

# Stigma, HIV/AIDS and prevention of mother-to-child transmission

A pilot study in Zambia, India, Ukraine and Burkina Faso

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## **Executive Summary**

For some time now, HIV/AIDS-related stigma has been a major stumbling block in addressing all aspects of HIV prevention, treatment and care across the globe. Undertaking a more systematic analysis of the nature of such stigma, its forms and determinants in different societies and contexts, can assist policymakers and non governmental organisations in ensuring that initiatives aimed at reducing stigma are integral to HIV and AIDS programme planning.

This pilot research initiative was conducted in four countries in different geographical regions: India (South Asia), Ukraine (Eastern Europe), Burkina Faso (Francophone West Africa) and Zambia (Anglophone Southern Africa). The specific aims of the project were to assess and provide an initial analysis of the extent of perceived and enacted stigma, consider stigma in general and, more specifically, that surrounding mother-to-child transmission, and to explore what steps might be taken to alleviate it.

In all research sites examples of stigma were numerous. Whilst there were many similarities in its causes and manifestations, there were also clear contextual differences. Women throughout the research were subjected to stigma as women, as HIV-positive women and as HIV-positive women who are pregnant and/or have children. Stigma was reported everywhere to be more extensively directed against women than against men. Stigma surrounding mother-to-child transmission (MTCT) prevents women coming forward for testing, reduces their choices in terms of health care and family life once they are known to be HIV-positive, and negatively impacts on their quality of life.

A number of recommendations were identified by the research to reduce the impact of stigma in general. Strengthening the legal framework to protect the human rights of people with HIV/AIDS was seen as paramount. Simultaneously, communities need to be empowered to understand and use policy and the law to obtain the care and support they require. In addition it was considered vital to create supportive environments to reduce stigma through national and community-based communication initiatives to combat fear and misinformation; to improve community based self-help services for people living with HIV/AIDS; and to increase accessibility to affordable antiretroviral (ARV) therapy.

The research highlighted the importance of prevention of MTCT programmes being integral to broad based preventive, education, care and support programmes and that there should be more direct focus on the mothers and fathers of potentially infected infants. The limited resources within communities to cope with HIV/AIDS and the current inadequacies of many health care systems to provide care and support must be taken into account. Also illustrated was how the rights and choices of HIV-positive women are repeatedly ignored or denied,

that the policy framework to support their rights is weak and that their needs are almost always secondary to those of others in the community.

## Introduction

As the HIV/AIDS pandemic continues to evolve, much has been documented of the social as well as the bio-medical impact that it has on individuals, their families and their communities. HIV/AIDS-related stigma<sup>[1]</sup>, and its associated discrimination, is known to negatively affect all aspects of HIV prevention, diagnosis, treatment and care (Brown et al 2001). Reducing such stigma is therefore a vital pre-requisite in both stemming the epidemic and providing adequate care and support to those affected. To do this effectively, requires a more systematic analysis of stigma and resulting processes of stigmatization, discrimination and denial (UNAIDS 2000).

In mid-2001, the Panos Institute Global AIDS Programme and UNICEF initiated a pilot project to explore the complexities of stigma in greater depth. The long-term aims of this work are to promote greater understanding among policymakers and non-governmental organisations (NGOs) of the causes, expressions and impact of such stigma and what action might be taken to reduce it. The specific aims of the pilot project were to:

- ? Assess and provide an initial analysis of the extent of perceived and enacted stigma among health providers for HIV/AIDS, those receiving care and decision makers.
- ? Consider stigma in general and, more specifically, that surrounding mother-to-child transmission.
- ? Inform a wider information programme about such stigma and the steps that can be taken to alleviate it.

The work took place in four contrasting countries – Zambia, India, Burkina Faso and Ukraine. This report provides a country by country analysis of the findings of the research in general, and a comparative analysis of the specific forms, contexts, determinants and implications of stigma in relation to mother-to-child transmission (MTCT).

It is important to note that for the purposes of the research project we have adopted the term mother-to-child transmission (MTCT) since this was a key focus of the research. An alternative term, parent-to-child transmission (PTCT) has evolved in recognition of the role and responsibility that both men and women have in protecting themselves and their families against HIV infection (SAfAIDS 2001). The term is important in that it removes the burden of responsibility and stigma from being solely on the mother of the child, although the male sexual partner involved in transmission may not necessarily be the father of the child. Furthermore, it provides greater opportunities for men to become involved in community based HIV prevention, diagnosis and support programmes. As is

argued later in the text, from a programmatic perspective there may be good arguments for systematically replacing MTCT with PTCT in the future.

## **Stigma, discrimination and denial – a brief literature overview**

There is a rapidly growing literature on stigma and its repercussions on societies across the world. Stigma has been defined as ‘an attribute that is significantly discrediting’ (Goffmann 1963), and ‘an attribute used to set the affected person or groups apart from the normalized social order, and this separation implies a devaluation’ (Gilmore and Somerville 1994). Stigmatization therefore describes the process of devaluation within a particular culture or setting, where certain attributes are seized upon and defined as discreditable or not worthy.

In the case of HIV/AIDS, stigma may be applied to actual infection or to behaviours believed to lead to infection. Because HIV/AIDS first affected groups of people who were already socially marginalised, the stigma attached to HIV/AIDS is often layered upon pre-existing stigmas of sexual conduct and drug use (Herek & Glunt 1988, Maluwa et al 2001). Stigma therefore plays into, and reinforces, existing social inequalities, being linked to power and domination in the community as a whole. The most marginalised and excluded groups in societies such as drug users, men who have sex with men and sex workers, not infrequently bear the brunt of stigmatization in relation to HIV/AIDS (Malcolm et al 1998). Similarly, those infected with HIV are often seen as members of these predetermined groups (regardless of whether they are or not), thereby enabling denial of the individual and general public’s vulnerability to infection. It should be noted however, that the concept of stigma may be unclear or differ in particular societies or languages.

Discrimination is essentially the different, and most commonly negative, treatment of an individual or group of individuals because of one or more factors attributed to them. Stigma and discrimination are intimately linked; stigmatization often leads to discrimination, and discrimination can take many forms (Maluwa et al 2001). Discrimination exists at many levels. Ten key areas have been identified by UNAIDS as of particular relevance to what might be described as arbitrary<sup>[2]</sup> discrimination (UNAIDS 2000) of people with or suspected of having HIV infection<sup>[3]</sup>. This pilot study explores some but not all of these key areas, and goes beyond recent UNAIDS research in Uganda and India (UNAIDS 2001) given its focus on mother-to-child transmission issues. Of particular interest was discrimination in health care, social welfare, reproductive and family life, employment and education settings.

Against the background of this ‘institutionalised’ discrimination, the research aimed to explore what can be termed as ‘social’ discrimination, manifested at family, community and public level. The study elicited extensive evidence of both forms of discrimination and reveals how, frequently, they are mutually reinforcing.

## **Research methodology**

The research team comprised a global research coordinator (GRC) based in the UK and working closely with Panos, a key researcher in each country and, in some cases, a research assistant. The GRC had responsibility for developing and later adapting research protocols, bringing together the findings and performing a comparative analysis of the findings. The key researchers in-country pre-tested and assisted in the adaptation of the protocols, conducted and managed the research in each of the sites, and prepared a final country report.

The research was almost exclusively qualitative, with evidence being gathered through focus group discussions and key informant interviews. Additional information was provided by local researchers on socio-demographic characteristics and, where possible, rates of HIV infection within the given area. Within each study site, three focus group discussions (FGDs) were conducted, one with service providers from health care settings and two with service users (one male, one female). A number of key informant interviews were also carried out.

## **The research questions**

The research tools included an interview schedule for key informant interviews and two separate focus group discussion protocols for service providers and service users. Stigmatization and discrimination in relation to mother-to-child transmission (MTCT) was a key focus of the research, so a significant number of questions focused on this issue. The questions addressed the following themes:

- Notions and understandings of stigma in different research sites
- The forms of stigma experienced
- The range of contexts in which stigma is manifested
- The perceived causes and impact of stigma
- Specific forms, determinants and contexts of stigma in relation to mother-to-child transmission of HIV
- Community perceived responses to stigma.

## **Research Sites**

The research was conducted in four countries in different geographical regions: India (South Asia), Ukraine (Eastern Europe), Burkina Faso (Francophone West Africa) and Zambia (Anglophone Southern Africa) The sites were chosen to ensure a global perspective, to examine settings at different stages in the

epidemic with varying degrees of available interventions and to include a mix of urban, semi-urban and rural settings.

## Zambia

In Zambia, the research was conducted in a rural 'chieftaincy' bordering Zimbabwe<sup>[4]</sup>, some 170kms south of Lusaka. The area is sparsely inhabited, and is most densely populated around a government-owned pontoon, the main access point to the area. The local economy depends on subsistence farming, selling produce, fishing, brewing beer and wage labour (Bond and Wallman 1993).

Since the 1990's, there has been extensive structural, economic and social change. One commercial farm now employs up to 2000 workers for over seven months a year and many of these are migrant workers. Women sex workers (both local and from other areas), are highly visible. Sex with a condom costs considerably less than sex without a condom. Malaria, diarrhoeal disease, upper respiratory tract infections and, latterly, HIV/AIDS are the most prevalent diseases and infant mortality is higher than the national average (Bond and Ndubani 1993).

