HIV-RELATED STIGMA AND DISCRIMINATION IN ASIA:

A REVIEW OF HUMAN DEVELOPMENT CONSEQUENCES

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A REVIEW OF HUMAN DEVELOPMENT CONSEQUENCES

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1. INTRODUCTION

> *"In the course of socially constructing an illness, symptoms are identified, and the disease is named… Responsibility and blame often are assigned. Those who contract the disease come to be regarded as victims or patients, guilty or innocent, dangerous or benign, heroic or pitiable."*
>
> *(Herek, 2003)*

Although there have been many notable successes in both the prevention and treatment of HIV, stigma and discrimination have been intractable problems associated with the AIDS epidemic throughout the world. Stigma certainly has well-established individual consequences: it has been shown to delay HIV testing, restrict utilization of preventative programs, and hinder the adoption of preventative behaviours like condom use and HIV status disclosure (Brooks et al., 2005). Stigma may also have consequences for individual economic well-being as well as broader socioeconomic development (beyond the impact of HIV disease alone). In Asia, where the epidemic arrived relatively late, HIV is spreading with rapid speed. In 2005, the number of AIDS cases in Asia topped 8 million; this is compared to approximately 3 million people just 10 years prior (UNAIDS, 2006). Determinants and consequences of stigma and discrimination on socioeconomic development in Asia have yet to be empirically assessed.

In this context, this review is aimed at generating informed discussion among key stakeholders including academia, policy makers, governments, donors and people living with HIV on the phenomenon of stigma and discrimination, with a particular focus on its human development context and impact. The paper also seeks to set a research agenda to foster compelling and disaggregated enquiries into stigma and discrimination.

This review takes an ecological perspective to examine the human development consequences of HIV-related stigma and discrimination in Asia. A report from the US Institute of Medicine (2002) has called for an ecological approach to research and health promotion (Institute of Medicine, 2002). Ecological Systems Theory (Bronfenbrenner, 1989) emphasizes the dynamic relationship between an individual and the social environment. Each domain may affect other domains, thereby influencing outcomes in indirect and/or reciprocal ways. While many studies have explored determinants of stigma, very few have taken an explicitly ecological perspective. Most studies included factors within the individual domain (e.g., sexual orientation, risk behavior), with scant attention to the family, institutional and structural/policy domains. The Ecological Model has been used in a process evaluation of an AIDS intervention in Zimbabwe (Laver, Van den Borne, Kok, & Woelk, 1996), a support program for pregnant women in Latin America (Langer et al., 1993), and maternal and child health programs in NY (Newes-Adeyi, Helitzer, Caulfield, & Bronner, 2000) and NC (Margolis et al., 2001).

In this paper, we first review stigma and discrimination using an ecological approach: at the level of the individual, family, institution and structure/society. The ecological approach views stigma and discrimination as a social phenomenon and helps examine the pathways, with a view to find effective and sustainable solutions. This particular approach is highly applicable in the context of stigma and discrimination because while the impact of stigma appears to be evident at the individual level, the nature, context and severity is influenced by the social environment.

The individual is seen within the context of the family, the community and the larger society. The existing norms and values within families and communities; prejudices based on race, ethnicity, caste and gender; and the socio-economic and political contexts, including that of power, play a significant role in the way stigma manifests.

TABLE 1. "INFLUENCE MATRIX":
Stigma and Human Development, Examples of Multiple Levels of Influence

STIGMA		INDIVIDUAL	FAMILY
	INDIVIDUAL	• Self-perceived stigma restricting choices regarding work/school • Depression, anxiety; potential for disease progression/decline	• Early entry into workforce among children and youth, restricting educational opportunities • Reluctance to seek care in formal sector drains family resources for home care
	FAMILY (affected individual)	• Loss of primary income • Push deeper into poverty • Lack of resources • Orphans & vulnerable children	• Withdrawal from economic activity for caretaking or secondary stigma • Differential treatment of orphans by family - forced into economic activity, internal migration rather than education
	INSTITUTION	• Prohibited access to schools, jobs, health care, insurance through compulsory testing/notification • Client discrimination by AIDS Service Organizations (e.g., CSW, drug users) • Absenteeism due to illness • Health care costs, if provided by the institution • Interpersonal relationships (trust, morale)	• No/limited access to micro-credit or market–level resources (e.g., farmers unable to sell food products at the market due to stigma) • Religious institutions denying socioeconomic support/ educational opportunities to affected families • Absenteeism due to caretaking, with further implications for stigma
	STRUCTURE/ SOCIETY	• Individual consequences of laws: privacy, access to health care thus affecting economic opportunities • Driving people into informal/ illegal/ unregulated economies (CSW, drugs) • Loss of savings/pension revenue	• Migration restrictions leading to reduced remittances to families • Restricted marriage for people living HIV thereby limiting access to pensions/land • Driving people into informal/ illegal/ unregulated economies (CSW, drugs) • Loss of savings/pension revenue

This section will address the social, physical and psychological affects of stigma and discrimination. The core of the paper addresses the intersection between stigma/discrimination and human development from this broad ecological perspective addressing the manner in which individual people living with HIV (PLHIV) and their families are affected by stigma and discrimination from the individual to structural/societal levels. We provide illustrative examples of these bi-directional effects as part of an "influence matrix" (Table 1). Finally, because empirical research in this area has been limited, we consider implications for future research.

