

A CULTURAL APPROACH  
TO HIV/AIDS PREVENTION AND CARE

UNESCO/UNAIDS RESEARCH PROJECT

**HIV/AIDS**  
**Stigma and Discrimination:**  
**An Anthropological Approach**

*Proceedings of the round table*  
*held on 29 November 2002*  
*at UNESCO - Paris*

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## Foreword

The World AIDS Campaign – a high point of which will be the celebration of World AIDS Day on 1 December 2003 – has for 15 years been drawing attention to a specific problem relating to HIV/AIDS prevention and treatment. In 2002 and 2003, the focus of the campaign “Live and let live” has been on combating all forms of stigma and discrimination.

Discrimination and stigmatization against persons living with HIV and those around them – one of the dramatic consequences of HIV/AIDS and a major obstacle to prevention and care – are grim realities that we sometimes prefer to ignore. All too often, infected persons are ostracized by their families and communities, evicted from their homes, rejected by their spouses and sometimes suffer physical violence, even murder. Subject to personal and institutional discrimination, they may find themselves denied access to health care, insurance coverage, entry to certain countries and employment. Fear of discrimination and stigma causes people to shun screening tests and prompts those infected with and affected by HIV/AIDS to remain silent and deprive themselves of essential treatment and social care and concern.

To help to overcome these obstacles to HIV/AIDS prevention and care, a round table entitled “HIV/AIDS, stigma and discrimination: an anthropological approach” was held in November 2002 as part of the joint UNESCO/UNAIDS project “A cultural approach to prevention and care”.

The round table, bringing together anthropologists specializing in HIV/AIDS, provided an excellent opportunity for bringing the issues of discrimination and stigma into focus. Linked to sociocultural concepts (such as sexuality, health and death), stigma is rooted in the breeding ground of power, domination and social inequalities (including those of gender and ethnic origin), which it then serves to reinforce. Prompting fear and denial in connection with questions that are frequently taboo, it is a source of shame, lowered self-esteem and despair; and, on the basis of these negative perceptions, persons living with – or presumed to be living with – AIDS are excluded from certain public places (hospital, work, village, place of worship, etc.) and deprived of some of their rights, no matter how fundamental. Anthropology can throw a unique light on such phenomena and propose a number of solutions.

This socio-anthropological approach to HIV/AIDS is being promoted by the project “A cultural approach to HIV/AIDS prevention and care”, successfully implemented by the Division of Cultural Policies and Intercultural Dialogue since 1998. Adopting an inclusive definition of culture (encompassing traditions, beliefs, values, family structures, gender relations, personal and social relations), the project urges the need for the culture of population groups to be taken fully into account in the development of HIV/AIDS prevention strategies, projects and programmes.

UNESCO’s intention in publishing the proceedings of this round table is to associate itself with the World AIDS Campaign by providing the contributions of some distinguished researchers as tools for reflection on HIV/AIDS care and prevention and as a further testimony to the key role of culture in this as in all other spheres.

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## **Abbreviations and acronyms**

AIDS: Acquired Immune Deficiency Syndrome

ANRS: Agence Nationale de Recherche sur le SIDA (National AIDS Research Agency)

CADI: Centre Anonyme de Dépistage et d'Information (Anonymous Screening and Information Centre)

GONGO: Government-Organized Non-Government Organizations

IEC: Information Education Communication

NGO: Non-Governmental Organization

HIV: Human Immunodeficiency Virus

IRD: Institut de Recherches sur le Développement (Development Research Institute)

PLWHA: Persons Living With HIV/AIDS

STI: Sexually Transmitted Infection

STD: Sexually Transmitted Disease

UNAIDS: Joint United Nations Programme on HIV/AIDS

WHO: World Health Organization

## Introduction

### Stigmatization and Discrimination: What Does a Cultural Approach Have to Offer?

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The history of diseases – especially epidemics – is not merely a history of microbial spread and medical efforts to check it: it is also a history of mistrust of the sick, avoidance measures, marginalization and, at the same time but less obviously, a history of compassion and solidarity. From the “plague victims” of the European Middle Ages to the African lepers of the last century, from tuberculosis sufferers in all societies to Asians regarded as potential SARS carriers in Paris at the start of 2003 – all have suffered to varying degrees from what may be called a “social disease”, that is to say a set of representations that each culture associates with disease and its victims, together with all the concomitant attitudes.

HIV/AIDS does not carry with it any positive connotation of the kind that attached to tuberculosis in the nineteenth century, when the disease was regarded in Europe as a “romantic fever” (Ruffié & Sournia, 1995). Running the gamut from mistrust to criticism, from ostracism to discrimination, from rejection to desertion, and from stigmatization to spoliation, hostile attitudes towards AIDS sufferers, reinforced by the negative associations of the disease, seem to be a cultural invariant. It is often more difficult for infected persons and those around them to live with this “social disease” than with the clinical manifestations of infection by the virus.

“Stigmatization” and “discrimination” are very general terms that cover a wide variety of practices and attitudes rooted in representations and modes of discourse, ranging from an unconscious gesture to a conscious decision, from passive negligence to rejection tinged with violence, and encompassing all spheres of existence, from the microcosm of interpersonal relations to the macrocosm of relations among social groups and between peoples. Given their very diverse aspects, it is not our intention to categorize these expressions – those affected being best placed to catalogue their local forms as shaped by social and cultural context. The point they have in common is: (1) to establish a *distinction* or *difference*; (2) that is *devaluing* or *pejorative*; and (3) is based on a *mark*, or “stigma”, associated with the disease or the risk of transmission.

These three notions, present to a greater or lesser degree depending on the case, constitute the hard core of practices that will be referred to in this article under the generic heading of “discrimination”.

#### **Discrimination-linked issues**

The issues surrounding HIV/AIDS-related discriminations are of several kinds. We are dealing with a violation of the principle of natural justice that should apply to all individuals regardless of the situation in which they find themselves; the right not to be subjected to discrimination is enshrined in Article 2 of the Universal Declaration of Human Rights and in many international legal texts.

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Discrimination must also be regarded as a public health issue in that it is an obstacle to the provision of information on the risks of transmission, which should be as broadly based as possible to boost prevention; it inhibits personalization of the risk of HIV for fear of generating mistrust or criticism, which reduces chances of negotiating preventive measures; it makes people less willing to learn about their serostatus and limits recourse to screening; it makes infected individuals deny that they have the disease and makes them less likely to seek treatment; it causes the specific needs of infected persons to be neglected and encourages inaction by public health institutions and a lack of commitment on the part of health professionals. Apart from this direct impact on the ability of prevention to limit the spread of the epidemic and on the ability of health systems to meet patients' needs, discrimination (especially in the world of work or as regards access to resources) may increase the social vulnerability of individuals and their families and indirectly increase vulnerability to the risk of HIV. In very broad terms, research on the concept of "social capital" has shown that highly inegalitarian societies lacking social cohesion which develop stigmatizing modes of thought or deny HIV infection are particularly vulnerable to the epidemic (Barnett & Whiteside, 2002).

Human rights and public health would therefore seem closely interlinked. In the history of public health, this represents a change of perspective, theorized by Jonathan Mann and the Harvard School of Public Health, and then by Peter Piot and UNAIDS, and a departure from protection measures based on constraint and segregation – such as quarantine, *cordon sanitaire* provisions and confinement in State-run leper houses and lazarettos as practiced from the eighteenth to the twentieth centuries. HIV/AIDS lent itself particularly well to this change of approach: the duration of the asymptomatic phase, extending over several years, and the fact that prevention is impossible without the agreement and participation of the persons concerned limited the scope of purely authoritarian measures. Moreover, the experience of countries that had hoped to limit infection by denying entry to HIV-positive persons or by establishing "AIDS sanatoria" has shown such eviction measures to be ineffective and to have unwanted effects. As we enter the twenty-first century, UNAIDS considers that no population group is completely safe from the epidemic and that only a global approach based on mechanisms that strengthen social cohesion, in which people are respected regardless of their background and lifestyle and of the group or social category to which they belong, can reduce the spread and impact of the disease (UNAIDS, 2001).

### **The cultural approach to discrimination**

The cultural approach to discrimination is predicated on the analysis of its roots and rationales. Two acceptations that may be singled out from the hundred or so definitions of "culture" proposed by anthropologists (Journet, 2002) are also valuable in this context. The first views culture "in general terms" as the whole complex of "habits and customs" acquired by people living in society, including their knowledge and values, symbolic and technical productions and modes of social organization. Culture is in no way rigidly set in "tradition" but is constantly being reshaped; it is inseparable from the physical and economic contexts in which it develops and constitutes a form of adaptation to an evolving environment. The second sense of the term focuses on the diversity of cultures. This approach does not define cultures *a priori* in ethnic terms but rather analyses in comparative terms their differences and invariances, their coherence and dynamics, on the basis of the identity-based categorizations that various social groups have developed. In an age of globalization, when individuals are becoming individualized and references are being globalized, cultural affiliations do not depend on fixed categorizations: most population are experiencing acculturation and each individual negotiates his or her affiliation(s) within the limits of the scope for manoeuvre. It is therefore in terms of dynamics that this cultural approach to discrimination must be envisaged. Intellectually, it presupposes an analysis of the rationales underlying discrimination and of the role played by culture in this regard and a study of the forces that sustain or oppose discrimination.