There are two rural health centres and a long established and recently extended Mission hospital at the nearby border post, some 12 miles away. A pilot prevention of MTCT programme was introduced here in 2000 (see page 27 for further details). Other treatment options include traditional healers, drugs purchased from local shops and herbal remedies. Conditions such as AIDS are frequently ascribed to witchcraft and/or traditional illnesses. Witchcraft accusations are common and periodically attract witch finders to the area.

In 1999, the average rural HIV prevalence in Zambia was 13.6%, although in Lusaka Province, the HIV prevalence was reported to be 27.3% (CBOH 1999). Given the number of risk factors identified, and counting the visibility of HIV/AIDS in the community, HIV prevalence would appear to be high in the locality. A survey showed that there are significant rates of STIs amongst the local farm population (Fylkesnes et al 1996).

Education and HIV prevention programmes have been sporadic and have included peer education programmes and anti-AIDS clubs. At the border post, World Vision International has implemented a sex worker and truck driver Cross-Border Initiative (CBI).

**Research participants:** The service provider FGD comprised two women and six men. They included health centre and community based health workers, the chairman of the neighbourhood health committee (village headman) and an environmental technician. The two service user FGDs comprised six men and six

women. Women were mainly small farmers and there was one traditional birth attendant (TBA). Men included small farmers, a court clerk and a fisherman.

In total, ten key informants were selected to provide both a rural and a more urban/national perspective. Within the locality, local representatives of political parties, churches, schools, traditional healing and HIV education were selected. In Lusaka, representatives from the media, health policy, law, people living with HIV/AIDS and an HIV/AIDS counseling organisation were chosen.

## **India**

India reportedly has the largest number of HIV-positive individuals in the South and South East Asia region. Sexual transmission is estimated to account for nearly 84% of all HIV infections and perinatal transmission for 2.04% (NACO 2001).

The local study was conducted in Mumbai (formerly Bombay), a major industrial and commercial centre. The city is divided into sixteen municipal wards and eighty-eight sections (Bharat 1996). Mumbai has a population of nearly 12 million, with a sizeable number of migrant workers, and offers employment opportunities in the organised and unorganised sectors. HIV prevalence among women attending for antenatal care has risen above 2.5%, supporting the view that HIV infection is percolating from various 'high risk groups' to the previously perceived 'low risk population' (NACO, 2001).

There is an official estimate of 50,000 female sex workers in Mumbai, between 28.2 and 62.8% of whom are estimated to be HIV-positive. 10,000 trucks enter the commercial centre of Octroi Nakas every day (MDACS 1999). Factors contributing to rapid HIV transmission include poverty, migrant labour, rapid urbanisation resulting in large slum populations, and untreated sexually transmitted infections.

The Government has launched a number of HIV/AIDS awareness campaigns and education programmes for both the public and for health and allied professions. The National AIDS Control Organisation (NACO) coordinates AIDS activities at the national level, and counterpart State AIDS Control Societies have been established in each of the states and union territories of India.

There are currently five voluntary counseling and testing (VCT) centres managed by NGOs and four by the teaching hospitals (MDACS 1999). As yet, these are not linked with the provision of antiretroviral therapy. MTCT prevention trials have been initiated in several sites (see page 27 for further details).

**Research Participants:** Nine service providers participated in the FGD, six women and three men. These included a counsellor from a VCT site, two social

workers, a ward attendant, a nurse, an allopathic doctor, a homeopathic doctor and representatives from a community based organisation and a support group. Eight women participated in the women's service user FGD. Two men's FGDs, involving a total of nine service users, were conducted. Eleven key informant interviews were conducted with four doctors (one involved in the MTCT trial); a research professor in the field of HIV/AIDS; a lawyer activist; a director of the Humsafar Trust (gay activist organisation); a health correspondent from a national newspaper and representatives from a Positive People's group, an Information, Education and Communication (IEC) programme, and a community based NGO.

## **Ukraine**

Ukraine is one of the largest countries in Europe with a population of about 49 million people. Since gaining independence in 1991, Ukraine has experienced a deep economic crisis as it has undergone fundamental structural and economic reform. There is widespread poverty and mortality rates are rising alongside a decline in birth rates. Child morbidity among the under-fives has increased by 42%, and among young people (under 14) by 18%. Infant mortality remains 2-3 times higher than in western European countries. A particularly striking tendency has been a rapid increase in sexually transmitted infections (STIs) particularly among young people.

Whilst the cumulative total of people with HIV infection officially registered is 41,332, sero-epidemiological monitoring and estimates by WHO indicate far higher levels of infection (72,000 and 300,000 respectively). Injecting drug use is still the major route of transmission and the majority of those infected are 20–39 years-old, with an increasing number of under 18 year-olds (constituting 30% of the drug using population) becoming infected. Medical care for people with HIV is mainly provided through specialised AIDS centres, clinics for the treatment of infectious diseases and departments of infectious disease in multi-profile hospitals. There has been a gradual increase in the number of private sector health providers.

**Research participants:** Nine key informant interviews were conducted with representatives from the Ministry of Health, government youth organisations, UNICEF, Path, the International HIV/AIDS Alliance, the Family Planning Association (Ukraine), the Ukrainian network of people living with HIV/AIDS, men who have sex with men (MSM) networks, and the Kiev Friendly Clinic. The service provider FGD of eight participants was medically focused and included two obstetrician-gynaecologists, one gynaecologist, one HIV/AIDS doctor, three HIV/AIDS specialists and one deputy head doctor of a health centre. These were from 3 regions (Kiev, Donetsk, Dnepropetrovsk). The male and female service user FGDs comprised ten participants each from across three regions ( Polava, Odessa, Kiev).

## **Burkina Faso**

The study in Burkina Faso took place in Koudougou, a small town located between Ouagadougou, the capital city, and Bobo Dioulasso, the second largest town of the country. Koudougou has 85,000 inhabitants. While the town hosts some factories including the national textile factory, breweries and a soap factory along with some public and private infrastructure, these account for less than 5% of all employment. The majority of the population is engaged in small-scale agriculture and livestock farming.

In 1999, 324 cases of HIV infection were officially reported in Koudougou, but this is considered to be far lower than the actual figure. Observers consider the HIV infection rate in Koudougou to be higher than the national rate of 7.2% (Regional Direction of Health 1999).

Movement between Koudougou and Cote d'Ivoire for work and trade is high. This was perceived locally as a key factor in HIV transmission with many migrants returning from Cote d'Ivoire when they are infected with HIV. Sex work is common and a distinction is made between 'official sex workers' who come from outside, mainly Nigeria, Togo and Ghana and 'non-official sex workers' or local women in their teenage years.

There are five public health units, including the regional hospital, ten private clinics and one reproductive health clinic for young people in the area. All of these provide ante- and post-natal consultations, along with group IEC initiatives on contraception and HIV/AIDS. There are a number of non-governmental organisations working in HIV prevention, some providing counseling and support to people with HIV.

**Research participants:** Ten key informant interviews were conducted with informants from health services, the police, the church, workers' unions and a woman's organisation, as well as a traditional chief. In the health providers focus group there were ten participants, three women and seven men, including three doctors, one traditional doctor, four medical assistants, one midwife and the president of a local NGO providing prevention education and support. Nine women participated in the female service users FGD, most of whom were accessing services on behalf of other people. The men's FGD comprised seven participants.

## Key findings

### Zambia

#### Forms

The ubiquitous nature of HIV was evident, with many research participants openly referring to relatives that had died of HIV/AIDS. ‘So many people are dying here from this killer disease... Each and everyone has to pull the wagon now.’ (Man, service user FGD) However, almost all had kept the disease hidden.

Powerful imagery, metaphors and euphemisms for HIV/AIDS were elicited. Terms applied to people with, or suspected of having, HIV/AIDS drew associations with socially perceived immorality (“promiscuity”), illness, death, denial, innocence and guilt. Shona<sup>[5]</sup> words applied to people living with HIV/AIDS included ‘zayero’ (prostitutes), ‘mombwe’ (for men having sex with many women), ‘mukondombero’ (incurable disease) and ‘kayaka’ (the light shines through, meaning they cannot hide that they are sick). Dominant in such discourse is the blame assigned to people with HIV/AIDS, and assumptions made about their past sexual history. Exceptions to this were identified as grandmothers who assist women in labour and “deserve pity” if they become infected.

Stigma assumed many forms, some more subtle than others. Subtle forms included strong resentment against the free medical scheme for local sex workers, resented for making the sex workers feel “special”.

There were clear ambiguities surrounding stigma. The Church’s response for example was fraught with such contradictions. There has been an upsurge in Christianity in Zambia in the last few years (Colson 2001), and on the one hand, local churches preached morality, condemned immoral behaviour, viewed HIV/AIDS as a punishment, and refused to discuss realistic HIV prevention strategies. Some churches were known to impose mandatory testing before allowing marriage. On the other hand, their own priests and pastors were known to be infected, “the same people who preached moral behaviour.” (Woman service user FGD) The important role of the congregation in praying and caring for the sick was, however, often mentioned.

Examples of further contradictions can be seen in the dominant response to sex workers. While focus group participants recognised that economic circumstances forced some women to exchange sex for money or goods, they in

turn made derogatory comments about these women. Similarly, there was clear discordance between the notions of blame and guilt attributed by research participants to people with HIV, and more compassionate responses to questions as to whether stigmatising behaviour should be challenged. When questioned further, participants acknowledged that notions of reciprocity (“Next year I might need the same care”), Christian principles (“love your neighbour as yourself”) and the hidden nature of HIV (“You can’t know if you have it”) were central to showing compassion to people living with HIV and AIDS.