2. OVERVIEW OF HIV-RELATED STIGMA AND DISCRIMINATION

Erving Goffman (1963) describes stigma as "an attribute that is deeply discrediting," transforming the affected individual into a "discredited" person. The definition of stigma has been continually developed and re-conceptualized since the publication of his foundational work. Stigma can be broken down into that which is felt or anticipated and that which is enacted (Jacoby, 1994; Malcolm et al., 1998). It has also been dichotomized into expressive and instrumental forms, where an individual may perceive another negatively but may only act according to this prejudice under certain circumstances (Herek & Capitanio, 1998). The process by which stigma occurs has also been well delineated as has its function of maintaining power, economic and social hierarchies (Link & Phelan, 2001). Extending from this, stigma has been conceived as occurring at the community, institution and policy levels, rather than being limited to the action of individuals (Parker & Aggleton, 2002).

The HIV/AIDS epidemic has created new opportunities for the manifestation of stigma. The disease's characteristics are similar to those of other ailments that commonly evoke stigma: the cause is perceived to be the bearer's responsibility even though it often may not be the case; it is incurable; it is infectious and can cause others harm; and in some cases it can be identifiable (e.g., severe wasting) (Herek, 1999). HIV/AIDS provokes further stigma in larger society as the epidemic commonly begins in subgroups already marginalized such as men who have sex with men (MSM), drug users and sex workers. Although the disease can rapidly spread to the general population, its perceived strong association with marginalized groups creates a legacy of discrimination that carries over to PLHIV who are not necessarily part of these groups (e.g. children and the partners of sex worker's clients and/or injecting drug users).

HIV-related stigma can have an additive effect when paired with discrimination toward other marginalized groups. Injecting drug users, sex workers and MSM who are living with HIV frequently face multiple stigmas. However, multiple stigmas can also affect categories of individuals who are not considered marginalized groups. For example, women, racial/tribal minorities, and the poor also suffer discrimination in society, which is heightened when combined with the stigma associated with HIV (Parker & Aggleton, 2002). Stigma can manifest on multiple levels. In the following sections, we review the stigma literature at the level of the individual, family, institution, and structural/policy.

2.1 Individual Stigma

Stigma is most often discussed at the individual level. Here, PLHIV are differentially treated by friends, family members and other individuals in one on one encounters. For example, friends may no longer be willing to associate with PLHIV for fear of infection or accusations of also being HIV positive. Family members may no longer feel comfortable sharing dishes or towels for fear of contagion. This behaviour occurs despite knowledge of modes of transmission. In a study of HIV stigma in Vietnam, family and community members were aware that HIV could not be transmitted through causal contact but remained hesitant to share drinking glasses or sit near someone who was HIV positive for fear of being infected "accidentally" (International Center for Research on Women [ICRW], 2004).

Individuals in various countries in Asia have reported coercion to move from their homes by landlords and refusal of service at food and other business establishments (Human Rights Watch, 2003; Paxton et al., 2005). PLHIV also reported being referred to by derogatory terminology by others in the community (Bharat, 2001; ICRW, 2004; Paxton et al., 2005; Songwathana & Manderson, 2001). Terms used frequently referred to individuals as drug users, sex workers, or carried connotations of imminent death.

Regardless of whether stigma is experienced or perceived, it can have detrimental impacts on the individual. Individuals who believe they will experience discrimination may be less willing to disclose their HIV positive status to others, thereby limiting their resources for much-needed social support. Numerous studies have shown that PLHIV suffering from discrimination are more likely to experience depression (Heckman et al., 2004; Joseph & Bhatti, 2004; Manopaiboon et al., 1998).

In turn, chronic depression among individuals with HIV hastens disease progression and mortality (Ickovics et al., 2001; Major & O'Brien, 2005). In addition, the intense stigma surrounding HIV reduces the likelihood that individuals in Asia will seek voluntary testing and counselling, basic medical care, and even adversely affects adherence to anti-retroviral treatment (Ainsworth, Beyrer, & Soucat, 2003; FHI; Ford, Wirawan, Sumantera, Sawitri, & Stahre, 2004; Kurmarasamy et al., 2005). Fear of stigma has also led PLHIV in India, Vietnam, and Thailand to quit their jobs and move to new communities for fear of stigma should their HIV status become known (Bharat, 2001; ICRW, 2004; Songwathana & Manderson, 2001).

2.2 Family

Families in Asia are affected by HIV/AIDS in multiple ways. Families may discriminate against their family members with HIV either because of fear of the infection or because they are ashamed by the behaviour (or presumed behaviour) that led to the infection. As previously mentioned, families decide to use separate dishes, towels, and even avoid washing clothes in the same water as that used by PLHIV following disclosure. Individuals who have disclosed their HIV status to their family have been excluded from family events, prevented from having contact with their own children, cut off from the family's financial support and even forced to leave family residences (Bharat, 2001; Human Rights Watch, 2003; ICRW, 2004; Joseph & Bhatti, 2004; Kumarasamy et al., 2005; Paxton et al., 2005).

Discrimination within the context of the family is particularly prominent against women. Numerous studies have reported that women in Asian countries experience greater stigma than men (Bharat, 1996; Bharat & Aggleton, 1999; ICRW, 2004; Paxton et al., 2005; Warwick et al., 1998). This discrimination has continued as the HIV epidemic has increasingly shifted from high-risk groups to the general population. Monogamous married women who were infected by their husbands are often scorned and even evicted from their homes by their in-laws when their HIV status becomes known (Bharat, 2001; Bechtel & Apakupakul, 1999; Shreedhar, 2000; ICRW, 2004; Joseph & Bhatti, 2004; Paxton et al., 2005). In a case study from India, a widow living with her in-laws was finally asked to leave the home after months of mistreatment as the family believed that her presence in the home was adversely affecting the marriagability of one of their sons (Shreedhar, 2000).