## Rationales of discrimination

Discrimination against HIV-infected persons is based on several kinds of rationale, which we summarize here with no claim to comprehensiveness.<sup>2</sup> Some take illness as their basis: they express in a new form what has been observed in other ages confronted by other epidemics. Thus the attribution of a “foreign” origin to the disease, in simple terms implying that the disease came from elsewhere, compounded by the near-universal representation of alterity as dangerous, is at the root of forms of exclusion that their initiators often defend as a means of protecting their own social group.

The interpretation of the disease as punishment involves holding sufferers “culpably responsible for their sickness”. Rooted in age-old explanatory theories according to which disease is caused by breaking “taboos”, an act punishable by supernatural powers, this rationale regards AIDS as the consequence of a failure to observe social norms and patients as guilty persons who have been “punished” and have to bear the consequences of their reprehensible behaviour. Because of its links with behaviour relating to sex and blood, both carrying high symbolic charges, HIV infection particularly lends itself to this interpretation legitimizing rejection and condemnation.

Another rationale grounded in illness is fear of contagion. Many people still regard AIDS as a contagious disease and shun infected persons so as to avoid transmission by direct or indirect contact. While not being exposed to moral judgement, infected persons in this way suffer daily marginalization in their place of abode. This is often the case in African families in which the women and girls who look after the patient have to bear the burden of constant fear in addition to their heavy workload. Infected persons themselves often contribute to this fear by not daring to assert that they are not contagious and by practising self-exclusion, hoping thereby to protect their close relations. This rationale of exclusion can be countered by informing people about the way transmission takes place and the precautions that need to be taken.

Fear of contagion apart, some attitudes of avoidance – particularly noticeable among health professionals in the South who know about prevention measures and show a certain compassion towards patients – seem to stem from the sense of helplessness induced by caring for an AIDS patient when no medicines are available. Here, it is not a matter of fear of contagion or moral condemnation, but rather of avoiding a sense of helplessness and the prospect of death. In this case, ensuring access to antiretroviral drugs is the only way of restoring hope, which is crucial to any genuine therapeutic relationship.

In some cases, HIV infection serves to highlight earlier forms of discrimination. The AIDS epidemic has often been said to be simultaneously generative and revelatory of social issues. During the early years of the epidemic, the language of prevention in North America emphasized on four “high-risk groups”, termed the “4 Hs”: homosexuals, heroine addicts, hemophiliacs and Haitians. Paul Farmer has shown that the inclusion of Haitians in that categorization had no epidemiological basis, but reflected the low status of that community in American society in the 1980s (Farmer, 1996). Very often, in North and South alike, prostitutes have been stigmatized as a “high-risk group”, whereas in fact their knowledge and prevention practices (in particular, use of the condom) were far superior to those of their customers, who were rarely regarded as a “high-risk group” and were not stigmatized at all. As numerous examples show, HIV-related discrimination draws on pre-existing discrimination – or at least inegalitarian relations – arising in particular from xenophobia, unequal gender relations, racism and homophobia.

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<sup>2</sup> The observations and ideas presented here derive mainly from research conducted in Burkina Faso and France.

Another type of discriminatory rationale leads to patients being rejected or deserted by their families in the countries of the South. In *Faso Fights AIDS*,<sup>3</sup> Mamadou Sawadogo graphically describes the process whereby a modest African family, after spending all its savings on a patient's initial treatment, falls into what is now generally known as the "medical poverty trap" (Whitehead et al., 2001) and is faced with the dilemma of whether to support the patient for a further course of treatment, in the knowledge that there is no cure, or whether to abandon him to his fate so as to have some hope of feeding his widow and children. Analyzed in coldly pragmatic terms, abandoning the patient is the rational choice; it is nonetheless extremely painful for the family, unless it has developed a reaction of denial-based indifference, which makes it possible to bear the humanly unbearable – as elsewhere described in cases of populations confronted by life-or-death situations (see for example Turnbull, 1973; Scheper-Hughes, 1993). The cultural approach thus reveals that economic inequalities are one of the underlying rationales of discrimination: communities that find themselves in dire straits quickly arrive at the limits of the "obligation of solidarity".

The same situation arises when, against a background of scarce resources, HIV-infected persons are "treated last": the rationalization of resource allocation dictates that those who are most likely to recover should be treated first. It would be wrong to criticize such choices – or rather decisions made under constraint: the focus of the ethical demand should rather be on securing the broadest possible access to treatment as one of the primary means of combating discrimination.

These limited examples show that the underlying rationales of discrimination can be very diverse. This diversity becomes even more complex when we analyze the various levels – individual, microsocial and macrosocial – at which these rationales operate.

### **"Cultural resources" for countering discrimination**

Understandably, the role of culture varies greatly with the different rationales that give rise to discrimination. The fact that discrimination is determined by the fault lines of social organization, that it reflects inter-group tensions and oppositions and that it is sustained by certain explanatory models of the disease, leading different communities and different cultures to tolerate or to reject discriminatory arguments and attitudes, shows that it is not "wholly cultural". Economic, political and social factors are also important elements in the production of discrimination, along probably with epidemiological factors among others: although the phenomenon has yet to be documented, it may be supposed that a substantial and steady rise in prevalence, spread evenly throughout the population, would mitigate discriminatory attitudes by encouraging a process of social adaptation. It would be excessive and ethnocentric to regard the abandonment of a patient by a family unable to afford treatment as a cultural trait.

The varied forms assumed by discrimination and by the rationales that underpin it call for a diversity of responses. Some of them involve a public health approach: information on modes of transmission and access to methods of prevention will reduce the fear of contagion; making access to treatment generally available will – among other things – serve to recreate satisfactory therapeutic links; the availability of drugs free of charge for the general public will enable families to avoid the spiral of impoverishment; the introduction of social, economic and nutritional support measures will protect families already afflicted by the disease, enabling them to look after "their patient". Other responses involve a legal approach: UNDP and UNAIDS have made great efforts to strengthen laws to ensure that they are more effective in defending the rights of infected persons subjected to discrimination.

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<sup>3</sup> *Faso Fights AIDS*. Documentary film by S. Rawdin and A. Desclaux, 2002, Paris, Europroject. Part 1: "Living together despite the virus".

What are the “cultural resources” that UNESCO proposes to muster in the fight against discrimination? While it is possible to argue that some cultures or subcultures favour discrimination to a greater or lesser extent because of their receptivity to some of the previously mentioned rationales, public pronouncements on the question come from institutions – for the most part religious, medical, political, legal or community-based: these are the institutions that express and fashion, or conversely combat, discrimination. As in the case of cultures, it is not possible in most instances to distinguish *a priori* and definitively those institutions that foment discrimination from those that curb it; most institutions proclaim – vis-à-vis their members at least – the values of equity and solidarity, whose real impact is not always immediately perceptible.

However, an analysis of pronouncements concerning HIV and infected persons shows that some institutions develop a language of exclusion that is turned to a variety of “social uses”. By declaring that PLWHA (persons living with HIV/AIDS) have been infected because they did not respect the social and moral norms that are laid down in their own prescriptive texts, some religious authorities assert the value of their own rules by maintaining that disease is the consequence of a failure to observe those rules. By calling for infected persons to be evicted (despite the fact that this measure has proved inapplicable and ineffective), political authorities exploit very ancient but enduring representations, which ensure a measure of support for their cause and strengthen their popularity. For these institutions, the impact of such propositions in terms of discrimination against PLWHA is secondary to other more immediate concerns, in particular their own legitimacy and popularity.

Other institutions may adopt ambivalent postures: public health officials have often based their prevention campaigns on stigmatizing stereotypes, believing this to make for more effective communication. It was to protect people in overseas departments or of foreign origin from stigmatizing attitudes that public health officials in France said little about their specific epidemiological situation, depriving them of targeted preventive measures that might have been better adapted to their situation.

Discriminatory language and practices thus embody a whole range of meanings and usages, which have still to be analyzed in many contexts. Moreover, the dividing line between singling something out for attention so that particular features may be taken into account and drawing a distinction that provides grounds for stigmatization is sometimes a fine and shifting one. In this field too, careful analysis in each case with the involvement of all concerned is essential for an understanding of the untoward effects of health-related initiatives.

The history of AIDS shows that the main resources to counter discrimination have been devised by persons infected or affected by the disease. A large number of community-based associations and organizations in the countries of the North and South have set up self-supporting projects to minimize the effects of discrimination, working on an individual basis, collecting personal testimonies, assisting the victims of abuse, contacting the abusers – especially when they are close relations – to make them understand the consequences of their attitudes and negotiate change through mediation, providing a network of solidarity and support for legal action, and working a great deal at the microsocial level. At another level, “advocacy” – based mainly on public testimonies by infected persons and supported by international organizations – has enabled the associations concerned to inform the “public at large” with a view to forestalling discriminatory reactions and strengthening social cohesion in the face of the epidemic. The impact of such action at the collective level, which varies from one context to the other, remains to be analyzed.