Stigma was perceived as highly pervasive, “There is stigma everywhere – in the church, at home, in the hospital.” (Man, service user FGD) Yet, while stigmatising behaviour was assimilated by many, there were also clear examples of positive, non-stigmatising behaviours.

Women of all ages were perceived as the most common ‘victims’ of HIV/AIDS-related stigma. Openly derogatory remarks were commonly made about women in clubs and bars. Poor women and single women were especially looked down upon. Blame for infection was frequently placed on women: mothers were blamed for infecting their babies; older women were accused of being ‘promiscuous’ and ‘grabbing’ young men at beer huts, and schoolgirls were cited as “going for an older man just for a few kwachas [Zambian currency] to buy books, pencils and lotions.” (Women, service user FGD) Women traders, and especially cross-border traders, were blamed for bringing HIV/AIDS into the area, as were women seasonal workers on commercial farms who moved back to town in the off season, “meeting truck drivers and returning to ‘spread disease’”. (Key informant, rural Zambia)

For many respondents in this site, sex workers represented uncontrolled and open sexuality, for which they are condemned. Participants were clearly angry about a local World Vision intervention with sex workers.

“Certain people are part and parcel of the problem...why do we give them sympathy? We spend billions on surveys and seminars but we know where the problem is. It lies with these girls flirting scott free, spreading HIV...We should do away with human rights [for such women]...We should deter them...Arab states’ rules on women seem to be discriminatory but at least they control sexuality.” (Key informant, rural Zambia)

Truck drivers and migrant workers were equally vilified with labels such as “the suppliers of AIDS” and being “on a suicide mission” (Men, FGD rural Zambia), and were considered as undesirable within the community. In addition, there was widely held resentment against people who returned sick from the town to the village.

Blame attributed to men was generally more limited. However, some men were likely to be blamed for HIV infection within a marriage, as in the following

example. “If a married woman suffers from HIV/AIDS and people have been seeing that she was a respectable person, the blame will be on a man.” (Woman, service user FGD rural Zambia) Older, richer men or ‘sugar daddies’, were frequently blamed for enticing younger women and giving them HIV/AIDS.

### **HIV/AIDS as traditional disease or witchcraft**

In rural Zambia, there was a recurrent theme of denial or ambivalence with respect to the existence of HIV/AIDS. For many respondents, HIV -related signs and symptoms were attributed to traditional diseases and/or witchcraft.<sup>[6]</sup>

Having said this, HIV/AIDS and witchcraft are seen as relatively distinct – AIDS is self-inflicted and can be prevented whereas witchcraft cannot be prevented or controlled (Bond 1998; Mogensen 1995). The men’s focus group was divided between those who still questioned the existence of HIV/AIDS and those who acknowledged it. The latter group said that the former were, “hiding behind witchcraft”.

Witchcraft and traditional beliefs provide an effective coping mechanism for individuals and communities. To be bewitched is not shameful, it is ‘curable’ and can be managed within the local cosmology and healing systems. The burden of blame and guilt is thereby shifted to those responsible for bewitching. People who are ‘bewitched’ receive greater acceptance, better treatment, and can be open about their condition. They receive sympathy and understanding. Witchcraft accusations also help the community cope with bereavement and witchfinders are consulted both at the burial, as well as when the person is sick (Yamba 1997).

“Some are not accepting that they are living with HIV, even if they are full-blown. They would rather say they are bewitched and blame others.” (Key informant, rural Zambia)

“Relatives may suspect AIDS but they keep up a front of going to n’gangas [traditional healers].” (Man, service provider FGD)

“It is easier to be bewitched since AIDS comes through misbehaviour... [with AIDS] your secret is exposed and you in turn are exposed to negativity.” (Key informant, rural Zambia)

### **Contexts of Stigma - health care settings**

The most extreme forms of stigmatization towards people known or suspected to have HIV were reported in health care settings. This included denial of drugs and treatment; being left in the corridor; being dealt with last; being labelled or

called names; being subjected to degrading treatment and breaches of confidentiality.

Care providers themselves claimed they found patients with HIV/AIDS more difficult because of their multiple infections, their “hysteria”, their “attention seeking” and their “many thoughts” (i.e. the need for psychological as well as medical support). They also admitted that HIV/AIDS patients were often not given the same services because doctors know they are going to die and, therefore, spent less time on them.

One HIV-positive key informant described the following reaction:

“I went to the health centre with gastritis. I am not supposed to pay because I am HIV-positive. When I told the clerk this he was amazed and went to see the sister-in-charge. She came to me and told me ‘There is no need for you to have medicine because you are going to die.’ This nurse was even a Christian!”

Another testimony described how a sick patient with HIV on a hospital ward was subjected to the most extreme forms of mental and verbal abuse, degradation, blame and stigmatisation. (See Appendix 1)

Importantly, while principles of confidentiality were rigorously adhered to in the hospital where clear codes of ethics were in force, elsewhere confidentiality was adhered to in a rather ‘loose’ manner.

## **The family**

In the household and family setting, stigma was manifested in the forms of verbal abuse, rejection, eviction and imposed restrictions on the person. People with HIV/AIDS were subjected to blame, bitterness, anger, denial and the withdrawal of treatment and care, sometimes leading to blatant neglect.

“During burial you will find the mouth and the eyes are open, an indication that the person died when there was no-one at home to at least close his eyes and mouth.” (Woman, service user FGD, rural Zambia)

“Once they know you have TB they isolate you. You will be eating alone on your plate, use your own cup and spoon. Sometimes the kid by accident touches your spoon or cup and the people around will scream and say ‘Give it to the owner! Don’t you know that you can get AIDS from this person...?!’ (Woman, service user FGD)

Importantly, participants felt that while men were likely to share their HIV status with their wives in the expectation of a supportive response, women were much less likely to disclose their HIV-positive status to husbands for fear that this might precipitate divorce, violence or further disclosure. Such concerns are confirmed

by a recent study in Lusaka (Chikwampu et al 2001). Underlying the women's discussion of the topic is the feeling that as a woman one is ultimately disposable.

### **Stigma or fatigue?**

Fatigue and the burden of care resulting from HIV/AIDS, requires special consideration. HIV/AIDS is different to many other diseases. It touches on sex and death (Wallman 1988), remains hidden for much of the time and challenges the family's capacity to offer support. There is limited capacity to cope with HIV/AIDS, and when a family has exhausted both available treatment options and its own meager resources, care and treatment of the patient is likely to be reduced (Bond 1998). In situations of poverty, being unable to contribute to household living or tasks adds to the stigma associated with HIV/AIDS: "You lose respect from other family members since you are sick and unable to participate fully in the household." (Man, service user FGD) It is, therefore, important when addressing stigma within the home and community that these factors are well understood. The insidious fatigue of caring often frustrates the best intentions of care and compassion (Bond & Ndubani 2000; Abrahamsen 1993).

### **The community**

In the community, people frequently reported putting physical distance between themselves and persons suspected of having HIV/AIDS. Not shaking hands, not sitting next to such people on buses, not sharing food and drinking utensils were all signals of rejection. Some forms of stigma manifested themselves as quite subtle looks or reactions, or were couched in what one respondent called 'cosy' language, such as in descriptions of a person living with HIV/AIDS as 'our friend with the problem'. People with HIV/AIDS were at times openly condemned for being irresponsible and becoming infected, or were subjected to public ridicule.

### **The workplace**

In town workplaces, people with HIV/AIDS were ostracised, isolated and gossiped about. One respondent characterized the process as one of "Mental abuse – people need not say anything – you just feel it [discrimination]." (Key informant, rural Zambia) Suspicions of HIV infection also prevent access to training and promotion. Deciding to take a test for HIV was often taken as an admission of infidelity and/or promiscuity.

## **In school**

In school, stigma manifested itself in the forms of rejection, gossip and taunts. HIV-positive teachers suffered from self-stigma, withdrawing themselves from the public eye. Leave was sometimes imposed upon them, making their sickness invisible. Children whose parents had died as a result of HIV/AIDS were sometimes taunted by other children, "Your mother's a prostitute!" (reported by key informant). As a result, they were reluctant to go to schools. Interviewees also reported feeling it was unsafe to send children who are HIV-positive to school, for fear of discrimination and bullying.

## **Politics**

Politicians were reported as making stigmatizing remarks such as "HIV/AIDS is only transmitted through "reckless behaviour" (Key informant, Lusaka) and to insist that no rich people were infected. They were also said to make a habit of implying that infidelity and prostitution lead to HIV infection. "The denial is from the top offices – they say you only get AIDS if you sleep around." (Key informant, Lusaka)

## **Causes and impact**

The main causes of stigma were identified as ignorance and misinformation about how HIV is transmitted. The shame of having a disease so strongly associated with "promiscuity" and "prostitution" was also seen as generating stigma. As one respondent put it: "HIV confirms stereotypes and underlying assumptions that move with one on a day to day basis, for example prostitutes are bad people. HIV/AIDS fits such stereotypes quite nicely." (Key informant, Lusaka)

In health care settings, respondents identified poor working conditions and fear of infection as contributing to stigma. Health care settings, like the household, are contexts in which the most intense forms of care are required and where the strain is often greatest.