Having a family member with HIV can also stigmatize the entire family - a phenomenon referred to by Goffman (1963) as "courtesy stigma." Several studies in Southeast Asia reported that communities were generally very supportive of families who had a family member with HIV (ICRW, 2004; Kespichayawattana & VanLandingham, 2003; VanLandingham et al., 2002). Yet, despite these high levels of support, families continued to experience negative reactions from their communities, such as gossiping and being refused service for fear other members of the community would discontinue store patronage (Songwathana & Manderson, 2001; VanLandingham et al., 2002). In a study in Thailand, negative reactions from the community resulted in numerous families wanting to leave the area, despite overall high levels of reported support (VanLandingham et al., 2002).

Families experience stigma from their communities because they are blamed for the behaviour (e.g., drug use or sex work) that led to infection (ICRW, 2004) or because members of the community fear that the rest of the family is also infected (Songwathana & Manderson, 2001; VanLandingham et al., 2002). The latter is often attributable to misconceptions about modes of transmission. Stigma and discrimination toward families can occur both during the period of illness as well as following the death of a family member to AIDS. Although one study in Thailand indicated that most stigma was short-lived (less than one month) and did not carry over following the death of the infected family member (VanLandingham et al., 2002), other studies in the country reported that stigma and discrimination did continue after death (Pitayanon, Kongsin, & Janjareon, 1996; Songwathana & Manderson, 2001).

To avoid this stigma and discrimination from the community, individuals often avoid disclosing their HIV status to family members (Bharat, 2001; Human Rights Watch, 2003; Kumarasamy et al., 2005). When families are aware of the positive HIV status of one of its own members, they often lie about the illness to avoid community stigmatization (Songwathana & Manderson, 2001). A study in Thailand reported that families often take dramatic steps and exhaust financial resources to ensure a "normal" burial for their loved one so as not to reveal that the cause of death was attributable to AIDS (Songwathana & Manderson, 2001).

In other regions of the world with high HIV prevalence, such as sub-Saharan Africa, there has been some attention paid to the plight of HIV orphans and vulnerable children. Studies have demonstrated that immediate and extended family rejects these children when their HIV positive parent(s) becomes too ill to care for them or passes away (Ansell & Young, 2004). Less attention

has been given to this matter in Asia. Although there is some evidence that children whose parents have died from AIDS are not taken in by family (Human Rights Watch, 2003; ICRW, 2004), studies in Thailand have shown that these children face less discrimination by family than children in other parts of the world (Knodel, VanLandingham, Saengtiechai, & Im-em, 2001).

Children whose parents are infected with HIV or who are themselves infected, however, have faced discrimination in the educational system. Although it is rarely written policy, children have been denied entry into schools because of their HIV status or that of their parents (Bharat, 2001; Human Rights Watch, 2003; Paxton et al., 2005; Safman, 2004; UNDP, 2003). In India, organizations providing care services for destitute children have carried out HIV testing for all children seeking services and have segregated or transferred those who test HIV positive (Bharat, 2001).

2.3 Institutional

Stigma and discrimination toward PLHIV is very common at the institutional level. Several studies conducted in Asia found that stigma was most common in the health care sector (Bharat & Aggleton, 1999; Bharat, 2001; Paxton et al., 2005). In a study of four Asian countries (Thailand, Indonesia, India, and the Philippines), 54 percent of respondents with HIV reported that they had experienced some form of HIV-related stigma and discrimination in the health care sector (Paxton et al., 2005). Stigma and discrimination occurred through being refused admission to hospital or clinics, being denied treatment, and experiencing delays in receiving treatment.

In extensive studies on discrimination in the health care sector in six Asian countries (China, India, Vietnam, Thailand, Indonesia and the Philippines), authors found that discrimination was most often attributable to individual practice of health care providers rather than legislation or institutional policy (Yang et al., 2005; Elamon, 2005; Ortega et al., 2005; Sringernyuang, Thaweesit, and Nakapiew, 2005; Khoat, et al. 2005; Merati, Supriyadi, and Yuliana, 2005). A study in Vietnam reported that health care staff refused to provide injection services to PLHIV for fear of infection (ICRW, 2004). This study also reported that hospital staff used separate medical devices to perform procedures on PLHIV; when these devices could not be purchased or borrowed from other departments, individuals were denied these procedures.

Studies in China, Thailand and the Philippines found that HIV positive patients were forced to wait for surgical procedures until those without infectious diseases had been treated (Yang et al., 2005; Ortega et al., 2005; Sringernyuang, Thaweesit and Nakapiew, 2005). In India, a growing number of private health care facilities have agreed to treat patients with HIV, however, staff wear at least one extra pair of gloves, use "AIDS kits," and fumigate operating and delivery rooms after they have been used (Bharat, 2001).

Other forms of stigma and discrimination include noting patient charts or rooms with identifiable markers indicating the individual is HIV positive, requiring repeated HIV testing at the patients' expense and beginning medical interviews presuming risky behavior (Yang et al., 2005; Elamon, 2005; Khoat et al., 2005; Bharat, 2001; Songwathana and Manderson, 2001). Due to the common experience of HIV-related stigma and discrimination in the health care sector, PLHIV are

less willing to seek healthcare for themselves (Ainsworth, Beyrer, and Soucat, 2003; Shreedhar, 2000; Kumarasamy et al., 2005).

As with HIV positive women in the general population, those interacting with the health care sector face specific discrimination. Women attending antenatal appointments are routinely tested for HIV without their consent (Paxton et al., 2005). When health providers learn the women have HIV, they have denied women antenatal care and coerced them into termination of the pregnancy or sterilization without being informed of risk of transmission and treatment options (Bharat, 2001; Paxton et al., 2005; Khoat et al., 2005). An Indian physician interviewed in one study reported that when poor young pregnant women test positive for HIV, he calls their mothers-in-law rather than informing the patient herself as these women are deemed too ignorant to understand (Bharat, 2001). This case clearly demonstrates the interaction of the multiple stigmas of poverty, gender and HIV-positive status.