During the last 20 years an “AIDS subculture” has grown up in biomedical institutions and associations, fashioned mainly with the support of UNAIDS, and has found its way through a host of international meetings and conferences into research and action programs and inter-association networks. This globalized culture, which has taken shape largely under pressure from militant

activists, has established higher ethical “standards” than those that existed previously, which were based mainly on the dissemination of a number of concepts (such as the notions of confidentiality, enlightened consent, etc.) and on recognition of the rights of infected persons. It has also transformed the hierarchical relationship between doctors and patients and has modified, to a certain extent, the balance of power among researchers, practitioners and association members. This “AIDS subculture”, which is more egalitarian than that of contemporary health-care systems and now constitutes the benchmark culture for many association members and health professionals, constitutes a resource from several standpoints.

Community dynamics and the “AIDS subculture” are unique in the history of epidemics. They suggest that progress in the area of patients’ rights acquired in the HIV/AIDS context might also be applied to other pathologies, provided these achievements are widely known.

### **Social science research and the cultural approach to combating discrimination**

How can social science research, especially anthropology, contribute to the cultural approach to combating discrimination?

Anthropologists are often called upon to act as “cultural translators” by providing interpretative elements that make it possible to distinguish between cultural practices that are *a priori* harmful and others that are in principle positive, the latter being regarded as resources. A careful examination of discriminatory practices in various fields suggests that this kind of demand calls for responses at different levels.

The first approach highlights constants in attitudes and similarities of rationale with regard to discrimination and other HIV-related fields, reflecting the unity of humankind underlying cultural diversity. Such an analysis may seem paradoxical on the part of researchers specializing in cultural specificities; however, it points out the need for caution as regards both ethnocentric and xenocentric approaches to the relationship between ethics and culture.

The second approach reveals that the same institutions – whether scientific, political, community-based or religious – may employ and apply a double language in relation to discrimination, without departing from their basic principles: it is therefore by interpreting their texts and references, and by examining the forms that their pronouncements assume when translated into practice, that their concern (or lack of concern) with the risks of discrimination becomes apparent. A personal interpretation by one or more “key individuals” is often enough to cause a provision to be construed in discriminatory terms. Such “flexibility” makes institutions particularly sensitive to local issues and to clusters of associations or other institutions that regard discrimination as an issue. More than the existence of favorable or unfavorable local cultural practices, an effective “resource” for combating discrimination would seem to be the presence in institutions of persons who are sensitive to the question of discrimination and can serve as “go-between”, introducing at the local level the egalitarian norms of the “AIDS culture” and building transcultural bridges between seemingly very distant subcultures. This has been done by the lawyer David Kaboré:<sup>4</sup> steeped in the egalitarian culture of AIDS, he has turned to account existing legislation and successfully alerted the Naaba of Bazoulé, a respected Mossi tribal chief in Burkina Faso, to the need to select those customary-law rules most favorable to PLWHA and proclaim them to “his people” with the full weight of his authority.

The role of social science researchers, especially in anthropology, may take various forms, in keeping with the principles and methods of that discipline. It may involve: describing discriminatory

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<sup>4</sup> Filmed in the documentary *Faso Fights AIDS*.

practices and language in the minute detail characteristic of ethnographical observation; reporting on the viewpoints of individuals (whether the victims or the source of discriminatory practices and propositions), thereby applying the principle of restoring subjectivities to their own cultural systems of reference; analyzing the rationales and concepts underlying discrimination and the different issues at stake for each institution; dissecting the local dynamics of discrimination and solidarity, while observing the principle that no object can be studied without also analyzing its converse and compiling an inventory of “resources”; or elaborating concepts that refine our understanding of discrimination.

The challenge, however, lies in using the findings of such research to combat discrimination. This “ancient challenge” is that of changing representations, attitudes and behaviour: attempts to do so over 30 years in the field of public health induce modesty in the setting of objectives, showing that cultural change tends to be possible only when external conditions, particularly material and social, are favorable. As to discrimination, experience has shown that campaigns relying on prescriptive injunctions asserting moral or social values, such as “Show solidarity, do not reject AIDS patients!” employed at the beginning of the epidemic, were ineffective and perceived as guilt-inducing. A cultural approach that produced such a result would be pointless.

Some of the initiatives of Act Up can be seen as an accomplished and particularly effective “cultural approach” to combating discrimination. In the early 1990s, Act Up engaged in a genuinely cultural campaign to modify, with the help of powerful symbols, the significance that health-care institutions gave to their decisions and programs (Lestrade, 2000). Brandishing the slogan “AIDS = death” and inviting ministerial officials to step over the bodies of activists lying on the ground during demonstrations called “zaps”, Act Up put a face on the death statistics, breaking with the quantifying – hence abstract – scientific culture of the public health services and signaling the practical implications of the lack of treatment. Act Up’s aim was to make scientific and political decision-makers see that the lack of care, previously viewed with fatalism, was a sign of a lack of activism on the part of government agencies, conducive to a particular form of discrimination against infected persons. The distinctive feature of their action was that it gave physical embodiment to ideas, by showing the faces of people who were the victims of such discrimination.

One of the most effective resources of anthropology for bringing about cultural change could be its capacity to make the connection between individual experience and the analysis of social and cultural phenomena affecting communities and societies. It is perhaps by means of personal accounts, which speak directly to people belonging to different sociocultural universes in terms of their “common humanity”, that relevant notions can be transmitted with respect to combating discrimination. If the writings of Paul Farmer have helped to create awareness of the inequalities experienced by Haitians, it is not only through his conceptual analyses but also through the use of photographs depicting the persons whose cases he was describing – in the context, moreover, of medical articles published in journals that rarely carry illustrations. This gives his publications a tangible dimension, of a kind likely to transcend cultural barriers and to be understood regardless of the codes of cultural subgroups. The same approach was used in the making of the documentary film *Faso Fights AIDS*.

The history of epidemics and of their litany of “social maladies” has shown that the introduction of treatment has had the effect of reducing discrimination, both individually and collectively, by lessening the physical, social and economic impact of the disease and by removing stigma, just as long as access is not reserved to certain categories of patients established on the basis of the membership of a particular community or social or cultural group or of their “ability to pay”. It is now up to social scientists to analyze the rationales underlying the production of inequities in access to treatment in the North and in the South, which may be at once the consequence and the cause of discrimination.

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## **Introductory Remarks to the Round Table of 29 November 2002**

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Twenty years after the world first became aware of the existence of AIDS and of its epidemic character and 15 years after the unprecedented institutional mobilization represented by the establishment of the WHO “Global Program on AIDS” and the UNAIDS program that succeeded it, the epidemiological situation is more dire than ever. The most recent estimates tell us that 40 million people are infected worldwide. Thirty million of them are in Africa and most of the others are in poor or crisis-stricken countries in Asia, Latin America and the Caribbean and Eastern Europe.

These figures reflect the stark inequality worldwide in confronting the disease – an inequality that combines two types of disparity: disparity in terms of vulnerability to infection and disparity in terms of access to treatment and care.

This inequality has existed ever since the epidemic began, and it is regularly and publicly decried. Yet it persists. Can we try to identify some of its roots in order to combat it more effectively? Without claiming to explain something that is the effect of a complex combination of factors, I should like to stress here an aspect of the problem that is often given little consideration and is very much in line with the topic that has brought us together today: I mean the cultural dimensions of the strategies adopted to combat the epidemic.

Criticism has rightly been focused on the meager financial resources allocated to combating AIDS in poor countries, in Africa in particular. The high price of drugs, especially antiretroviral drugs, is also decried, although it must be pointed out that countries like Brazil and South Africa have shown that something can be done about this situation.

The economic dimension of the question is beyond dispute. Yet is it the only one? Is it even the most essential? Should we not, first and foremost, call into question the conceptual models and the representations that underlie the way in which the campaign is being fought? Experts, too, construct their practices on the basis of representations!

To pose the question is to ask oneself what vision of the individual and of human behaviour has informed the strategies developed in Africa, which were subsequently transferred with little change to other continents.

The question I would ask then is this: why have the methods of combating AIDS adopted in poor countries been focused from the outset and up until recently on mass information, education and communication campaigns? Why has so little been done, and so late (where something actually has been done), to enable infected persons to do something with the information, often presented in the most dramatic manner possible, on the disease and its devastating effects? Those to whom the messages are addressed (the “recipients” in the language of communication) have often been left to cope by themselves when confronted by such basic questions as: what is my serostatus? How can I reorganize my life, in view of all the constraints to which I am daily subject, to reduce the risk of being infected or of infecting the person(s) with whom I have sexual relations? Until quite recently, there were no or few free and anonymous screening centers in most African countries, or centers providing individualized counseling. In most cases, infected persons were told they were HIV-

positive after being hospitalized, in a fairly blunt manner, with no psychological help and, all too often, with no concern for anonymity. Why has so little been done to cater for the sick despite the fact that the flood of sufferers was foreseeable well in advance? Antiretroviral drugs apart, basic medicines to treat opportunistic diseases are often unavailable. As for material, economic and psychological support for infected persons and their families, despite the praiseworthy initiatives taken on occasion, nothing has been done that matches the scale of the challenge.