While a few men and women felt that stigma might act as a deterrent, presumably to risk taking behaviour, overall stigmatisation was seen as having a negative impact by pushing the epidemic underground and making people scared of testing for HIV. Here, the causes and impact of stigma were understood as mutually reinforcing.

As noted in other contexts (Mukasa et al 2001, Bharat 2001), although stigma is prevalent in this rural Zambian community, there is also evidence of changing values, together with increased pragmatism, care and compassion. Media images of the epidemic are now more positive and informative, and a gradual shift in the attitudes of health workers was noted. While clearly far more needs to be done, there is increasing recognition that, 'so many people close to you are dying that you cannot always run away and have to offer care and spiritual support.' (Key informant, rural Zambia)

## India

### Forms

In India, people with HIV infection are subject to much labelling and name calling. HIV/AIDS is frequently associated with immoral behaviour (galat kaam), extra-marital sexual relations, prostitution and deviance. There are powerful links too between HIV/AIDS and death, disease, pain, suffering, isolation and ostracisation. People with HIV are labelled 'khoon kharaab ho gaya' (those with dirty blood), 'lafdebaaj log' (those who have many affairs), 'bimaari' (the diseased) and 'gandi naali ke keede' (worms from the gutter). In India the word 'victim' is used to denote the innocence of unsuspecting persons who have acquired the infection, mostly women and children, through no 'fault' of their own but by implication labelling the perpetrator as 'culprit'.

Participants said that the term 'AIDS' itself, is stigmatising because of the strong negative reactions the term evokes. Identifying an HIV-positive person as having 'AIDS' is indicative of a highly discriminatory attitude. One man in the service user FGD gave this example:

"Before going to the Gulf for a job, I was required to test my blood. When I went to collect the report, the lady ignored me for 20-30 minutes, asked me to wait aside. When people standing behind me collected their reports, I demanded mine too. She shouted loudly, "You have AIDS, now stand aside." Can you imagine what happened to me? There were 20-25 people who just kept staring at me...."

Some participants felt that women were as stigmatized as men, others that they received more compassion, especially if seen as 'innocent victims'. Most felt, however, that women were labelled and blamed for passing on the infection to the husband, even if he too was positive. Younger HIV-positive women are open to greater suspicion by family members, who imply that they may have had pre-marital sexual relationships.

## **Contexts of Stigma - health care settings**

The health care context is where HIV/AIDS-related discrimination and stigmatisation was perceived to be most prevalent. Negative and judgemental attitudes from doctors and nurses who are considered 'experts' and 'healers' generate anxiety and fear among HIV-positive people. Consequently, many of them prefer to maintain public silence, fearing worse treatment from family and lay people who are seen as less informed (Bharat 1996). Stigmatisation in health care settings is evident through the attitudes of nurses, ward boys, doctors and technicians.

Service users reported that the most common manifestations of stigma took the form of neglect, denial of access to treatment or refusal to treat, shunting persons from one service to another, labelling, breaches of confidentiality and even violence. Such experiences cut across private and public sector health services.

A woman FGD participant narrated her experience of when her husband was admitted to a municipal hospital for treatment:

"Initially no one knew, but when they did his blood test the nurses came to know. They placed a bucket of water with bleaching powder under the bed and asked me to soak his clothes in it. They also instructed me to wash his utensils, give him medicines ... so much so that the ward boy stopped making his bed and changing his bed clothes; everyone in the ward came to know immediately; they began looking at us meaningfully...."

One woman FGD participant said, "I was refused admission for delivery because of my HIV status. Finally I delivered at home" and another, "When my child fell ill and the doctor found out the status, he told me to take him home as there was no treatment...."

Health care providers and key informants also highlighted the discriminatory practices existing in health care settings. There were many examples of blatant discrimination and, in one reported incident, this culminated in violence, with a junior doctor slapping a patient and sending him away without treatment, reportedly out of "sheer frustration" at being left to do all the "dirty work."

Despite a national confidentiality policy in relation to HIV status, there is little shared understanding of confidentiality and how policies should be applied. A recent Supreme Court judgement ruled that confidentiality may be breached to protect any prospective partner that a person with HIV is likely to marry. There was an identified need among service providers for clearer guidance on applying

policies and the conditions under which confidentiality breaches could take place, for example in relation to spousal notification.

In practice nurses, doctors, ward nurses, attendants all know about a person's HIV status before the person themselves. Although most municipal hospitals have discontinued the practice of labeling the patient records of those who are HIV-positive, some continue, resulting in denial of treatment and shunting of patients. There were reports of people's HIV status being disclosed indiscriminately to family members and principles of pre-test counseling and informed consent prior to HIV testing being flouted.

### **The family**

The burden of care, particularly on women, was once again alluded to. The family frequently carries a double burden of caring for the sick person and maintaining secrecy in order to avoid community backlash and isolation. Participants gave examples of both supportive and non-supportive actions. The following testimonies illustrate some common manifestations of stigma from both natal as well as marital families:

“When my blood was tested, I was found to be positive; the doctors advised my husband to test his blood but he refused. Everyone started blaming me, calling me names, that I was a woman of loose morals, bad character and that their son was good. I had brought on bad luck to their son and the entire family. My mother in law stopped accepting water from my hand..., my husband also shunned me.... Later they threw me out of the house. My mother brought me home but my brother's wife left the house on knowing that I have HIV; so my family rented a room and I live there with my children ....” (Woman, service user FGD)

“... I was even told not to burn my husband on the funeral pyre but to electrocute him, as the smoke would also pollute the air!” (Woman, service user FGD)

### **The community**

In contexts where an individual was known to have HIV/AIDS, the community was said to slowly reduce contact with the household. In some instances, loud proclamations about the person having AIDS were made locally to isolate and reject people, and there were extreme examples of mass rejection. In one instance, on learning that a man was HIV-positive, the whole community got together to buy train tickets and forced him and his family to leave the village and go to Mumbai.

One service provider reported that a prestigious school in Mumbai refused to admit children affected by HIV/AIDS, and that some childcare institutions demand to know the HIV status of children before admitting them. More positively perhaps, religious leaders were perceived as passive, yet largely tolerant, towards people with HIV infection.

### **The workplace**

For men, the workplace emerged as a significant context of HIV/AIDS-related discrimination. For fear of being rejected by colleagues, most participants in the male service user FGD had not revealed their status in their present workplace. Mandatory HIV employment testing was reported as common practice, especially for work in the Gulf countries. Four out of six male participants in the service user FGD reported that they had discovered their HIV-positive status through this process. Three men were sent back to India, without being told why their employment was terminated, and one was disqualified before he joined the organisation.

“My employer told me I have so-and-so problem and have to go back to India. Police were searching for me, I was caught and put in the lock-up for 2 hours. I was given a third class air ticket and sent back.” (Man, service user FGD)

### **Government and official responses**

Informants made frequent reference to official talk of ‘targeted interventions’ and of the need for special institutions for “these people [with AIDS]”. Such talk tended to be stigmatising and to deny the high prevalence of HIV among the general population. Concerns were expressed about pendulum-like responses to people with HIV/AIDS. From total secrecy, the trend was now to ‘lionise’ people, asking them to come out in the open and share their sero-status to create awareness and sensitise people. Given the current climate of stigma this approach was deemed totally inappropriate.

### **Causes and impact**

The media was seen as largely responsible for both creating and reinforcing stigma. Earlier messages about HIV/AIDS were felt to have highlighted it as a fatal disease, and strongly associated it with certain perceived high-risk groups. As a result, many people did not see themselves at risk. As the epidemic has spread, however, it has generated what was described as ‘a fear psychosis’ because of its long-standing associations with suffering and death.

The main impact of stigma was self-imposed isolation and social exclusion. All HIV-positive participants in FGDs stated that their social networks had shrunk and they mixed only with positive people or professionals from HIV/AIDS organisations. They experienced fear of being discovered and further isolation, remorse and guilt. Some men even reported feeling vengeful towards society in general, and those who had outwardly shunned them. Men also tended to be more suicidal, often questioning the value and meaning of life, while women appear to be more accepting of what they perceived as 'their fate'.

## **Ukraine**

### **Forms**

Within Ukraine, HIV/AIDS is viewed as a disease of the 'depraved' and the majority of society treat people with HIV/AIDS with disdain because of the 'immoral' lifestyles they are assumed to have led. The origins of such perspectives are complex, but relate to the fact that the HIV epidemic was first associated with injecting drug use, and attitudes to people who use drugs are frequently negative.

HIV-positive drug users are said to be subject to the most extreme forms of stigma. They experience rejection, accusation, abuse and contempt by the community, are refused or receive sub-standard medical care, may be estranged by relatives, and are either refused work or face immediate dismissal from work should their serostatus become known.

Sex workers provoke similar reactions to drug users and are characterized as "perverted" elements of society. Sex workers who work on the street are said to spread infection since they "practice unsafe sex for big money." Generally speaking, and irrespective of how people really become infected with HIV, the assumption made is that men are either injecting drug users or gay, and women are prostitutes.

Examples were given of how gay and bisexual men were sought out and attacked, being forced eventually to move away. Early on in the epidemic, mandatory testing in prisons and reformatories was introduced with the resulting segregation of HIV-positive inmates. The result has been extreme forms of discrimination, abuse and rejection from other prisoners and prison officials.