Stigma and discrimination also occur in the employment sector. In Paxton et al.'s study (2005) in India, Thailand, Indonesia and the Philippines, they found that both men and women had experienced some form of discrimination in the workplace. Approximately 7 percent of individuals from these countries had lost their jobs because of their HIV status and nearly 10 percent had experienced changes in their job responsibilities after their HIV status became known. Employers in some countries also require HIV testing for job applicants, thereby discouraging PLHIV from applying (Manopaiboon et al., 1998).

A survey of over 200 companies in Hong Kong in the late 1990's revealed that very few companies had specific policies regarding protection of employees with HIV and less than half were aware of legislation limiting employers' access to an applicant's HIV status (Lau and Wong, 2001). This study also showed that nearly one-third of employers were willing to dismiss or transfer an employee against his/her will upon learning of the employee's positive HIV status.

There is limited information available on stigma and discrimination by religious institutions in Asia. Some studies have stated that religious leaders do not harbour judgmental attitudes toward people living with HIV and even permit places of worship such as wats (Buddhist temples) and mosques to be used for hospice care (Bechtel and Apakupakul, 1999; Songwathana and Manderson, 2001). However, it is suggested elsewhere in the literature that religious leaders preserve the status quo by claiming that individuals infected with HIV have sinned and deserve their punishment (Parker and Aggleton, 2002). A study in Thailand claimed that Buddhist philosophy perceives HIV/AIDS as both the result of immoral action as well as karma from misdeeds in past lives (Songwanthana and Manderson, 2001). Attitudes toward HIV also extend to religious leaders in Thailand who believe that individuals who are infected with HIV should not be allowed to become Buddhist monks.

Finally, there is evidence that stigma and discrimination occur in private institutions and organizations. Individuals in India have been required to be tested for HIV when applying for life insurance; upon receiving a positive result, insurance has been denied (Bharat, 2001). Paxton and colleagues' study (2005) of four Asian countries reported that 8 percent of PLHIV were denied private health insurance after their HIV status was known; with rates as high as 15 percent in Thailand. Organizations providing services to disadvantaged groups such as women and youth have denied services to PLHIV and their families in Vietnam, arguing that they are less deserving than other groups (ICRW, 2004).

2.4 Structural/Policy

There is abundant evidence of discriminatory policies toward PLHIV across Asia. These national level policies extend from the health care sector to immigration and marriage laws. These laws often target groups stigmatized as "high risk." An extensive review of the health care sector found evidence of some discriminatory policies in Asia (Reidpath and Chan, 2005).

Policies in Thailand and India have required physicians to provide the names and addresses of persons testing positive for HIV and exempted them from regulations protecting patient confidentiality (Ainsworth, Beyrer, and Soucat, 2003; Shreedhar, 2000; Elamon, 2005). This legislation has been repealed in Thailand.

Numerous countries also restrict border access to immigrant populations. These restrictions include forbidding individuals with HIV from entering the country, requiring testing for HIV to receive work permits, or demanding declaration of negative status before entry to the country is granted (Ainsworth, Beyrer, and Soucat, 2003; Ortega et al., 2005; Parker and Aggleton, 2002). In China, cases have been documented where immigrant workers were deported once their HIV positive status became known (Human Rights Watch, 2003). Serodiscordant families have been separated between the mainland and Hong Kong due to HIV-related legislation (Human Rights Watch, 2003). Both China and India had put in place legislation banning PLHIV from marriage (Shreedhar, 2000; Human Rights Watch, 2003). Individuals found in violation of the law in India were subjected to the country's penal code; however, this legislation was repealed in 2002 (Action AID, 2003).

Individuals deemed to be high risk have also been subject to stigma and discrimination at the structural level. One of the hallmark examples comes from Vietnam and the "social evils" media campaign (ICRW, 2004), designed to eliminate the "social evils" of drug use and sex work. A separate administrative department within the national government was put in charge of this campaign. With the growth of the HIV epidemic in the country and its high prevalence within these two groups, HIV was included as part of the "social evils" triangle. The common mind-set linking HIV, drug use, and sex work was further fuelled by the merger of the "Department of Social Evils Prevention" with a national task force to address HIV/AIDS in the country (subsequently called the National Committee for AIDS, Drugs, and Prostitution). High-risk groups have been further targeted by compulsory rehabilitation if arrested.

Compulsory rehabilitation for drug users has also been implemented in China (Human Rights Watch, 2003). Additionally, there is a mandatory testing policy for drug users, sex workers, and residents who have lived outside China for more than one year (CHAP and LR, 2001; Yang et al., 2005). If found to be HIV positive, these individuals are put under quarantine; Chinese jails are segregated by HIV status (CHAP and LR, 2001; Human Rights Watch, 2003).

It is important to note that although the passage and upholding of legislation discriminating against PLHIV has occurred in Asian countries, governments also have instituted protective legislation for individuals who are living with HIV. In 1997, the Indian Supreme Court ruled in several cases that PLHIV (and their widows) could not be barred access to employment should they be fully capable of performing the duties and responsibilities of the position

(Subramaniam, 2004). In one case, the judge stated that by continuing to work, the individual's physical and mental well-being is enhanced.