Is it surprising that, confronted by the threat of a disease that progresses by stealth, not knowing where to turn when feeling personally vulnerable and having no prospect of being cared for medically, materially and morally when they learn of their infection, many find refuge in denial as an illusory means of allaying their anxieties? At the same time, in rich countries, information, screening, counseling, many forms of care and, more recently, access to treatment have constituted the links in a chain in which prevention and care form an inseparable whole.

Obviously, material and economic constraints can be cited to justify the choices that have been made in the case of poor countries – in Africa particularly. I remember a public debate at the International Conference on AIDS in Vancouver in 1996, where it was argued that a mass information policy was more cost-beneficial, and therefore more effective, in a situation of scant resources than a policy focused on screening, counseling and care.

Economic arguments are not without point; but one may also ask what is the vision of the human being and of the way behaviour is shaped that underlies such choices. It seems to me that that vision may be reduced to a few simple ideas:

- there are knowledge gaps to be filled;
- cultural blockages to be removed;
- traditional practices to be combated;
- and, on occasion, poverty to be alleviated.

Where is the human individual in all this? Where is the complexity that is, everywhere and at all times, present in the lives of those one is trying to reach: their aspirations and their fears, the contradictions confronting them when their culture comes up against the modern phenomena that pervade their lives, as they do our own, although they live in the heart of Africa?

My question is therefore the following: have the members of the “populations” targeted by the anti-AIDS strategies in poor countries truly been conceived as individuals in their own right – in all the complexity implicit in their humanity? Or have they rather been reduced to a few simplistic models that justified in turn the simplicity of the measures adopted? If that is indeed the case, does it not amount to one of the original, most fundamental, forms of discrimination in which all other forms are rooted? Is this not then one of the main causes of the ineffectiveness of the anti-AIDS programs so far devised?

I shall not respond to questions here, but it seems to me that anthropology – by virtue of the special attention it pays to the links between representations and practices, between individual actions and collective determinations – is particularly well equipped to attempt to explore them. The following presentations, in the diversity of their approaches and the variety of situations they describe, will no doubt offer some clues to the answers.



## The Shortcomings of Culturalism and the Relevance of the Social Dimension in the Approach to AIDS in Africa

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Some analyses have strongly emphasized the causal link between behaviour and representations regarded as culture-specific and the dynamics of the AIDS epidemic in Africa. These analyses can lead to culturalist interpretations of the epidemic – interpretations that pose two major problems with which I should like to deal here. Firstly, they lead to an excessive characterization – usually but not exclusively negative – of African societies in terms of their cultures; and, secondly, they tend to mask the real factors that explain the AIDS situation.

I shall begin by looking at the approach to the question of circumcision, which has assigned to culture a role that, while admittedly “protective”, remains ambiguous. I shall then review a number of analyses of cultural practices put forward as being responsible for the spread of HIV. Thirdly, I shall try to show the value of refocusing the debate on the social dimensions of the epidemic, which presupposes paying special attention to individuals.

### **A tendentious over-emphasis on culture: the case of circumcision**

Circumcision is a recurring topic of discussion in the specialized literature on AIDS, and is emblematic of an ambiguous process involving the “culturalization” of AIDS in Africa.

In the early 1990s, epidemiologists put forward differing interpretations of the role of circumcision in HIV infection. Some believed that the statistical link between circumcision and a lower rate of contamination was proven, while others thought that it had not been. In any case, no one knew for certain “whether circumcision has a direct effect on HIV transmission or an indirect one through, for example, its protective role in relation to ulcerative STDs” (Ferry, 1999). These uncertainties concerning the effect of circumcision on HIV transmission did not, however, prevent the development of culturalist analyses. Circumcision was defined as a cultural practice (this remains to be demonstrated), and one could therefore point to the cultures “at risk” (those that did not practice circumcision) and position them on a map of the circumcision “belt” (Caldwell & Caldwell, 1993). This led to the designation of “good” and “bad” cultures. What such categorizations overlooked were the conditions governing such practices, their uneven spatial distribution, and the existence of other factors that might explain why HIV is more prevalent in the non-circumcising populations.

More recently, epidemiological studies have advanced our understanding of the link between circumcision and the reduced risk of HIV infection. First of all, herpes is very clearly associated – more systematically than the absence of circumcision – with a strong prevalence of HIV. The protective function of circumcision is attested in some areas, and less so in others. Nonetheless, the epidemiological and clinical studies allow us to conclude that the effect of circumcision in the reduction of the risk of HIV transmission – to which all analyses tend to point – “are probably not due to the cultural and behavioural factors with which they are supposed to be associated” (Weiss & Lagarde, 2000). What this means is that a statistical association does not signify a causal relationship,

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since numerous other factors come into play, contrary to what was advanced in the early culturalist simplifications. Thus, in practice, what is critical from both an epidemiological and sociological standpoint, more so than a given religion or “culture”, is the age at which the first sexual relation or marriage takes place and the presence of other STDs (especially herpes).

The identification of “circumcision cultures” thus formed part of a kind of “culturalization” of AIDS. While undoubtedly hasty and ill-founded, it was aimed in a way at enhancing the status of cultures that practiced circumcision. Yet this leaves an essential question unanswered: even if one accepts the conclusions of recent epidemiological studies that specify the role of circumcision in protection against HIV, what public health measure can reasonably be promoted on this basis? How are populations to be encouraged to practice circumcision from now on? One solution would be to highlight its medical value, without however decrying populations that rejected it; the rejection of circumcision should not be assimilated to cultural inertia. In any case, it is important that this objective should not be made the be-all and end-all of an information campaign on ways of controlling the spread of HIV infection.

### **The rhetoric of cultures as obstacles to prevention**

Because of their restricted vision of reality, some culturalist interpretations of AIDS go so far as to designate cultures in negative terms: – with reference, for example, to the levirate, polygamy, recourse to hairdressers and “traditional” nail-cutters, and the use of condoms. The perpetuation of these practices or, in the case of sexual relations, the reluctance to adopt them has long been viewed as the archetypal expression of African cultures potentially at risk from and exposed to AIDS.

As regards the levirate, the question needs to be carefully weighed: firstly, the real issue is access to the HIV test and information on AIDS prevention; and, secondly, anthropologists have stressed the importance for a woman whose husband has died – from AIDS, for example – of remaining in the family circle, whereas breaking with the practice of the levirate would lead to the abdication of family responsibility towards infected women (with the very real risk of their infecting other partners) (Taverne, 1996). In the case of polygamy, no higher prevalence has been noted for polygamous couples compared with monogamous ones. What is essential is that each partner should know the other’s HIV status and that sexual relations within and outside the couple should be protected, whether the couple is polygamous or monogamous. Where so-called “traditional” practices are concerned, no case of HIV infection has been formally attested consequent upon a visit to the hairdresser’s or to a nail-cutter.

Lastly, with respect to the use of condoms, obstacles can also arise as the result of inappropriate information. The conclusion to be drawn from all these observations is that greater prudence should be exercised with regard to the culturalization of explanations for the spread of HIV infection in Africa.

### **The myth of isolated and immutable cultures**

Prudence requires that we should pause to consider a number of universals in the field of HIV prevention. Although the link between information on AIDS, the way it is interpreted and its effects in terms of changing behaviour remains a complex question (involving psychological, economic and social factors at once universal and culturally delimited), there is broad agreement that without information on AIDS, however delivered, the behaviour required to avoid HIV infection cannot be adopted. It is a minimal position admittedly, but one universally held. When arguments predicated on “African cultural traits” are advanced, it is findings of this kind that, although virtually beyond

dispute, are either called into question or else overlooked by this culturalist reductionism.

It is moreover striking that the cultural dimension should obscure the social in this way. An image of “asocial” cultures is thus gradually built up in which urbanization, the search for work, the processes of individualization and many other phenomena are sidelined. Culture is thus isolated from other cultures, creating an illusion of cultural isolates. The illusion is that of a culture capable of defining itself in relation to and for itself, whereas a culture essentially defines itself in its relationship to other cultures. J.L. Amselle speaks in this regard of “interconnections”, placing the emphasis on the analysis of relationships rather than on the elements brought together, so as to dispense with the image of cultures as “closed systems”.

Finally, an obstacle that is deemed “cultural” is judged, in the minds of those who so define it, to be insurmountable. This is the case when the reluctance to use condoms is attributed to “cultural obstacles” (always leaving open the possibility of having children, not “wasting” one’s sperm, not accepting reduced sexual pleasure ...) The inference is that it is impossible *ipso facto* to overcome them. This amounts to a “fixation” of cultures which is purely arbitrary.