There are many negative terms and expressions used when speaking about HIV-positive people. Derivations of the word 'spid' (the Ukrainian acronym for AIDS) such as 'spidosmy' are used to denote different levels of negativism and discrimination. Other terms such as 'tvarj konchennaya' (creature) and 'zhivotnoje' (animal) are used to denote HIV-positive injecting drug users, especially women. Early on in the epidemic the media is remembered as having reported, "AIDS is not just a disease, it's a sanitary inspector, which helps rid society of people who have led an immoral way of life." (National Press, Kiev Culture 1986) It was said that there are still examples today of how the media portrays HIV as an incurable plague.

## **Contexts of Stigma - health care settings**

In Ukraine, there are a number of specialized 'AIDS institutions' where people are referred if found to be HIV-positive. Here, it was felt they would receive 'professional' assistance and treatment, and careful consideration is reportedly given to confidentiality issues. In other health settings, serious stigma is reported. A new system of confidential codes on patient records was said to confuse many health workers who had reverted to writing 'HIV+' on records. These are kept, open to public view, at the registration desk. Frequent violations of confidentiality occur. Medical staff at anonymous HIV test clinics were known to inform people attending the clinic about the HIV status of other people they know who have tested positive. Health workers believed they were "acting with good intentions to prevent promiscuous contacts with HIV-positive people." (Woman, service provider FGD)

## **The family**

Negative attitudes to HIV -positive people were said to be more pronounced in the families of drug users, alcoholics, gay men and imprisoned persons. Participants felt that most people with HIV/AIDS do not disclose their HIV status to their relatives, being concerned about the impact it might have. Their biggest worry is that they will die before their parents, leaving parents both devastated and with no one to care for them in their old age.

## **The community**

In rural communities, information on HIV/AIDS is fragmented and frequently inaccurate. People known or suspected to have HIV/AIDS, and their families, experience such extreme rejection and discrimination that they can no longer work locally, and their children can no longer go to school. The following story told by a key informant in Kiev illustrates this further:

"A village man with eight children and a wife had an accident while driving his tractor. He required a blood transfusion and subsequently became unwell. A blood test confirmed that he was HIV-positive, most probably acquired through the transfusion. Knowledge of the man's HIV status became known within the village through members of the community that worked at the hospital. As a result he lost his job, as did his wife (a dairymaid) as there were concerns that they might infect people and animals on the farm. Their family, friends and relatives started avoiding them and accusing them of causing danger, other village children were not allowed to play with their children. In the end, the family were forced to move to another region where they were not known."

Stigma appears to be less pronounced in urban settings. With the rapid spread of HIV, gradually all social groups are beginning to understand the importance of the problem. In urban areas, different NGOs and international organisations have more of a presence and this seems to have had an impact on reducing stigma which was described as being more “tolerable” than in rural areas.

### **The workplace**

People living with HIV/AIDS were reported as keeping their HIV status secret in the workplace. If their status becomes known, they experience rejection by colleagues and excuses may be found to dismiss them from their jobs. Some commercial employers enforce pre-employment testing as part of their recruitment process, refusing work to those who are HIV-positive. While there are laws to protect employees from such practice, there is limited enforcement or legal recourse for those subjected to discrimination.

### **Causes and impact**

The inter-relationship between causes and the impact of HIV/AIDS-related stigma was clearly expressed by participants. Fear, misinformation, concerns about sex and sexuality and existing negative reactions to certain groups all combine to create further fear, intolerant attitudes towards HIV-infected people, and a failure to access prevention and harm reduction services.

Fears of disclosure were similar to those reported elsewhere, although men reported being fearful of becoming alcoholics and persistent drug users in an effort to cope with the adverse reactions of society.

Fear generally was identified as the key determinant of stigma, caused by the lack of information and education about HIV and its modes of transmission. HIV is still believed by many to be “caught” like “flu.” Therefore, shaking hands, hugging and being in close proximity to people with HIV, is thought to be dangerous. A lack of adequate information, training and skills among health workers working with HIV-positive patients was identified as a major cause of stigma.

## **Burkina Faso**

### **Forms**

In Koudougou, HIV/AIDS-related stigma was understood as the negative characterization of people with or suspected of having HIV. Stigma carries clear religious and sexual connotations, and is simultaneously perceived as a disease of unfaithfulness, of refusing God, of sinners and of sexual wandering. Some spoke of it as the “curse from God”. (Women, service user FGD)

Older people especially spoke of the “sinners disease” and of “people forsaken by God whose major concern was the pleasure of the flesh.” (Women, service user FGD) The only form of transmission referred to is sexual, and taboos surrounding sex and sexuality make it difficult to address, “Nobody has the right to deal with this taboo or sacred thing without consequences.” (Woman, FGD)

Service providers interviewed defined stigmatization as the rejection of people with HIV/AIDS, and such rejection was understood to result from the fact that AIDS is shrouded in mystery, it destroys the human person, and has no remedy. All of these factors caused anxiety and fear. The women services users defined stigmatization as the rejection, and then the abandonment, of people with HIV disease. The majority were the carers of people with HIV/AIDS, so this rejection impacted directly on them. Male service users, on the other hand, said that stigmatization results from the association of HIV with illness (the walking dead) and the fears it provokes. “Stigmatization is a kind of self non-conscious defense against death.” (Man, service user FGD)

People with HIV said they felt systematically rejected by everyone. In the group discussions and interviews, religious leaders and some of the community leaders were identified as perpetuating stigma. They were said to constantly reinforce blame and talk in terms of retribution for “immoral” behaviour. AIDS is “hell on earth ” and those infected “disciples of Satan.” (Man, service user FGD)

Women, and in particular single women of all ages, are the target of much stigmatization and abuse. Women who are known or suspected to be involved in commercial sex work are perceived by the community as a public danger and are associated with immoral behaviour, “getting money [for sex] from all the men she can catch.” Widowed women are perceived generally as “man eaters” and sex workers are considered as “curses” and “agents of disease.” Stories were told of women being shunned in the street, and left unsupported and uncared for when sick. Migrants from Cote d’Ivoire are accused of leaving behind the moral values of their original community once away from home. When they do return home, they are also blamed for bringing HIV to their native villages or towns.

## **Contexts of stigma- health care settings**

Participants in the men's service user FGD talked of rejection and a change in behaviour towards people with HIV, once their status was known. One participant explained, "[in the clinic] the staff welcomes you well at the beginning, and this makes you happy to come back to them. After a while, they reject you, always saying they are over busy, avoiding you more systematically."

Health care workers were identified as contributing to stigmatization, and were seen as responsible for breaches of confidentiality. There is a clear lack of policy guidance on confidentiality at both national and local level and, as a result, service providers make individual decisions about who should be told. Service providers were said by service users not to understand concepts of confidentiality or consent. Numerous instances were reported of HIV testing being carried out without consent. In some cases, health care workers wait for an occasion for other medical examinations requiring blood testing and conduct an HIV antibody test at the same time without telling the patient.

## **The family**

Within the family context, stigmatization was particularly marked, and conformed to a now familiar pattern. As one participant described:

"Nobody wants to eat with you, to sit where you are sitting. Even your children throw the remaining food from your dish and do not touch to the spoons you used. Apart from your mother or your wife, everybody is fleeing from or abandoning you...if you are a woman, far from your mother, you will inevitably be forsaken." (Woman, service user FGD)

## **The community**

Ridicule and derogatory remarks were common behind people's backs: "They speak of the man with a lot of girl friends, the girl/woman with a never satisfied sexual appetite, the money lover lady who is paid with more than money, the person who did not respect any social rule." (Woman, service user FGD)

In church people reported being shunned. One participant said, "Officially, nobody knows your problem. Nobody will speak publicly of your problem, but in private, they say you are paid back for your misbehavior, that you deserve such suffering, you are paying the price of your disobedience to God." (Man, service user FGD)

## **Causes and impact**

In health care settings, stigma was seen as the result of the inability of health workers to understand and manage HIV/AIDS. They see no remedy or solution to the despair surrounding the disease and felt they did not have the psychological resources to cope with somebody whose death is inevitable. As one participant said, "Such a dreadful fear makes people reject death and also the person bearing this death." (Man, service provider FGD)

Stigmatization was seen as creating permanent suspicion between people and, as a result, people with HIV feel rejected and isolate themselves. Stories are fabricated in the community of people, knowing they are HIV-positive, deciding to transmit the disease to others, so they would experience suffering, death and dishonour. In such a context, people do not disclose their HIV-positive status, they try to hide it away: "When it happens that you lose weight, you always try to find another explanation." (Key informant, Koudougou)

HIV was seen as causing major divisions within the community. It threatens the existence and reveals the limits of traditional values such as compassion and mutual assistance. The intensity of the problem, and the lack of any evident solution, causes the community to become resigned and discouraged.

Stigma also triggers an intense fear of disclosure, especially in relation to an HIV-positive status. One woman service user highlights this thus: "We are always considered as wicked and cruel witches, accused of bringing shame, dishonour and destruction to the families of our husbands. In this context, how can we decide to disclose our HIV-positive status? If we do it, we are participating for sure in our own destruction, because the solidarity between members of the husband's family will be aimed at us as the scapegoats. Not only will they send you back to your family, but they will ill-treat you for bringing all the evil on earth."