Both Vietnam and China have made efforts to protect children orphaned and made vulnerable by HIV/AIDS. The Vietnamese government issued a policy that children with HIV should be permitted to attend school; no cases have been documented that would indicate the policy has not been upheld (ICRW, 2004). In its efforts to protect vulnerable children, China ratified the Convention on the Rights of Children, which would provide special assistance to children who are temporarily or permanently without a source of care (Human Rights Watch, 2003).

Protective legislation, however, can be undermined by other policies. For example, Vietnam passed a decree to protect PLHIV from stigma and discrimination, requiring government agencies and families to provide support and prohibiting the mass media from providing personal information without consent. Yet the dominance of the social evils campaign counteracts the potential benefits to be gained from such a policy (ICRW, 2004). Furthermore, Reidpath and Chan (2005) have noted that the presence of protective policy and legislation may do little to reduce enacted stigma and discrimination as these laws are rarely enforced and have minimal cultural credibility.

3. HIV-RELATED STIGMA AND HUMAN DEVELOPMENT

Because of the stigma associated with HIV, negative names and behaviours are attributed to individuals and families. The physical realities of the infection are exacerbated by the ingrained stigma attached to it. Table 1 (on page 2) provides an "Influence Matrix," providing illustrative examples of how HIV-related stigma at each level (i.e., individual, family, institutional, structure/society) can influence human development of PLHIV and their families. This multi-level framework provides an ecological approach by which we can examine the impact of stigma and discrimination on the socioeconomic situation of PLHIV. It is important to recognize that these relationships are complex and bidirectional. The discourse will focus primarily on the impact of stigma and discrimination on human development. However, as individual and institutional economies are adversely affected, stigma and discrimination consequently may increase. The examples in Table 1 are meant to be illustrative rather than exhaustive.

Although human development is often measured at the national or macro-level, these measurements are primarily reflections of aggregate individual/family or micro-level economic activities and standards of living. Much of the research to date has focused on the effect of HIV on economic development in sub-Saharan Africa given the well-established presence of the epidemic in that region; less research has been carried out on this topic in Asia. Examples will, therefore, focus on Africa, and drawing on experiences from Asia when available.

To elucidate the intersection between HIV-related stigma and human development, it is first necessary to create a working definition of human development. Amartya Sen (1999) argues that development can be seen as the level of freedom (or the capability) individuals have to

engage in the economic, political and social life of their communities. Sen defines five freedoms that are essential to development: (1) political freedoms, (2) economic facilities, (3) social opportunities, (4) transparency guarantees, and (5) protective securities.

He argues that establishment of these freedoms enhances the capabilities of individuals on these five dimensions and their ultimate engagement in the civil structure of society. Sen's concept of capabilities provides insight regarding individual/family-level development. Sen notes that the standard of living as defined by capabilities is the set of attributes it is possible to attain. Individual- and family-level development must be operationalized as capability sets linked to economic and social freedoms, such as economic productivity, access to health care, and education. These areas are often the focus of research investigating the developmental impact of HIV.

3.1 Individual and Family Stigma Influences on Individual and Family Human Development

Reduced economic productivity is the most common area of focus when looking at the impact of HIV on personal development. AIDS-related death of a family member has significant adverse effects on family income. HIV-related illness leads to absences from work, thereby reducing individual and family earnings. A recent study on the socioeconomic impact of HIV and AIDS in India reveals that households with an HIV positive member(s) (HIV households) lost 9.2 percent of the total income due to leave/absence not only of a person living with HIV but also of working family members to provide care (NCAER, NACO and UNDP, 2006). In a community-level survey in Viet Nam, 25 percent of caregivers reported giving up employment in order to care for their ill family member; one-third of caretakers reported cutting back on work hours in order to meet caretaking responsibilities (UNDP, 2005).

HIV-related illness also increases medical expenditures, putting further financial burden on the household. The aforementioned Indian study shows that HIV households spent almost 4 times as much on medical expenses in comparison with non-HIV households. In addition, HIV prevalence is highest in the most economically productive age groups.

HIV-related stigma and discrimination can exacerbate these already fragile economic circumstances of individuals and households affected by HIV. The loss of income due to illness and premature death is intensified when an individual with HIV/AIDS or their family members are denied employment or dismissed from their jobs because of HIV status. Individuals working in the informal sector can experience loss of income as community members deny them patronage by refusing to purchase their goods in local markets or rely on them for unskilled labour (Muyinda and Seeley, 1997). Economic impact of stigma at the individual and family level has been documented in Viet Nam and elsewhere in Asia (ICRW, 2004).

HIV-related stigma can also have indirect effects on individual economic productivity and the financial well-being of the family. Perceived stigma and discrimination have been associated with increased prevalence and severity of depression among people living with HIV

(Heckman et al., 2004; Joseph and Bhatti, 2004; Manopaiboon et al., 1998). Depression, in turn, has been linked to subsequent declines in health status (Ickovics et al., 2001; Major and O'Brien, 2005). Depression and physical health decline consequently can result in increased absenteeism in the workplace and reductions in income.

Restricted access to resources - or denial of access to these resources - is another important way capabilities are affected by HIV and HIV-related stigma. Studies of agrarian households affected by HIV in Rwanda and Zimbabwe demonstrated marked reductions in economic activity– both labour inputs as well as overall crop production (Guiness and Alban, 2000; Kwaramba, 1997). Declines in economic production adversely impact the capabilities of individuals and families. Crops are available neither for sale nor for household consumption, compromising the nutritional status of family members.