### **Taking the social dimension into account**

Anthropology has endeavored to show that the conditions governing the spread of AIDS and its consequences are predominantly social. This shift of analysis from the cultural to the social is not to be construed as a denial of any explanatory value to the former: what is being contested is the reduction of a set of behaviours or representations to a uniquely cultural thesis. In the processes of urbanization and migration, the organization of schooling and the plantation economy (for example, in Côte d’Ivoire), population movements resulting from conflict and, more generally, the everyday relations between men and women, it is possible to identify a whole range of situations that contribute to the exposure of individuals to HIV. It is certainly reductionist to assert that such situations remain culturally determined; we are dealing here with social issues that cut across cultures. They do not exclusively concern either given linguistic communities, the followers of a particular religion or the inhabitants of a given region or town. These different factors contain within them explanations for the spread of the HIV infection. It is indisputable that they combine to intensify the risk of infection and that they are linked to cultural particularities; it is essential to underscore the paramount importance of social conditions as distinct from cultural considerations in the spread – or control – of the epidemic.

### **The individual as the key to the social dimension**

Under the common denominator of “social conditions”, we must group the patterns of family life of the infected person, the everyday situations of all concerned – whether it be a sick person, a woman in a relationship, a young man looking for work, a midwife in a health clinic – and also the functioning of a variety of structures (medical, public health, the “fight against AIDS”, associations...) The diversity of forms of the “social” should always be approached through individual experience. In order to understand the way therapeutic treatment functions, one should therefore explore the motivations of the sick and the way they organize their lives, or describe the fear that midwives have of contracting AIDS in the course of their work. But the main thing is to view the situation from the point of view of others. Many lessons are to be drawn from the way HIV-positive individuals perceive the work of health personnel or AIDS-prevention campaigns. This is also true when HIV-positive people talk about the experiences of their sick friends and their attempts to secure treatment or to cope with the reactions of the people around them who know about their HIV status. Placing individuals at the center of our thinking implies analyzing their

choices and exploring their representations for what they can teach us not only about their own attitudes but also those of other people. The way the caregiver sees the patient should also be scrutinized to understand the way the patient sees the doctor or the nurse, as well as to have a better grasp of the issues governing the patient's choice of treatment as well as the caregiver's.

This focus on individuals – their relations to others, what they “reveal” of others and what others in turn “reveal” of them – takes us into the social arena as a place where collective strategies are expressed. In concrete terms, when the observer of a society notes the development of an association that assumes responsibility for health problems, the researcher's acquired knowledge of the way therapeutic treatment functions and the representations of risk among health personnel can be turned to account. Moreover, a researcher who is familiar with the political, statutory and economic strategies of the leaders of religious movements will be best placed to understand the complexity of the issues that arise on the appearance of a new form of worship or church. The conclusion we draw is not only that familiarity with the “field” is important and that it immediately permits a relevant and operational approach, thereby facilitating sociological or anthropological analysis, but that the “familiarity” that is really necessary and the anthropological “expertise” that is crucial are those that enable the connection to be made between the individual and social levels of a practice. That is to say, describing the process whereby a set of individual attitudes expresses a social tendency, namely a series of positions or reactions shared by groups whose interests and strategies may diverge (family groups, associations of the sick, professional bodies, members of a faith...)

## Conclusion

The culturalist interpretations of AIDS have been part of a confining movement of stigmatization: confining because the impugning of individuals because of their practices (“punished” by HIV infection) finds a discreet echo in a culturalist approach in which, above and beyond the individual, it is a whole culture that is placed beyond the pale. It is a case, then, of stigmatization dictated on the one hand by behaviour and on the other by cultural referents. True, this process of stigmatization does not have the same cause in both instances, and is not aimed at the same people or expressed in the same way. Nonetheless, the image that emerges is in the final analysis, that of “cultural individuals”, with presuppositions of inertia and immobilism, whereas individuals who try to come to terms with the threat of AIDS or to live with the disease are also, and possibly above all, “social individuals”.

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# Associations of Seropositive Individuals and Management of the Risk of Stigmatization in Bobo-Dioulasso (Burkina Faso)

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## Introduction

In 1997, Burkina Faso had a seroprevalence rate of 7.17%.<sup>1</sup> More recently, in 2000, WHO/UNAIDS data indicated that 500,000 people were living with HIV/AIDS out of a total population of 10.9 million.<sup>2</sup> The epidemic is growing and it is estimated that 122 individuals are infected every day: these figures mean that Burkina Faso ranks second only to the Côte d'Ivoire (12.7%)<sup>3</sup> among West African countries in terms of HIV prevalence. These figures are, moreover, lower than the actual numbers owing to the biases and limitations of epidemiological studies.

However, aside from the epidemiological constraints of sentinel studies, one of the major obstacles to the visibility of AIDS would seem to be difficulties of a social order: seropositivity continues to be experienced as a disaster, a taboo and a shameful secret in many societies (Le Palec, 1994). The interdependence between the social and the public health aspects of HIV/AIDS has led us to focus, from a socio-anthropological perspective, on the mechanisms of stigmatization as they relate to seropositivity in certain social contexts (Desclaux, 1996, p. 267). In Burkino Faso, as in other countries with high infection rates, the spread of the epidemic has been accompanied by the designation of certain groups, such as women, sex workers and truck drivers, as being "at risk" and has led to these groups and individuals being stigmatized and discriminated against.

To study these phenomena, we shall attempt to describe and analyze the way HIV-positive individuals are integrated in a number of PLWHA associations in the city of Bobo-Dioulasso,<sup>4</sup> where in the year 2000 HIV seroprevalence was estimated at 5.22% in a population of 2,450 persons ranging in age from 13 to 49 years.<sup>5</sup> While it might, in principle, be assumed that associations would be shielded from ostracism, observation of their functioning and analysis of the attitudes expressed within them reveal an entirely different picture. For example, PLWHA in Bobo-Dioulasso usually have recourse to associations for material assistance, and it is often not until they have taken care of their material needs that seropositive individuals discover the benefits of psychological help. Relations between PLWHA association members are not straightforward either. Like any social universe, PLWHA associations are marked by the coexistence of a whole range of viewpoints concerning HIV/AIDS – a tendency often reinforced by the lack of clarity surrounding the definition and role of these associations, whose members are divided on various issues. For example, the desire of young women members to have children is often a subject of dispute among PLWHA association members.

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<sup>1</sup> Source: WHO/UNAIDS.

<sup>2</sup> For 1997, the number of HIV orphans in Burkina Faso was estimated at 200,000.

<sup>3</sup> Source: United States Census Bureau, HIV/AIDS Surveillance Database, 6/6000. Note that these figures date from 1997.

<sup>4</sup> Bobo-Dioulasso, located in the southwest of the country, is the second largest city in Burkina Faso. Twenty-six percent of its population, estimated at more than 600,000 in 1999, is employed and 46% is under 15 years of age. Bobo-Dioulasso is a crossroads town. It is characterized by a significant mix of urban and rural populations owing to its location on the main highway (Mali, Ghana, Niger) and railway axes (Côte d'Ivoire). Bobo-Dioulasso is also the largest industrial area in Burkina Faso.

<sup>5</sup> Survey conducted by the Muraz Center, Bobo-Dioulasso.

The field data cited here were collected as part of a research project supported by the Agence Nationale de Recherche sur le SIDA (National Agency for AIDS Research). The research is being conducted jointly by social science researchers belonging to a research unit at the Institut de Recherches sur le Développement (IRD, UR 002) in Marseilles and a SHADEI<sup>6</sup> research unit at the Muraz Center in Bobo-Dioulasso.

## **Establishment of PLWHA associations**

*The Espoir-Vie (EV) association: "While there's life, there's hope!" From assistance to mutual support*

The history of the EV association is closely linked to that of the SAS Center. Initially, it seems, the Center was to be called "SIDA Actions Sociales" (AIDS Social Action). However, to shield users of the center from stigma, it was decided to call the center "Solidarité Actions Sociales" (Solidarity Social Action). SAS centers are located in several African countries; their mission is to provide support for children and families affected by HIV/AIDS with a view to enabling them to be reintegrated and/or remain integrated in their community of origin. The support can take various forms: advice, socio-economic help, legal aid, economic development assistance in the form of support for income-generating activities, and the linking of this initiative with local association and community networks.

From its first year of operation, the Bobo-Dioulasso SAS center was confronted with a growing demand for services. Faced with this "enormous need for someone to talk to" and an overworked staff, it was decided to reorganize the center's clients into an association with a view to promoting mutual support among individuals with common identity markers, thereby lessening their feelings of isolation. That was how the Espoir et Vie association came into being in 1997.

Espoir et Vie, a non-political, non-denominational and non-profit-making humanitarian association, has the following aims:

- to provide moral and psychological support to any person affected by and infected with HIV/AIDS;
- to defend the rights of persons affected by and infected with HIV/AIDS;
- to collect drugs and donations for redistribution, ensuring that they will be used for those who need them the most;
- to work closely with African and other associations pursuing similar goals with a view to undertaking coordinated action, and to support any initiative to improve the psychosocial, medical or legal situation of PLWHA in Burkina Faso.

Between June 2000 and May 2001, the association provided services to 171 previously enrolled clients and 114 new ones, or a total of 285 individuals (197 women, 35 men and 34 children). Of the clients, 167 were known to be seropositive and 88 were asymptomatic.

Many of the sick arrive in a "fatigued" state even when they are unaware of their serological status. Most are experiencing social and economic difficulties and have come to seek help. Membership in the association is based on a positive test result or simply on suspicion of infection by the virus. Members of the association (numbering 62 at the end of 2002, out of which 22 were women) are no longer over-concerned about serostatus; they are looking for people who can contribute something to the fight against HIV/AIDS: "What have you got to give to the Association that makes you want to become a member?"