## **Responses to stigma and recommendations**

Across all research sites, similar actions were identified as holding the potential to reduce HIV/AIDS stigmatization and its impact on individuals and communities. These included:

- Strengthening the legal framework at local, national and international levels so as to protect the human rights of people with HIV/AIDS.
- Empowering communities to understand and use policy and the law to obtain the care and support they require.
- Developing clear policies about confidentiality and mechanisms for their effective implementation at all levels.
- Promoting mutually reinforcing national and community-based communication initiatives to combat fear and misinformation.
- Enforcing current legislation against mandatory HIV antibody testing and testing without consent.
- Improving community based self-help services for people living with HIV/AIDS
- Promoting the rapid completion of ARV therapy trials and increasing accessibility to affordable treatment.

## **Mother-to-child transmission of HIV**

### **Introduction**

Mother-to-child transmission (MTCT) is the primary source of HIV infection in children below the age of 15 years, and since the beginning of the epidemic an estimated 5.1 million children worldwide have been infected with HIV (UNAIDS 2000). The prevention of MTCT has become a primary focus of efforts in coping with the HIV pandemic. Clinical trials in a number of countries have demonstrated that MTCT can be greatly reduced through a short course of antiretroviral (ARV) therapy. As a result of these trials, ARV prevention therapy is now recommended as part of the standard package of care for HIV-positive women and their potentially infected infants (Leonard et al 2001).

Previous studies have highlighted how stigmatisation, and the fears that it provokes, can impede efforts to work effectively with pregnant women in reducing MTCT (Bond et al 2000, Nyblade et al 2001). The core component of any successful MTCT programme is voluntary HIV antibody testing and counseling (VCT). Earlier discussion has already highlighted the fears, reactions and responses associated with being HIV-positive and the shortfalls in capacity and for the majority of local health economies to adequately address these issues.

### **Vertical transmission of HIV**

The availability of data, knowledge and awareness of vertical transmission from mother-to-child, was different in all research sites. In Zambia, an estimated 30-49% of infants born to women infected with HIV become infected constituting around 21,000 infant infections each year (Bond et al 2000). In Mumbai, India, the seropositivity rate among women attending antenatal care is estimated to be between 2.5% to 3.75% (NACO 2001). In Ukraine, between 1997 and June 2001, 2,605 children were officially registered as HIV-positive. (CAP 2001). Data was not available on the extent of MTCT in Koudougou, Burkina Faso.

### **MTCT prevention initiatives**

The extent to which information and education on the prevention of MTCT was integral to existing health services, varied enormously across the research sites.

While in Zambia's capital, Lusaka, information and education about HIV prevention appears to be a normal component of antenatal services, particularly in certain centres where specialist MTCT programmes have been established, in rural areas this is not always the case. At the two rural health centres in this study, health care providers said that HIV/AIDS was only occasionally talked about during antenatal care (ANC), most commonly if a woman appeared to be symptomatic with HIV-related illness.

At the border post mission hospital in rural Zambia, there is a comprehensive MTCT programme, which includes VCT and antiretroviral therapy, along with a range of pre- and post-natal counseling and support services. By September 2001, only 140 pregnant women had chosen to test for HIV and the uptake of the intervention was considered to be low. The focus group discussion provided an opportunity for rural health staff, traditional birth attendants (TBAs) and community health workers (CHWs) to learn about the programme and consider the possibility of referring pregnant women to the intervention. Some of the women service users were already aware of the programme.

In India, MTCT prevention trials initiated by NACO are currently underway in three sites in Mumbai, one in a government run teaching hospital and two in municipal corporation teaching hospitals. Women accessing services in the three sites have free access to ARV therapy.

At Koudougou, in Burkina Faso there is neither a specific MTCT programme nor a VCT initiative. At the national level, a new MTCT programme is scheduled to be implemented in late 2001, but at the time of the study it was not yet up and running. Apart from this national project, a prevention of MTCT project has been running at Bobo Dioulasso since 1994, and to date this is the only place where ARV therapy is available. In Koudougou, issues relating to MTCT are not systematically addressed in health care settings.

Given this background, the research questions on MTCT prompted limited discussion in Koudougou, since these aspects of HIV/AIDS prevention were largely beyond the experience of the study participants. Service providers reported that they never suggested HIV testing to women because they were not sure what to do if there were positive results. In the rare situations where an HIV antibody test had been discussed, this is very much doctor-led. Currently, the only services available for antenatal consultations are group information, education and communication (IEC) initiatives which include elements on HIV transmission and prevention.

In Ukraine, respondents reported that pregnant women with HIV are referred directly either to an 'AIDS Centre' or to a specialised antenatal care department for HIV-infected people. There is no provision for HIV-positive women within mainstream antenatal care. While the quality of counseling was considered to be

better in these centres, specialised and separate HIV/AIDS clinics do little to reduce HIV/AIDS-related stigma.

At the time of the study, the Ministry of Health in collaboration with UNICEF and NGOs was reported to be developing an MTCT prevention programme which will be introduced gradually throughout the country.

### **Forms of stigma surrounding MTCT**

In all of the research sites, there was evidence that stigma attributed to being HIV-positive in pregnancy further compounds the powerful stigmatization already experienced by women who are known or thought to be HIV-positive and the stigma that women suffer in general. Furthermore, stigma is clearly more accentuated if women belong or are deemed to belong to marginalised groups such as sex workers or injecting drug users.

Indeed, it could be argued that the terminology alone – ‘mother-to-child transmission’ - to some extent invites stigmatisation, since it implies that the woman is solely to blame for the infection of the child. An alternative terminology, ‘parent-to-child transmission’ (PTCT), is used with increasing frequency, thus shifting the emphasis away from women, and encouraging fuller exploration of the role of fathers and partners in managing the HIV-positive status and its impact on the child and the mother (SEA-AIDS 2001). Furthermore, this shift in emphasis permits a broader inclusion of men in the range of prevention, diagnosis, treatment and support services. There is now increasing evidence that adopting the term PTCT more systematically can positively reduce stigma surrounding transmission of HIV to infants (SAfAIDS 2001).

The burden of blame for women was heavy in all research sites. In India, motherhood is perceived as the ultimate validation of womanhood. With the increasing risk of married, monogamous, women contracting HIV, it was reported to be common for women to be stigmatised and blamed for passing on the infection to her unborn child. Blame is accentuated if a male baby becomes infected, due to the high value already awarded to male children.

“When I was found [to be HIV] positive, no one talked to me about my well being. The doctor told me to do MTP [medical termination of pregnancy] as I had no right to pass on the infection to my baby.” (Woman, FGD Mumbai)

Pregnant women who appear ill, or who deliver babies that die soon after birth, evoke strong reactions at community level, since they give credence to hidden fears and refute denial of the existence of HIV. In rural Zambia, repeatedly, respondents talked about how visible HIV/AIDS has become as a result of pregnant women falling sick and their babies dying.

“If a pregnant woman is sick and has a sick, premature baby who dies before three months, then we know she is affected [infected with HIV] and turn away from her. This is our [HIV] test!” (Man, FGD rural Zambia)

Little sympathy or respect was expressed for pregnant women with HIV, who were open to blame, ridicule and rejection as the following example illustrates:

“My husband’s sister had two daughters who were prostitutes ... They came back pregnant with private parts open and purging, and their grandmother and myself looked after them. I delivered their babies, wearing gloves, but both the babies died. People called them prostitutes – makulingo [women who exchange sex for money]. Some people came to visit them to help them; others came to set them up, proposing them [asking them to have sex] and then laughing at them. They have both died now.” (Woman, FGD rural Zambia)

While some US studies have suggested that direct contact with people with HIV/AIDS can be successful in reducing stigma, this seems not to be in the case in many communities in Africa (Brown et al 2001). The research conducted here seems to verify this statement and indeed pinpoint that it is the ubiquitous nature of HIV that seems to accentuate stigma. In Zambia, for example, there is a recurrent notion that the pregnancy of an HIV-positive woman heralds a chain of deaths after the woman delivers, with the baby, herself and then her husband dying.

In Ukraine, respondents reported that pregnant women with HIV are assumed to have led “immoral” lives and are labelled as drug users, prostitutes or having had sexual contact with many men. In small towns, in particular, stigma is accentuated by the fact that communities are closely knit, assimilate each other’s views and opinions very quickly and that in health care settings notions of privacy and confidentiality are lacking. When women were found to be HIV-positive during routine antenatal blood tests, nurses were said to disclose their status to other people in the community, with often devastating results. Women were subsequently reported as being subjected to extreme forms of abuse, rejection and abandonment, often culminating in being forced to move away.

In Koudougou, the pattern was similar, with stigmatization being mainly focused on the pregnant woman and rarely on the father. If the mother is HIV-positive, it is assumed that she has been unfaithful or “promiscuous.” If her HIV-positive status is disclosed, it is likely she will be sent back home to her natal family. These attitudes were said to be a reflection of a patriarchal society where good and positive values are associated with men, and anything negative, in this case HIV infection, is attributed to women.

## **Contexts of stigma - health care settings**

Support for pregnant women in clinics, hospitals and through community based care varies greatly. In Zambia, community based care through TBAs, outside of clinics and hospitals is available in rural areas. In Ukraine, on the other hand, the health care system is far more medicalised with antenatal care being delivered much of the time by gynaecologists, obstetricians and medical doctors. Here, there was evidence that the hierarchy within this medical model and the inherent power of medical practitioners to make decisions, undermines the choices that women have.

In some antenatal care establishments in Ukraine, women were not allowed to use the same gynaecological couch as those believed to be HIV negative. There were also reported cases where nurses refused to swaddle babies born from HIV infected women for fear of becoming infected, and similar fears among surgeons also affected the quality of antenatal care. One HIV -positive woman described how the surgeon postponed her Caesarian section for so long, that she ended up delivering vaginally.