This is relevant to the Asian context as many Asian families and national economies are still highly dependent on agriculture. A study in rural Thailand documented declines in farm output and income ranging from 52 percent to 67 percent among households affected by HIV (ActionAid, 2003). Using survey data from Viet Nam to conduct statistical estimations on HIV's effect on levels of poverty, UNDP (2005) found that expenditure and income changes attributed to having a family member with HIV in the home forced some non-poor families to fall below the poverty line, while driving other families further into poverty - falling below the food poverty level. The compromised nutritional status of families and lack of previously available financial resources severely restricted individual and family capability sets. Individuals who are malnourished do more poorly in school and are less able to work at former capacity levels. Reductions in household earnings limit resources that can be used for education, savings, or small enterprise.

In a study on land-use rights in Kenya, Drimie (2004) found that HIV-related stigma adversely affected women's and orphans' right to inherit and use land. In many cases, women were dispossessed of their rights to inherit land owned previously by their husbands - in part because the community blamed them for the death of their spouses. Orphans faced similar types of barriers to inheriting property and were left destitute after the death of their parents.

Bharat (2001) noted that families in India have denied daughters-in-law's access to property, pension, or insurance benefits because they are blamed for infecting their husbands with HIV. Another Indian study of over 400 HIV-positive widows shows that almost 80 percent of the respondents had been denied the right to their husbands' property (NCAER, NACO and UNDP, 2006). The public rationale may be stated as responsibility/blame; an alternative explanation is the economic vulnerability of women and children and the family or community simply taking advantage of their lack of resources or public voice to defend their own rights - particularly during a time of care taking and mourning.

HIV can have a detrimental impact on the family's long-term economic prosperity through limiting children's access to education. A major portion of the caretaking and housekeeping burden falls on children, who then find it difficult to attend school (Gaffeo 2003). Families also rely on fees saved from school enrolment and purchasing school supplies as means to cope with the financial burden of HIV. Short-term economic gains are exchanged for longer-term financial

benefits for families (UNDP, 2005). Studies in South Africa and Senegal found that when children are withdrawn from school, they are more likely to be female, thereby exacerbating the impediments to gender equality in both countries (Booysen, van Rensburg, Bachmann, Engelbrecht, and Steyn, 2002; Ibrahima Niang, and Quarles van Ufford, 2002).

Reliance on children as caretakers for ill family members and its subsequent economic impact may not universally apply to the Asian context. Studies in Thailand, Viet Nam and India have rarely reported children to be caretakers of ill family members, but rather parents and spouses seem to take on this responsibility (Joseph and Bhatti, 2004; Kespichayawattana and VanLandingham, 2003; UNDP, 2005). Withdrawing children from school may not be a strategy currently employed by HIV-affected families in Asia, however, the potential impact this could have on families' future economic coping can be inferred from other studies in the region. A study carried out in Thailand demonstrated that families with lower educational attainment were more likely to make cuts in consumption (e.g. food and household goods) than those families with higher educational levels (Pitayanon, Kongsin and Janjaroen, 1996). Such measures have a negative impact on families' capabilities.

In addition to the practical concerns of resource conservation, access to education, resources and social capital, are also significantly influenced by HIV stigma and discrimination. As stated previously, cases have been documented in Asia where children have been denied access to education due to their HIV status or that of their parents (Bharat, 2001; Human Rights Watch, 2003; Paxton et al., 2005; Safman, 2004, UNDP, 2003). Harassment by children in school as well as discriminatory attitudes and practices of teachers (e.g., segregation within the classroom) undermine the educational process of children living with or affected by HIV. Outright denial of education or unequal education hinders the access of children and families to a wider capability-set, such as future employment in the skilled labour force and improved social status.

Gaffeo (2003) notes that HIV-related stigma undermines personal connections, presents barriers to participation in community life, isolates individuals living with the disease, and reduces the safety-levels of the social network in which people are embedded, thus severely compromising their social capital. This has long-term implications for the economic and social capacity-sets of individuals and families. In Senegal, the practice of sharing meals with the community is a sign of social prestige and contributes to the establishment and maintenance of social networks (Ibrahima Niang and Quarles van Ufford, 2002). HIV stigma reduces the number of people with whom meals are shared, thus isolating the family and leading to a decline in the family's social status in the community. Community connectivity is also established through marriage. Individual and family stigma of HIV can interfere with the cultivation of important social relationships, and the "marriagability" of a family member is restricted due to the presence of an HIV-affected individual in the household (Shreedhar, 2000).

Moreover, stigma undermines the ability to depend on social networks in times of economic need. For example, in Viet Nam funeral costs for a person who has died from AIDS are often not mitigated through financial help from family members whose lack of sympathy is driven by HIV-related discrimination (Aus AID and UNDP, 2005). A rise in the rates of AIDS-related deaths increases the number of orphans who need care (Booysen, 2004), and loss of social capital (as a result of stigma) compromises the ability to draw on social networks for care provision. Furthermore, orphans who are brought into the home may be denied opportunities given to other children of the household, such as education, and forced into the informal economy

(e.g., sex work) at an early age in order to supplement family income (Ansell and Young, 2004). By thus inhibiting education and occupational opportunities for the individual and family, HIV stigma ultimately limits long-term national economic development (Betchel and Apakupakul, 1999).

In presenting barriers to education, employment, economic resources, and the maintenance of social networks, HIV-related stigma compromises the capacity-sets of individuals and families. This could have a bi-directional effect on individual and family socioeconomic development. In a study of communities in China, those with low levels of human development had the highest levels of HIV-related stigma (Chen, Choe, Chen, and Zhang, 2005). Stigma, in turn, may perpetuate the family's restricted development as individuals are denied access to jobs and participation in the community. The authors suggest that this may also contribute to increased risk-taking behaviours as individuals are forced to obtain income through any means possible, such as transactional sex. It might also lead to further HIV risk in the broader community, if as in some cases documented, HIV contaminated blood is sold to generate revenue.

