better understand their condition, to share feelings, and to participate in activities for risk reduction such as provision of clean syringes and needles, condoms and leaflets for IDUs in the railway area.

Source: The Lao Dong (Labor) electronic newspaper, August 28, 2002 and Report on the Project Implementation, Le Chan District Health Centre, Hai Phong.

3. The Women's Health Club in Can Tho

The Women's Health Club has officially been in operation since September 2000. The club invites sex workers and waitresses for meetings, entertainment and access to IEC activities on behavior change, counseling and examination for STDs. The club has attracted over 12,000 women, including more than 8,000 sex workers and 400 waitresses. The club has 869 members (317 sex workers and 552 waitresses). Results of an evaluation survey indicated that among those members who are street sex workers, the proportion using condoms has increased from 30 percent in the end of the year 2000 to 80 percent in 2002. The club has also been successful in encouraging sex workers to take up different employment by conducting occupational training such as cooking, cosmetics, hair styling, manicure and massage.

Source: The Can Tho Department of Health, 2003

Appendix C

Words and phrases used by the community to describe HIV and AIDS, people living with HIV and AIDS, injection drug users and sex workers.

| Vietnamese | English |
|---|---|
| SIDA, ếch, hiv | AIDS |
| lám gái, mại dâm, đi, điếm, gái đung đường, đi khách, cave, làm nghề nằm gữa ăn sẵn | Sex Worker: serving girl, pro, whore, prostitute, nightwalker, guest catcher, cave, doing job with easy earning by lying on back. |
| khách làng chơi | client—guest of playing village |
| xì ke, nghiện | drug addicted/ junkie |
| Nhận án tử hình | got the death sentence |
| bệnh thế kỷ | disease of the century |
| hết đời | life comes to an end |
| cặn bã của xã hội | scum of society |
| tệ nạn xã hội | social evils |
| đáng kiếp / đáng đời | it serves him/her right; her/his life got it |
| không giây với con/thằng SIDA | Not to drag in with that SIDA guy/scamp |
| hình nhân thể mạng | like a paper mummy |
| cá khô= chết | dried fish = death |
| vô loài | unclassified/ not acceptable to any class/any kind |
| dính chường | got a blow |
| nợ đời | debt of life |
| gánh nặng của xã hội | burden of society |
| ổ tiêm chích | Nest of drug users |
| vô công rồi nghề | a layabout |
| ăn không ngồi rồi/ vô tích sự | to be at a loose end |
| nghiện là đưa mất chất | The addicted is a person who loses self-quality |
| phê | High moment of satisfaction after drug use |
| mày chết đi cho tao nhờ | Please let die so I can have a relief |
| Gái đẹp bóng bẩy ngoài da, Bên trong rỗng tuếch tim la tám tầng | Beautiful girls just look glossy, but are completely empty with only syphilis deep on the 8 th layer inside. |
| bán thân nuôi miệng | sell body to feed mouth |
| cửa tử | Gate of death |

Appendix D

Case Study of YT, 23-year-old female sex worker living with HIV in Can Tho

In 1996, when YT was 16 years old, she was trafficked to Cambodia to work as a sex worker, returning home one year later. Since then she has been working as a manicurist and barber. One month after her marriage, her husband died in a motorbike accident. She was pregnant at the time. In her fourth month of pregnancy, YT had low blood pressure and went to a polyclinic for a health examination and was admitted.

YT's mother reported that she suspected that her daughter had HIV because the health workers' behavior in the polyclinic changed—after a few days they used gloves and put YT's belongings separately. Only when YT was eight months pregnant, however, were they informed by the head of the commune health center that she was infected with HIV. The family was in a panic, puzzled and worried for YT and her baby because they thought that the baby would definitely be HIV-infected, too.

When she learned about the infection, YT became very dispirited and afraid. She reasoned that she had not done anything "bad," so thought she might have become infected through her manicure work (she has hidden the information that she was a sex worker in Cambodia). YT did not want to continue her work and stayed home. She worried that neighbors and relatives would learn about her state and keep away from her. She did not want to go to hospital to give birth because she thought she would be stigmatized there. YT thought that her neighbors did not know about her sero-status. She confided that she had not communicated with anyone since knowing about the news: *"I did not go out. Before I went here and there to repair nails for people, but now I do not go anymore. I am afraid that the surrounding people know and they would avoid me...It's better for me to stay at home."* Stigmatizing attitudes at the hospital where YT stayed last time made her decide to give birth at a private health service. She said, *"Now I will not tell them that I have the illness [HIV] but I will go to a doctor for delivery, so that people do not treat me badly."*

Giving birth and the baby's future are the most worrying concerns for YT and her mother at the moment.

YT's family, especially the mother, is trying hard to hide the information about YT's HIV infection because they worry about avoidance by the community. In addition, the mother worries about the future of YT's two younger brothers. If it is known that YT is living with HIV, her two brothers would face difficulties in finding girlfriends and getting married.

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