There were numerous examples where women, and in some cases men, once diagnosed as HIV-positive, either faced rebuke or condemnation for their decision to have children, or were denied the right to make choices over their reproductive and family lives altogether.

One HIV -positive man in urban Zambia described the reaction by health workers on learning that his wife had had a baby. He was told, “how could you do this to your wife?...this is terrible [the pregnancy] – don’t do a thing like that.” It was, he said, as if he has no right to have children.

In Mumbai (India), it was reported that if a woman tests positive in the first trimester she is “counselled.” (meaning advised or ordered) to undergo a medical termination of pregnancy (MTP) by health workers. Such coercion derives from the assumption that such advice is for the ultimate well being of the child.

In Ukraine, it was reported that a considerable number of obstetricians and gynaecologists have received no training in HIV/AIDS-related counseling. Given the doctor-led system in health settings, women are given little choice about their treatment and care. Doctors were reported to often act “at their own discretion”, and to make the decision to terminate pregnancies of women who are HIV-positive.

In small towns in Ukraine, it was reported that health workers would sometimes insistently recommend abortion to a woman, believing that they are acting in the best interests of the baby. HIV-positive women participating in the FGD reported

the following comments from nurses: “Who are you going to bear a child to?”, “You [will] die, and [then] who will take care of child?”

Across all countries there was, however, evidence that women were likely to receive different levels of care and responses in different types of health care settings. In addition, there appears to be an undercurrent of change as health and social care systems become more familiar with HIV/AIDS. In Zambia, for example, there were clear differences between how participants perceived health care providers working in the pilot urban MTCT programme (where they were felt to be supportive and caring), and those working outside the pilot site:

“Health workers would be really mean, especially if you are young, and at the urban health centre they would advise you to terminate the pregnancy and would chide you.” (Woman key informant urban, Zambia)

In India, there was evidence that the practice of coercing women into termination is undergoing gradual change as a result of increased awareness and discussion of the ethical issues surrounding advising MTP to HIV-positive women. In Ukraine, collaborative MTCT prevention programmes run by UNICEF and the Ministry of Health in some urban areas were reported as having had an impact on levels of stigma in health care settings.

There are clearly many challenges in providing adequate and appropriate care to pregnant women with, or who fear they may have, HIV. Many health providers said they are faced with difficult choices in relation to providing care and ensuring their personal well being. In the absence of adequate training, resources and information this is not easy. There was evidence in all sites of health workers feeling overwhelmed and powerless. Some service providers were forced to deal with situations beyond their means, but ultimately chose to provide care rather than to deny it. In Zambia, for example, when women are denied treatment within clinics, the traditional birth attendants (TBAs) are left to provide the care to women in the villages. At times, the level of primary care expected at community level is complex. The following abstract from an interview with a TBA highlights these points:

“As a TBA, Mrs S has seen cases of women with HIV on many occasions, and she has helped these girls deliver babies. She claims some girls are so sick during labour. Some girls she has helped have their birth canals eaten up and open.... She lamented over the lack of protective materials, or gloves, to use when delivering a baby. She said some babies are born with sores in their eyes and sometimes both ears eaten up. She said that the hospital sometimes discharges pregnant girls who are very ill and HIV-positive. The hospital asks them to go back to their respective villages to deliver.”

Here, despite CHWs and TBAs having good knowledge of the need for universal precautions, delivering babies to women who are HIV-positive “using their bare

hands” was common. TBAs or older women are also often asked to assist in the deliveries of neighbours, relatives and friends, and feel unable to refuse. This even happens in the rural health centre, as one nurse/midwife recalls:

“We are also at risk of HIV and are negligent, not using gloves.... If a woman comes [to the health centre] in the second stage of labour and the baby has the cord around it's neck, what can you do? You have to assist.”

### **The family**

Within the family, pregnant women described fears of being ignored, isolated and made to feel disgraced and blamed. One key informant in Lusaka commented, “Friends and relatives would not focus on how to improve her life and get treatment but would dig up her history. The family will think that she and the child are going to die ‘any time’ after birth, and will be concerned about the health of the child and the husband.”

In India, if a pregnant woman has a positive HIV test, the husband is called and results shared with him. If he is also found to be HIV -positive, the woman may either receive support from him, or may be blamed for giving him the disease. Generally women in Mumbai, as elsewhere, feared rejection, isolation and being shunned by family members. They were also apprehensive about the impact such disclosure might have on their natal family and children. In the case of one focus group participant, the doctor had advised her not to disclose her positive status to anyone.

### **HIV antibody testing: consent, partner notification and disclosure**

In India, although there are guidelines forbidding HIV antibody testing without consent, all pregnant women were reported as being routinely tested for HIV with or without pre-test counseling, both in municipal and government run hospitals and health centres. Pre-test counseling is not universally available, but even when it does happen women are rarely in a position to make a decision whether to have the test or not. The practice of seeking consent for HIV testing from the husband or mother-in-law is common. At times, women give their consent without fully comprehending the implications of a test, so there is in effect no informed consent given. At other times, women feel coerced into undergoing the test for fear that health workers will refuse to conduct a delivery, or will deny them access to treatment. One service provider, recounting how a woman attending a VCT centre attached to a hospital where deliveries are conducted, said:

“Madam, why are you putting me in a problem? Just do the test, otherwise they will not register my name for delivery and will also not give me medicines.”

In resource poor maternity settings with a heavy caseload, there were reports of “group orientation”, rather than counseling women individually prior to HIV testing. In some cases, individuals perceived to be at high risk (e.g. in the presence of a sexually transmitted infection) were reported as being given an HIV test without pre-test counseling. In most instances, there is little or no preparation for receiving HIV test results, particularly if they are positive.

“My wife was tested in the seventh month [of pregnancy]; no information was given to us. I was told to do the test. I, too, did not know anything. Later my wife was told that my baby would also be positive. She took tension and died fifteen days after delivery.” (Man, service user Mumbai)

In Ukraine, it is common for women to attend antenatal care without their husband or male partner. During the consultation, the woman is recommended to give blood for an HIV test. It was reported that if the woman hesitates or is unwilling to agree to the HIV test, the care provider’s task is to persuade her. This happens without any specialist pre-test counseling. As a result, practically all pregnant women have an HIV -test.

In Koudougou, it was reported that although generally HIV testing is less common than in the other settings (for reasons of cost and test kit availability), in some exceptional cases, the test is done without the knowledge of the patient.

### **Reasons for testing**

Few incentives were identified for pregnant women to test for HIV. “It’s better that you [a pregnant mother] stay in the dark without knowing”, said one informant. Not trusting your husband, chronic illness or a doctor’s recommendation could encourage a pregnant woman to have an HIV test. In Lusaka, other reasons were mentioned such as deciding whether to terminate the pregnancy if the woman was found to be HIV-positive. Mostly, however, the many disincentives of receiving a positive result, and the resulting likely stigmatization, outweighed the perceived advantages of testing.

In Koudougou, one woman key informant said, “A woman will never decide to do the testing. If she finds herself HIV-positive, she is signing three deaths: psychological death, social death, and later physical death. Don’t you think that is a lot?”

Although the decision to have an HIV test is rare in Koudougou, it was reported to be more common among women from affluent backgrounds. In these cases, women make the decision to test if they feel that they have been at risk of infection themselves, or suspect partners or husbands of having other sexual relationships. In such cases, women choosing to have the test are given their

results directly. Otherwise, where the decision to carry out an HIV antibody test is made by the service provider, women found to be seropositive generally appear to have little control over their test results and how this information is shared.

Issues of the lack of confidentiality may affect reasons for not testing. In India, it was reported that if a woman is found to be HIV-positive, health care workers assume that she cannot understand anything, and demand that the husband be brought to the hospital. At times, the news is shared with both the husband and indiscriminately with other insistent family members.

In Koudougou, discussions about sharing HIV test results illustrated that, in the absence of any clear guidance or official regulations, health care providers make individual decisions as to who should be told. Cases were reported where positive HIV test results were given to parents, relatives and husbands of women if the health worker felt that they would be able to “manage the situation”.

The implications of a positive test result for woman are, therefore, enormous. Depression, suicidal feelings and a loss of hope were thought to be common responses. As well as fear of discrimination, isolation and rejection, women often fear the reactions of a partner or husband, since the implications for him are either that she was infected through another partner, or that he may also be infected. Sero-discordance in couples was reported as very hard to accept in both Zambia and India. In India, in sero-discordant couples where the man is negative, the woman is more likely to experience rejection and isolation from the spouse and the marital family than if her husband is HIV-positive. Some women are thrown out of their marital homes to fend for themselves.