3.2 Institutional and Structural Stigma Influences on Individual and Family Socioeconomic Development

Discriminatory policies driven by antipathy towards people living with HIV compromise the economic well-being and capabilities of individuals and families. Company-wide mandatory testing policies can prevent skilled workers from applying for higher-level positions (Manopaiboon et al., 1998). This practice in conjunction with dismissal of HIV positive employees can put families in economic hardship due to additional loss of earnings (and earning potential) from those attributable to illness. National policies requiring testing of entering migrants or individuals applying for work visas extend the economic impact of HIV discrimination across international borders.

In many Asian countries, sending family members abroad is an important means by which families increase household income due to limited economic opportunity or low-wage employment in local communities. In some countries such as the Philippines and Sri Lanka, remittances from overseas migrant workers constitute a vital source of foreign exchange earnings. Families from economically depressed communities rely on remittances as one of their primary sources of income. Refusal of entry or deportation due to one's HIV status not only denies one's right to work but also has a negative impact on a family economic well-being.

Microfinance institutions are also important in developing countries and are often the only financial sources of small loans to community members. These loans have been an important financial means for individuals and families to fight poverty (Vonderlack and Schreiner, 2001). Microcredit has been particularly successful in helping families in South Asia start up and maintain small businesses (Khandker, 1998; Latif, 2001). Since these loans are often secured through one's status in the community and personal interactions with loan-officers, institutionalized HIV-related stigma can severely undermine an HIV-affected family's access to this money. This has been demonstrated in Vietnam, as the dual stigma of drug use and HIV has made it difficult for families to borrow or get credit (ICRW, 2004). In addition, Parker (2000) has chronicled the greater difficulty of HIV-affected families in repaying these loans, further jeopardizing the role of microfinance as an avenue out of poverty for families affected by HIV.

Lack of access to health care or affordable health care services can also have a negative impact on the capability sets of individuals and families affected by HIV. Where health care is not available or affordable, PLHIV have fewer opportunities to effectively manage the disease, such as treating opportunistic infections or receiving antiretroviral therapy regimens. Poorly managed illness can lead to a weakened physical state of the HIV-infected individual. As mentioned previously, this limits the capability sets of the individual by restricting economic activity in the form of absenteeism from work or restructuring of duties, which in turn, affects the capabilities of families who are relied upon for caretaking responsibilities.

People living with HIV who are denied access to health care or face significant barriers to receiving adequate care are likely to experience declines in their health status, thereby interfering with their ability to actively participate in economic activities or tasks crucial to household subsistence. For example, restricted access to health care due to stigma among rural women in Africa has resulted in high mortality rates and undercut food production given that women comprise 60-80 percent of the agrarian labour force (ILO 2000 in Gaffeo). Requiring people living with HIV (or their family members) to pay for excessive and unnecessary care such as extra gloves, AIDS kits, and additional testing directly depletes a family's scare resources. Stigmatization by health professionals reduces contact with the health care system. This behaviour in addition to the denial of necessary procedures can lead to deterioration in one's health, increasing absenteeism and loss of earnings.

Lack of access to health care among people living with HIV can have transgenerational effects as well. Not being able to access health care services can lead to severe malnourishment among women living with HIV. Gaffeo (2003) notes that malnourishment among mothers with HIV leads to iron-deficiency, mental retardation, general sickliness and interrupted growth among their children, thus hindering the children's health and future work capacity. HIV-related discrimination in the health care system was frequently reported in studies on stigma in Asia (Bharat and Aggleton, 1999; Bharat, 2001; Paxton et al., 2005; Reidpath and Chan, 2005).

Institutional stigma also exerts an independent effect on individual and family level development. Sex workers and injecting drug users are at the highest risk of HIV infection in South and South East Asia (ADB 2005) and often the focus of discriminatory policies. Compulsory rehabilitation for injecting drug users and sex workers, such as those in China and Vietnam, restricts individual economic activity. Although it is commonly assumed that injecting drug users are not employed, a 2003 study in Vietnam demonstrated that approximately one-third of this population had some form of employment (UNDP, 2003). These mandatory rehabilitation programs are criticized for not providing individuals with vocational training that would enable them to become economically productive citizens in sanctioned sectors of the economy upon completion of the program. Such practices may be counterproductive and undermine dually stigmatized groups' ability to maintain a satisfactory standard of living.

Social capital can also be limited as a result of institutional or structural level discriminatory policies. Gains in social capital can be made through marriage or occupation. Laws prohibiting marriage of people living with HIV, such as those in India until 2002, have negative impacts on an individual's ability to create important social networks. Not only do such restrictions carry economic repercussions by preventing legal rights to pensions and property, but also isolate individuals and wear away social safety nets.

Prohibitions against people living with HIV entering religious orders have a similar effect. Sending a family member into a religious order is one way in which economic burdens can be alleviated in some rural communities. In addition, having a family member as part of a religious order improves a family's social status in their communities. By prohibiting entry of people living with HIV into religious orders, community-level stigma is reinforced and its economic impacts exacerbated. Moreover, individuals lose their freedom of self-determination.

4. RESEARCH AGENDA

The consequences of HIV stigma and discrimination are complex and multi-dimensional. Stigma has important physical and psychological effects, ranging from diminished social support and depression to inadequate medical care, insufficient treatment and increased mortality. These consequences contribute to and exacerbate pernicious socioeconomic outcomes, such as loss of earnings and earning potential. Furthermore, the economic effects of stigma feed back into detrimental physical and psychosocial outcomes, creating a complicated interplay of cause and effect. This is only one of many topics that must be addressed in future research. In addition to the physical, psychological and economic challenges presented by infection, PLHIV and their families are faced with a host of additional challenges due to prevailing societal stigmas.