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<sup>6</sup> Sciences Humaines Appliquées à l'Évaluation des Interventions.

Since April 2001, the EV association has decided to “adopt a higher profile” and to make some of its activities more visible. A charity run (“*cross de l’espoir*”) was organized in April 2001, with the aim of informing the public of the existence of the associations and their activities in support of individuals infected with and affected by HIV/AIDS. The event provided an opportunity for some members of the association to make personal testimonies – a topic to which we shall return later. Similarly, since August 2002 the statutes of the association have been modified, so that it is no longer a body providing support to PLWHA but rather a PLWHA mutual-support association.

From the outset, the SAS center has been the parent structure of *Espoir et Vie*: SAS counselors are also EV counselors and EV Headquarters is located on SAS premises. However, EV officials have the impression that the relationship with SAS is infantilizing and stands in the way of EV developing and maturing. They are also critical of the fact that EV is left out of SAS center activities:

“EV considers itself to be an SAS-center association. We would like to participate, if only in SAS meetings, so as to keep ourselves in the picture. We would also like to have access to the offices and equipment, which we are equally concerned to look after. We look to you also for information on project development, fund-raising and advocacy initiatives.” (EV executive committee member, March 2001)

The SAS center, for its part, has accused the Association of making improper use of SAS property at a time when SAS is having difficulties in mustering funds. In addition, certain members of the association have been criticized for having told partners that SAS no longer exists.

*The Yèrèlon Association: “Know thyself!”*

The creation of the Yèrèlon Association (“Know thyself”) was linked to a public-health research project of the same name. This project was launched in response to a growing awareness of the difficulty of combating STIs (sexually transmissible infections) and HIV/AIDS among women categorized as “prostitutes”.

A study on prostitution carried out from December 1997 to May 1998 by researchers at the Muraz Center<sup>7</sup> helped to deconstruct this category by demonstrating the wide variety of practices engaged in by women classified as “prostitutes”. This anthropological investigation identified six categories of women classified as most vulnerable: “stools” (prostitutes who work in small studios), “street-walkers” (women who solicit on the street), waitresses (women in bars), sellers (of fruits and vegetables), students and “cabarets” (sorghum-beer sellers). Nevertheless, the use of such categories can in the long run lead yet again to stigmatization of the individuals so classified. Careful distinctions must therefore be made by researchers wishing to employ these categories or to refer to certain social practices to explain the propagation of an illness in general and of HIV infection in particular (Taverne, 1996; Vidal, 2000). For public health purposes, the project is conducting a clinical follow-up on a cohort of 300 women representing these six categories.

The *Yèrèlon Association* was set up at the suggestion of those in charge of the *Yèrèlon public action project*, in response to the large number of requests to participate in the cohort study. The association, which was founded on 28 September 1999 and now has over 800 members, is a community-based

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<sup>7</sup> See P. Huygens et al. 2001. *L’initiative Yèrèlon. Comprendre et atteindre les prostituées clandestines à Bobo-Dioulasso dans le contexte de l’épidémie de VIH: vers une approche étiologique et compréhensive de la prévention auprès des femmes vulnérables*. [The Yèrèlon Initiative. Understanding and Reaching Clandestine Prostitutes in Bobo-Dioulasso in the Context of the HIV Epidemic: Towards a Comprehensive Aetiological Prevention Approach for Vulnerable Women]. Report, UNAIDS/SHADEI (Muraz Center).



organization bringing together vulnerable women in Bobo-Dioulasso involved in prostitution.<sup>8</sup> The membership of the association, reflecting the circumstances in which it was set up, is not limited exclusively to HIV-positive women. It is not, therefore, a PLWHA association technically speaking.

The aims of the *Yèrèlon Association* are to improve the physical, social and economic well-being of the women involved; to prevent the emergence of new cases of STI and HIV in women through awareness-raising and education; to promote the use of condoms and establishment of a support fund for the creation of income-generating activities for the women to ensure their economic self-realization.<sup>9</sup> Since its inception, the association has been organizing HIV/AIDS prevention activities, followed by “talks/debates” at prostitution sites. The purpose of these activities is to promote the association and to make a profit.

The difficulties encountered by the association, which was a spontaneous “spin-off” from the cohort study, arise from the fact that it tends to distinguish between two types of members: participants in the cohort study, who receive free health care, and others who must pay. As a result of this two-track system, the association has to cope with the disappointment of some of its members (not included in the cohort) who feel left out. In addition, the linguistic and cultural diversity of the association members leads to distinctions being made between English-speaking and French-speaking women.

Unlike other associations working to combat HIV, which target their efforts on an outside group, the *Yèrèlon Association* sets out to provide counseling services for its own members, functioning as both a service provider and a mutual-help group. Because of the risk of indiscretion, owing no doubt to the close link between counselors and patients, the *Yèrèlon Association* is a care provider without “patients”. Concerned about leaks in confidentiality about their serostatus, some association members voice the fear during the consultation process (notably when receiving psychological support) that other members of the association will find out about their seropositivity. Concealment of seropositivity within the association itself explains why it has proved difficult to organize discussion groups among seropositive members.

More recently, the association’s PLWHA members have timidly begun meeting in mutual-support groups, fearful that their serostatus will become known.

The fact that they engage in clandestine prostitution makes it difficult for certain women to join the association or be active members. Some of these women do not attend the monthly meetings because they do not want to be regarded as prostitutes. Furthermore, the association’s executive committee is eager to demonstrate that the association is not composed solely of sex workers.

Like *Espoir et Vie*, the *Yèrèlon Association* retains close links with the context in which it developed: its headquarters are located on the health service premises, adjoining the *Yèrèlon* project, making the association dependent on the latter: “The project is on vacation; so where can we meet? We are not free. We would like to be independent so as to pursue our goals all the way”<sup>10</sup> (a member of the executive committee).

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<sup>8</sup> All the women concerned do not define themselves explicitly as sex workers and this can have implications for the life of the association. For example, English-speaking woman calling themselves sex workers tend to be excluded from the association’s activities by the French-speaking sex workers. In addition, women who are “clandestine” prostitutes are afraid to be seen in the association and to be openly associated with other prostitutes.

<sup>9</sup> Declaration of the *Yèrèlon Association*.

<sup>10</sup> Following recommendations made by a socio-anthropological study, the coordinators of the project had begun to look for premises outside of the project site to enable the association to become independent. However, if the project itself decides to move the association to another location, that would hardly be a token of independence!

*Responsabilité-Espoir-Vie-Solidarité (REVS+): “Always remember that our efforts are meaningless unless they contribute to the well-being of people and their community”*

REVS+ defines itself as an association of persons infected with and affected by HIV/AIDS. Aware of the difficulties of informing individuals of their seropositive status and the consequences of such a disclosure, health professionals took the initiative of establishing an association to assist HIV-infected and -affected individuals. Study groups were set up with a view to improving the organization of disclosure and ensuring the follow-up of individuals testing positive. Against that background, and with the support of a French physician, a group of individuals infected by HIV/AIDS established REVS+ on 10 June 1997. By the end of November 2002, the association had 412 members – 329 women and 83 men – and was taking care of 220 orphans.

REVS+, which was officially recognized on 17 February 1998 and whose headquarters are located in the precinct of the Bobo-Dioulasso Regional Health Department, is sponsored by the regional director of health. Apart from the executive committee, the association’s staff includes the chiefs of the: home and hospital visit unit; the information, education and communication unit; the advocacy unit; the training and documentation unit; the unit for the follow-up of orphans and vulnerable children; and the medication unit.

The overall aim of the association is to combat the stigmatization of PLWHA. Faced with the abandonment and stigmatization of PLWHA, the REVS+ association hopes to improve the lives of people living with HIV/AIDS, orphans and their families in Bobo-Dioulasso. The specific objectives are as follows:

- to combat AIDS-related stigmatization, discrimination and rejection;
- to assert and defend the rights of seropositive individuals, AIDS sufferers and orphans;
- to facilitate exchanges between PLWHA by furthering mutual support among its members;
- to develop the skills of its members through training, information and counseling.

Once again, advocacy and personal testimonies are regarded by the association as a means of publicizing its work. Indeed, one of the members of REVS+ was the first PLWHA to speak about his HIV infection in public. According to the president of the association, individuals should prepare their testimonies in advance to cushion the impact on themselves and their families. At the same time, testimonies should not be made in the sole interest of the individual and to the detriment of the association: “Individuals must not see themselves as separate; we are part of a group”. Another REVS+ official believes that the “appropriation” of HIV is essential to dealing with the fear following upon the disclosure of seropositive status: “we must ‘own’ HIV, master our fear of it and continue to be committed at the international level. AIDS is not something that only happens to other people!”

### **Protecting associations against stigmatization**

Having described the background to the creation of these associations, and outlined their aims, we may now focus on their common characteristics, with particular reference to stigmatization.