### **The cost of care**

Participants in India, Ukraine and Burkina Faso talked of the prohibitive cost of antiretroviral treatment for the baby, and how this made it inaccessible for the majority of people from lower socio-economic groups to access treatment outside the MTCT research sites. As a male service user in India put it:

“We know they have found medicines for pregnant women so that the baby is not infected, but no one told us about this. Most poor people also do not know. The treatment costs a lot of money.” (Man, service user FGD, Mumbai)

In Koudougou, focus group participants felt that the financial inaccessibility of antiretroviral treatment for the majority, meant that it was not worth even considering the possibility of voluntary testing:

“The day you tell women they can benefit from some financial support for treatment for themselves and their babies, then they will do your testing. Why do you want somebody to realise he/she is going to die? Why?” (Key informant woman, Koudougou)

## **Preventing vertical transmission**

The range of advice and support given to women to reduce the risk of MTCT, reflects the extent to which health services have made MTCT an integral part of service provision. Where MTCT prevention initiatives are up and running, the range of options offered to women are more comprehensive, and the care provided reported to be of better quality than in situations where there are no such initiatives. In rural Zambia both the men's and the health providers FGD mentioned using condoms and other family planning methods to prevent further pregnancies. They mentioned also the importance of being part of the pilot MTCT programme, taking "drugs" and food supplements as ways of reducing the risk of transmission to the infant. In Ukraine, as noted earlier, practically all pregnant women have an HIV test and if they are sero-positive, are directly referred to a specialist unit where they receive antiretroviral therapy as part of a care programme which includes the promotion of safer sex practices. In Mumbai, in the absence of affordable treatment, safer sex practices were advised, either condom use or abstinence, to prevent further HIV infection and/or pregnancy. In Koudougou however, there were no recommendations given regarding safer sex practices.

## **Infant Feeding**

Advice and guidance around infant feeding was universally discussed in all the research sites, and highlighted a number of complexities. The capacity of care providers to adequately counsel women on infant feeding options and the level of stigma associated with choosing alternatives to breastfeeding varied greatly.

In rural Zambia, for example, mixed messages were coming across regarding recommended practice in relation to infant feeding. Women had heard that HIV-positive women should not breastfeed their babies, while the senior headman and traditional healer interviewed thought that babies of HIV-positive mothers should be exclusively breastfed because "formulas are not good for babies".

One HIV-positive key informant raised the point that the decision regarding breastfeeding must be an informed choice and that breastfeeding is important in establishing a bond between mother and child. The informant estimated that about three-quarters of the HIV-positive women he knew on a Lusaka MTCT programme had chosen to breastfeed their babies after weighing up the options.

Of all the research sites, it was rural Zambia where stigma in relation to breastfeeding was most pronounced. The women's FGD described the dilemma for positive women. Here, not to breastfeed is seen as stigmatizing since it is taken as revealing that the mother is infected, yet women who do breastfeed are

simultaneously accused of “killing the baby.” In response to this, “Many women just pretend and continue breastfeeding as if all is well.” (Woman service provider FGD, rural Zambia)

In India, it was reported that during the early years of the epidemic, pregnant women were encouraged to breastfeed their babies according to WHO guidelines and due to concerns of vulnerability of infants given the lack of access to safe drinking water and the prohibitive costs of milk substitutes. These days, HIV-positive women are advised to refrain from breastfeeding and, as alternatives, to express and boil the milk before feeding or introduce milk substitutes. In instances where the family is supportive, women are able to follow such recommendations and sometimes despite economic hardship, families manage to buy milk substitutes. However it was felt that often the risks of transmission via breast milk are not discussed due to a lack of information and training amongst service providers. Health care workers were said to rarely put alternatives to breastfeeding across convincingly since there appear to be few affordable options. Participants in both the women service user FGD and the service provider FGD identified the need to support such discussions with economic support to women to carry out the alternative feeding options. It was reported that as yet stigma around breastfeeding is not that evident since women testing HIV-positive in antenatal care is a fairly recent phenomenon and the numbers of infants to date becoming infected are relatively low. The changing nature of the HIV epidemic was however discussed and that its full impact on women and infants has not yet been realised.

In Ukraine, it was reported that generally many women choose not to breastfeed their babies, mainly as a result of extensive advertising campaigns for powdered milk substitutes. As a consequence, there appears to be no reported stigma associated with HIV-positive women deciding not to breastfeed their babies. This fact was confirmed by the UNICEF office in Kiev which is currently the only international organisation working on MTCT issues in Ukraine. Despite encountering extensive stigma against HIV-positive women, as yet UNICEF Ukraine has no evidence of stigma associated with infant feeding options.

In Koudougou, focus group participants said that women found to be HIV-positive would be advised to avoid breastfeeding their infants. For the majority of people, this was considered financially impossible with the cost of milk substitutes being prohibitive. A lack of information amongst service providers about the risks of transmission of HIV via breastfeeding was considered to be a major issue so that in many cases feeding options were not discussed. Some service providers reported being involved previously in UNICEF programmes to promote breastfeeding and found it difficult to counsel women about alternative feeding options if they are HIV-positive. However, the main reason identified for not following recommendations regarding alternatives to breastfeeding were said not to be related to stigma but were purely economic. In addition, there were elements of fatalism and resignation as the following quote illustrates:

“Suppose a woman finds herself HIV-positive..., she will do what mothers have always done: close her eyes on everything, and give the breast to the baby. All is in the hands of God.” (Woman, service users FGD, Koudougou)

In Koudougou, once again the lack of discussion surrounding feeding options is a reflection of the relative lack of organisational framework to address MTCT. There was no MTCT initiative within the research area and a reported general lack of awareness within communities and political leaders about these issues.

In all the research sites, stigma surrounding MTCT was seen to accentuate the stigma already associated with HIV infection and women systematically appear to bear the brunt of negative attitudes and actions within health care settings, families and the wider community. Whilst the forms and manifestations of stigma differ across the research sites, they universally have the same impact of marginalising and discriminating against HIV-positive women. What is evident however, is that the combination of historical, social, cultural and economic factors surrounding stigma and its manifestations are unique to each of the research contexts. Systematically developing a sound understanding of the sometimes subtle as well as blatant stigma within each context is paramount to informing appropriate interventions to reduce it.

## **Implications and recommendations**

A number of recurrent themes emerge from the study and the recommendations of research participants that have implications for addressing HIV/AIDS-related stigmatisation and discrimination in general, and stigmatisation and discrimination with respect to MTCT in particular.

- Future MTCT programmes need to be part of an integrated preventive, education, care and support approach which addresses the broader issues surrounding HIV, including widespread fears and misconceptions that reinforce stigma and discrimination.
- MTCT programmes need to focus more on the mothers and fathers of potentially infected infants and not only on the infants themselves.
- The systematic adoption of more inclusive language surrounding programmes designed to prevent vertical transmission of HIV infection such as parent-to-child transmission need to be explored further.
- Communities are limited in terms of their resources and capacity to cope with HIV/AIDS. Poor families and communities have little spare time or money to adequately provide for people with HIV. The burden and fatigue of care, particularly on women, is huge.
- Health care systems face many challenges in providing care and support to people with HIV. Breaches of confidentiality, unclear and inconsistent notions of informed consent, and insufficient knowledge and skills as a result of limited access to training and professional support are common. These combine to inhibit the adoption of universal precautions and the normalising of care given to HIV-positive women. Future MTCT initiatives have to take this into account.
- The rights and choices of women in relation to treatment, care and family life are repeatedly ignored or denied. The policy framework to support their rights is weak, within the community their needs are secondary to husbands and children, and in health care settings women are denied their rights to making informed choices about their health, reproductive and family life.
- Legal and policy frameworks are of little use without efforts to promote their active implementation and evaluation through partnerships at local level.
- Access to ARV therapy is perceived by most people to be beyond their means.
- A systematic analysis of stigma within each context is a vital part of HIV/AIDS planning and programming.

## **Appendix 1**

### **Testimony of woman participant in service user FGD, rural Zambia**

“I witnessed an incident in a Southern Province hospital recently. My father-in-law was admitted in the hospital with TB. It happened that one day I had gone to visit him in the hospital. In the ward where he was there was this man who looked to me to be very sick and the nurses sat him outside the ward. I asked my father-in-law why a man in such a state should be sitting outside. My father-in-law said the sick man wanted to go to the toilet. As we were talking the nurses went over to the sick man and said, “if you want to go to the toilet get out of that wheelchair and help yourself on the ground outside. When your relatives come they are going to clean up the place and make sure you dress up before you climb back on the wheel chair.” The sick man pleaded with the two nurses that he didn’t have the strength to get off the wheelchair and that made the nurse go mad and they started shouting at him. “Were we there when you were enjoying yourself? And why is that your relatives are not taking care of you?.” My father-in-law felt very bad and he told me that if only he had the strength he would have gone to the rescue the poor man from the two tormentors. I am sure they heard what my father-in-law was saying. They took him back in the ward shouting and threatening him that if ever he messes up the linen on the bed he was going to see what they the nurses are going to do to him. It was sad, so sad that everyone who was present in that ward felt very bad. I went to the hospital the following day again. I found the man outside on the same wheelchair asking for food from well wishers. One man attempted to give him some food. The nurses refused them and said who ever is going to give him food will be responsible for any mess that he was going to make on the bed, and that person is going to wash up the linen. From that day, I avoided going to the hospital in the morning.”

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[1] Stigma throughout the report refers to HIV/AIDS-related stigma unless otherwise specified.

[2] Any measure entailing an arbitrary distinction among persons depending on their confirmed or suspected HIV serostatus or state of health (UNAIDS 2000)

[3] For a more extensive literature review of the issues, see UNAIDS' *Compendium on Discrimination, Stigma and Denial. Comparative Analysis: Research Studies from India and Uganda*. First revised edition August 2001, pp 9-16.

[4] The exact location of the research is not cited in this report and is henceforth referred to as rural Zambia.

[5] Shona is the main language of the research site.

[6] There is much evidence that witchcraft is not unique to this rural setting and is common elsewhere [Colson 2000].

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