This overview of the role of stigma on human development of PLHIV and their families in Asia highlights important areas for future research. We have just commemorated the 25th anniversary of the first cases of HIV, and we now stare into the face of an epidemic that, by all accounts, is expanding in Asia. Lessons learned about HIV prevention and control in one country have failed to inform decisions in other countries (Sepkowitz, 2006); as a result, the epidemic continues to spread throughout the world. Merson (2006) suggests that in the countries hardest hit by the epidemic (or soon to be hardest hit), the foundations of human development, governance and national security are eroding, and that this will have multi-generational implications. Although not exhaustive, listed here are some initial ideas to promote further empirical research in the area of stigma and human development in Asia.

Women and Stigma: The prevailing gender inequality and disproportionate vulnerability of women to HIV in the region is reflected in the manifestation of stigma as well. Bearing the burden of blame, shame and lower status in society, women suffer disproportionately from stigma as well. Limited avenues for redress, oppressive societal values and norms and coping mechanisms make the situation much worse for them than men.

Impact of Multiple Stigmas: Moreover, there has been limited attention focused on the impact of multiple stigmas; that is, being HIV positive, as well an ethnic/tribal minority, mother, widow, orphan, MSM, unemployed, commercial sex worker, and/or injecting drug user, et cetera.

Socioeconomic Impact of Stigma and Discrimination: Stigma and discrimination have an associated socio-economic cost arising out of absenteeism, denial of jobs, denial of education and access to property and wealth, and isolation from economic activities. Stigma induced medical manifestations such as depression and stress accelerate disease progression,

while real and perceived discrimination drive people living with HIV to suicides. Research in this direction can help advocacy for specific policies and programmes.

Cultural and Religious Beliefs/Practices: One must identify resources that faith-based organizations might bring to stem stigma and discrimination, and consider ways to leverage these organizations to do greatest good. One must also minimize the potential constraints that cultural or religious norms and values might impose.

Healthcare Sector: Healthcare providers and institutions are important sources of information, education, prevention and treatment. Individual and family level stigmas result in deleterious health behaviours (e.g., poor medication adherence, testing behaviours, and HIV status disclosure), underlining the importance of strong healthcare resources. At the same time, some of the most profound institutional stigmas have been documented in healthcare settings. More research is needed to determine how best to train healthcare providers to offer non-discriminatory care, and to promote equitable services/policies at the institutional level. This is important because unfounded concerns about disease spread through casual contact have resulted in limited resources being wasted.

Stigma and Access to Treatment: The development and distribution of highly active antiretroviral therapy has changed the course of the HIV epidemic. However, stigma poses barriers to accessing treatment because of the fear of disclosure of HIV status and possible discrimination. Enhancing access to treatment and reducing stigma can be mutually beneficial and research into inter-relationship between stigma and treatment can help policy and programme interventions.

Impact of Stigma on Prevention Efforts: The stigma of disease and its associated risk behaviours (sex, drugs) have restricted prevention efforts. To truly stem the epidemic, we must consider the best approaches to primary, secondary and tertiary prevention - in light of stigma – and to protect the social and economic integrity of communities worldwide. This may mean finding ways to challenge norms of discourse regarding "acceptable" behaviours and their consequences for health and disease. Clinical approaches to prevention that must be considered given recent evidence for effectiveness include male circumcision, pre- and post-exposure prophylaxis against sexual transmission in high-risk populations, and microbicidal agents.

Vaccine Development: There may also be individual to institutional impacts of vaccine development. On the individual level, stigma and discrimination can impact who elects to enrol in a vaccine trial and/or actually would be willing to take an approved vaccine. The role of dis-inhibition following distribution of an HIV vaccine will also be critical for the spread of HIV through the region. Of course, should an effective vaccine be approved and distributed - not expected in the next decade - the impacts for stopping the spread of HIV would have profound impacts on human development.

Education/Employment: The bi-directional effects of stigma and development in the education and employment sectors are critical as these are the domains with the greatest opportunity for individual and collective growth and development. Restrictions in either sector based on individual, institutional or structural (i.e., policy) related stigma can have devastating long-term impact on children and youth as well as adults of productive age. Critical empirical

attention must be focused on the determinant and consequences of stigma in these domains as they are at the heart of human development in a community/country/region.

Political Leadership: It would be critically important to identify the role of political leadership in defending against HIV-related stigma, and also in supporting the growth of economies despite constraints of disease.

Policy Implementation and Enforcement: The impact of discriminatory policies against persons infected or affected by HIV/AIDS must be evaluated. Rigorous structural-level evaluations are difficult to conduct; however, there may be an opportunity for "natural experiments" insofar as one can evaluate outcomes (e.g., HIV risk behaviour, disease prevalence, disease progression, economic progress/decline) before versus after policy implementation.

Stigma and Disease Spread and Progression: One must determine whether stigma actually has any impact on high-risk behaviour and subsequent spread of disease, and/or whether stigma can directly/indirectly influence viral replication rate. Specifically, with secrecy and lack of disclosure, one could evaluate whether HIV would spread more rapidly through the population. Further, in the absence of HIV, one could evaluate how economic development might be expanded.

Impact of Stigma on "Capabilities": Sen's approach to human development is based on political freedom, economic facilities, social opportunities, transparency guarantees, and protective securities. It will be challenging to investigate the impact of stigma and discrimination on these outcomes. This work will likely have to be conducted by economists, and others (e.g., sociologists, anthropologists, political scientists) who take a broad perspective beyond impact on individuals. In turn, the impact of these aspects of development on stigma in a community must also be evaluated.

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