PLWHA associations in Bobo-Dioulasso are all recent creations. Although AIDS was officially recognized in 1986, it took 10 years for “self-help” associations to emerge.<sup>11</sup> The creation of such associations and the expansion of their activities undoubtedly owe something to the first testimony by a seropositive individual (November 1997). The creation of these bodies was also a consequence

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<sup>11</sup> Self-help associations bring together individuals sharing the same social circumstances (vulnerability for example) or victims of the same stigma; these individuals meet to defend their common interests.

of the official recognition of AIDS as a social disease in 1995. The official declaration of AIDS cases and the establishment of plans and programs to combat HIV/AIDS dates from 1986; but it was not until the long-term government plan for 1996-2000 that the psycho-social and social care of individuals infected with and affected by AIDS was identified explicitly as a main line of action<sup>12</sup> by the national authorities.

Moreover, because of the risk of stigmatization, the associations avoid all reference to “AIDS” in their acronyms. The same is true of their slogans: “As long as I am alive, I have hope!” (EV); “Know thyself” (Yèrêlon); and “Always remember that our efforts are meaningless unless they contribute to the well-being of the people and their community” (REVS+).

The significant problems of visibility experienced by all these bodies is linked to the fact that they are all located in and/or affiliated to public health structures. This can help to protect them by not raising suspicions about the seropositive status of their clients, who can justify their visit to a health center on grounds other than those of being a member of a community of seropositive individuals.

“We have a big family. We have the same mother, but different fathers. I don’t have my father anymore – he died. We don’t all live together but we get together in the family compound. I don’t want to tell them about my problem. They have money, but they can’t help me. Worse, they’re going to tell other people that I’m infected. My sister also goes to the health service. She took a test and got the results. Each time she asks me why I don’t go back to pick up the results. I told her I didn’t have the courage. I was really worried that she would find out that I am infected; but she didn’t discover anything; I sounded her out and realized that she didn’t know anything. She doesn’t even talk about it anymore. That encouraged me; that’s why I keep going to the health service.” (a female member of the association).

The associations described here are far from uniform, at least as regards the criteria used to define members. On close examination, one finds that these are based on “constructed” categories: members, active members, group leaders, volunteers, beneficiaries, PLWHA, infected persons, affected persons. Classified in that way, members are not necessarily beneficiaries and vice versa. Nor is account taken of the fact that a PLWHA might be infected with and affected by HIV at the same time.

We are faced with a variety of concepts whose content is still far from being firmly established. This constellation of concepts necessarily gives rise to ambiguity, an uncertainty with regard to whether members of the same “self-help” association can openly share their serostatus. Within a PLWHA association comprising infected and affected individuals, it is often a delicate matter for a seropositive person to speak openly about their serostatus to other members. The distinction between “affected” and “infected” persons leads to feelings of suspicion among members, which hardly makes life any easier for some individuals, who end up seeking strategies to hide their seropositive status.

We found that in the Yèrêlon Association, which brings together vulnerable – including seropositive – women, very strong emphasis is placed on discretion about members’ seropositivity. Secretiveness leads seropositive women to avoid going to meetings with donors involved in the combat against HIV. Paradoxically, even within the Yèrêlon executive committee, it is impossible for officials to designate individuals to attend donor meetings since that would be tantamount to a public revelation of their seropositivity. As an administrative official put it: “it’s like a masked ball since no one knows who is infected and who is not!” It was these “community facts of life” that led the

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<sup>12</sup> Decree N98-467/PRES/PM/MS of 2 December 1998 provides for the establishment of a solidarity fund for AIDS patients and AIDS orphans.

psychologist/counselor for the Yèrèlon Association to orient the women towards another self-help association in which seropositive women can speak more freely about their seropositivity with their fellow members.

### **Individual management of seropositivity within the associations**

The membership of PLWHA associations is in the main female. This finding poses certain questions: are women more affected by the epidemic than men? Or why, given equal infection rates, do women turn to associations more than men? To what extent are women faced with social difficulties outside of these associations? How do women cope with questions about their seropositivity within the associations?

Generally speaking, knowledge and disclosure of seropositivity leads to a drop in self-esteem and a fear of rejection. Social attitudes with regard to AIDS make it difficult to share the information about being HIV-positive with other people. Knowing that one is HIV-positive therefore means devising strategies for hiding this serological status.

The decision to go for HIV testing generally follows the illness or death of a loved one. Often it is a decision prompted by the appearance of physical signs resembling those associated with AIDS. Nonetheless many women go for HIV testing under pressure from their husbands. When the results are negative, some husbands show the test results to their friends to prove that they are not HIV-positive.

In countries practicing the levirate, when a husband falls ill, a brother-in-law may urge HIV testing to be sure that the woman who will become his wife is not infected. If the test turns out positive, “social camouflage” strategies may be deployed: the brother-in-law will take the precaution of publicizing the marriage to the entire community, but the two partners will abstain from any sexual relations.

#### *Reasons for resorting to associations*

People generally contact an association after visiting an anonymous screening center, hospital clinic or health center. In an environment where seropositivity will most likely entail stigmatization, recourse to an association becomes necessary to lighten the burden of silence. Still, the frequently advanced explanation for contacting an association is the material and therapeutic help it can offer. The importance of psychological support only emerges after a person becomes a member of an association. That being said, PLWHA are confronted with the difficulty of communicating their serostatus after as well as prior to membership.

#### *Strategies for communicating seropositivity*

Who should you tell? How should you say it? When should you say it? These are the questions haunting the PLWHA whom we met in the associations. PLWHA are worried first of all about how their family will view them, and then about their reputation among friends or neighbors. A difficult family situation, often linked to family size and its socio-economic status, can discourage talking about HIV/AIDS infection:

“In polygamous families, the wives are afraid of each other; people don’t trust each other. If they find out, they will tell on me; I don’t want one day to be pointed at in

public like an AIDS victim. I can't tell anyone at home; we have a very large family.”  
(30 year old woman, mother of two children, living in the family compound)

For an adult female, the fact of living in the parental compound is already problematic. Disclosing her seropositivity would accentuate the disrespectful behaviour towards her.

“It made me sick, I was depressed for two days. I was sick all the time, my parents had spent too much; since I didn't get any better, I decided to have the test done; when I found out, it was sad, I felt sorry for myself, I said to myself ‘How can a person who is not respected when they haven't got AIDS be respected when they have it.’” (27 year old woman, mother of three children, single)

Anita's situation says a great deal about how family circumstances can lead individuals to hide their serological status from their parents. Anita is the mother of a two-year-old boy. Two other children died very young. Following repeated hospitalizations during a pregnancy, she decided to take a screening test. Even though her results were positive, her son is not HIV-positive. The father of her child is a civil servant, but it is Anita's father who pays for the medical expenses. Anita's boyfriend decided to “pull out” (leave her) when his mother told him (on the telephone) that Anita was seropositive: “He says that he cannot take care of me, that he is sorry, he doesn't know why he did it, but he doesn't want to squander his life. And to think I had two children with him (the second one died).” Anita and her son live in her parents' compound. At the time we met, she had still not told her parents about her serological status. Even though she says she is ready to tell them, the constraints of family life make her hold back:

“No one in my family knows. As for me, well, I am ready to tell them, but we have a large family, in our family there are 60 people because there are the wives of my older brothers, my sisters have male children who have wives. I have sisters, my mother has co-wives, and there are the children of my older brother who are there, so we are a big family. So my father is not going to be understanding, he is going to say – you went out and picked up a filthy disease, he's going to say that in public. He won't kick me out but he will say it in public and you will feel ashamed in front of the others. Then your life will be difficult. He is not going to keep it to himself, he will say it out loud, he doesn't think that's going too far, he will say it and then according to him it will be all over with, but he doesn't know that the others are going to take note. Then in the neighborhood your name will be dirt and you will have problems living with your own family. So that is why even the father of my child does not... know.”

Anita urged one of her younger sisters to take an HIV screening test, and this younger sister found out that she was HIV positive. Even though she gives her cotrimoxazole everyday, Anita does not feel ready to share her serostatus with her sister who, she believes, would not be able to keep the secret if a conflict arose.

Let us take the example of another woman:

“I didn't tell my parents anything. If my father finds out he is going to tell everyone; when someone comes to our house my father starts to tell him what the father of my children did to me. I already complained to him about his behaviour one day and asked him whether I was not his daughter? Especially because there are already problems in the family: I have twin sisters who are complicated, you can't sit around the fire with them (chat); one day they told me that they have money and that I could become like them. Yesterday, my father hit my mother. We all slept outside, he told

us to leave with our mother. We told our uncle what happened, he wanted the old lady to leave and go to Niangoloko, she refused; the old man isn't speaking to us anymore; today when you haven't got any money! When I had money, I would give it to everyone and I was appreciated! But today, this same family buys their wood elsewhere while I sell wood." (37 years old, mother of four children)

The case of another HIV-positive woman, forced to leave the home she shared with her husband to go and live with her parents even though she was ill, is instructive. This woman is from a large polygamous family (three wives and more than 20 children). She left her husband two years ago:

"My husband says that he has spent too much and that he couldn't spend anymore. After my two stays in hospital, his behaviour towards me completely changed. He could go for two or three days without speaking to me. When I was feeling a little better, with the agreement of his family he asked me to go back to my parents, saying that he had no more money to take care of me. 'I sold goats, sheep, everything, to pay for your medical care; all I have left is my bicycle. I am not going to sell it to pay for your treatment', he told me. I don't know if he was thinking of AIDS. He never mentioned it to me; anyway, I was very ill, to the point where I couldn't even get up. Aside from my health problems, we got along fine; I have always shown him respect. I keep asking myself where I could have gotten infected. My husband is still alive; he has never fallen ill; in fact he is in very good shape. With this illness, I am afraid to go back to my husband; he has not remarried; but if I get sick he might throw me out again. I am afraid of that happening. My father would curse me! He says it's because of another man but not my ex-husband. He is very frustrated, my father, especially since my husband is a relative; he comes from a neighboring village. I prefer to be by myself. If I leave, I will find the family door shut in my face; I choose to be by myself." (30 years old, mother of two children).

As for sex workers, their relatives are far from the city and it is difficult for them to tell their partners about their seropositivity owing to the instability of the relationships. While they speak of their "regular" partners as significant figures for them, they confess that they still fear being abandoned by them if their seropositivity is discovered. They evince a general mistrust of men ("you can never understand men"), but also fear economic vulnerability ("at the cabaret if they learn that you have AIDS, the clients disappear one by one"). English-speaking sex workers fear that social networks will reveal the secret of their seropositivity. In one of the associations, the issue of fellow members failing to respect confidentiality has been raised. Sharing information is not any easier for women who are "clandestine" sex workers. The couples are unstable. Naturally the decision to disclose one's seropositivity is made only after assessing the discretion of the person who will be told. Making one's serostatus known may lead to belittlement in the eyes of others.

For widows, revealing their serostatus to the members of their former husband's family is a strategy to preserve their dignity, in anticipation of illness: "so, in case I fall ill my parents-in-law cannot accuse me of having become infected after my husband died".

When is the right time to tell one's family about being seropositive? The seropositive individuals we met tended to adopt a strategy which consisted of frequently bringing up the topic of AIDS with their family. Such frequent discussions can even lead in the long term to the decision of another family member to have a screening test. What we observed is that while tensions and conflicts in large families can discourage the disclosure of an individual's serostatus, conflict in a small family can provide an opportunity for PLWHA to announce their seropositive status. The disclosure serves to underline the vulnerability of the infected person and the need for their relatives to be more indulgent with them. The family then becomes more compassionate.

Regardless of whether they are members of an association, PLWHA have strategies for keeping their seropositive status secret, from hiding symptoms associated with the illness (diarrhea, weight loss, dermatosis, hair loss) or any medical bills which might arouse the suspicions of the family to denial of the illness in cases where family members suspect HIV infection. Because of the risk of being found out during social interaction, the daily life of seropositive individuals is characterized by behaviours based on pretence.

### *Social camouflage*

For some women social camouflage means finding a stable partner and/or having a child. A seropositive woman, age 27, describes it this way:

“I have a boyfriend – you really have no choice. He is married, he’s a policeman, he doesn’t know my serostatus, from time to time if he wants to have sex with me, he uses protection ... When you are alone at home all the time, you think too much, you imagine yourself being rejected, that’s the reason, you want to have fun and then, if you tell a man that you are seropositive, it’s all over. He’s going to reject you and tell everyone. So you will be rejected, that is why we control ourselves, we’re here, the family insults us, that we don’t want to get married, that we want to be prostitutes, and on and on; it really hurts, often if you think about it, it keeps you from sleeping, it really worries you!” (young woman, member of an association).

Within the associations, women are often very preoccupied with the source of their infection: widows wonder if they were infected by their dead husband. It seems as if being a widow is proof of the absence of guilt. However, in reality, the situation is often more complicated.

We met Aline, a young woman, widowed and mother of a two-year-old child, at one of the associations. Aline says that she was at her husband’s bedside until his death. Her husband had had a screening test while he was ill but had not informed anyone in the family, not even Aline, his wife.

“When he came in, I asked him if he had got the results, and he said that they had not given him anything. I said: “they didn’t say anything, not even what illness it was?” He said that they suspected it was that, but that it wasn’t. And until he died he never showed me the results. It was when we were doing the paperwork after his death that we found the results in one of his garments, it was positive. I don’t know how he managed to hide it there since he could not even get up by himself.”

While her son was in the hospital, Aline’s mother-in-law learned through a relative who was a public health worker that her son had HIV/AIDS. She decided to take him out of the hospital on the pretext that she had no more money: “They said that he wasn’t going to live, that it wasn’t worth wasting any more money.” She then accused Aline of infecting her son: “Because before she tells me to go take the test, they are already accusing me of bringing the illness into the family”.

After the death, the mother-in-law continues to accuse Aline: “They discussed it with my older sister, that since the time I married their son, I didn’t get any better, that her son also didn’t get better, that our child didn’t get better, so that it was me who brought the illness into the family”. But Aline’s parents defended her: “She is not someone who runs around, she would probably have become a nun if your son hadn’t proposed to her!” “So”, Aline continues, “since my parents spoke out, they have stopped; but then they started up again, saying that he was living with a girl before he got married, that he had a child with her and that she died.” After taking a screening test, which turned

out positive, Aline decided to tell her mother-in-law, who replied “May God help us!” After her disclosure, Aline decided, on the advice of her parents, to remain in the compound of her parents-in-law. While she has not been banned from the family household, she has been dispossessed of most of the household goods.

As we have already seen, in associations with members who are both infected and affected, PLWHA have to keep their serostatus secret, which leads them to employ concealment strategies.

A 32-year-old woman, the mother of four children and belonging to an association, expresses her doubts about the discretion of another member of her association:

“Aside from E., no one else in the association knows me personally. How did I discover my HIV-status? My husband was sick, I learned that his first wife had died of AIDS. He also had diarrhea: after he died, I wanted to be tested. I discussed it with one of my friends, she is very attached to me, we do everything together, and she was worried. Why do you want to take the test? She asked me. Your son is nice and chubby (*it was after giving birth that she decided to test her serostatus*), what are you afraid of? I insisted and she spoke to her brother who is a counselor at an anonymous screening and information center (CADI). I went to see him. I didn’t even have enough to pay for the test, I only had 250 francs and the test cost 500 francs. He agreed to do a blood test on me after asking a lot of questions. I said that I wasn’t afraid. He told me to come back for the results in 15 days; but it took me 30 because I got scared after the test.

“When I heard the results, I was shocked; I couldn’t say a word. I didn’t want to talk about it with anyone; not even with his sister (*the counselor’s*), who is my close friend; he told me it wasn’t good to hide it from his sister; so I told her.

“A few days later I went to an association meeting. At the meeting, the president of the association said that the association had signed an agreement with the screening center so that members of the association could find out their serostatus, that any woman who was interested should give her name.

“E., who had asked me to take the test after the death of my husband, signaled me to put my name on the list for the test. I gave my name, my stomach in a knot; I didn’t want to tell her that I had already taken the test and that it was positive. That day, they said that there was a counselor for individuals who were infected or who needed to talk to someone confidentially; so I went to meet with the counselor. I told him that I had already taken the test and that I didn’t want to go back there; but I didn’t want to disappoint E. either by telling her I didn’t want to do it. I didn’t want to give her my results either because E. can’t keep her mouth shut; she told on a woman who lived in the neighborhood (*she disclosed her results*). So I said to the counselor that I didn’t want E. to know; since I wanted to see him again without arousing E.’s suspicions, he gave me an appointment elsewhere. These meetings helped me to understand certain things.”

One day when the counselor was seeing people in his office on the association’s premises, while she was waiting her turn, a group leader who knew her went into the office and told the counselor: “she’s a member of the association; she lost her husband to a disease which looked like AIDS. X, who is her neighbor, tried to get her to come and take the test. Her husband died of AIDS. She herself had severe health problems especially during pregnancy. Today she is sick, persuade her to



take the test, it is important that she learns how to take care of herself.” Later, during the consultation, a dialogue takes place between the patient and the counselor:<sup>13</sup>:

“- So, you’re here to take the test?

- She (*the group leader*) came by to check on my health and then she asked me again to take the test. Can I tell her that I know my results?

- I don’t know.

- Her sister was sick; she sent her to the village to get medical care. She had her take the test. When she learned her sister’s results, she let it be known. I would like to tell her, but how can you trust her in those circumstances? I still think she wants what’s best for me. When I think of that, I say to myself that I shouldn’t hide anything from her. It’s thanks to her that I am being treated: before, I took whatever medication I could get my hands on; that gave me diarrhea; so she helped me live longer. I think that she has been honest with me; she supports me.

(After a moment of silence, she asks me to call in the group leader. I asked her some questions about her social environment; after some hesitation, she maintained that the decision to tell the investigator about her status was a good one; as soon as the investigator came into my office, I noticed that the consultee was a little embarrassed; she lowered her head; she asked me to explain the situation. I explained to the group leader that the consultee had already taken the test at CADI a while ago; only she had not had the courage to share her serostatus with anyone, not even the members of her family). ‘It’s a bad neighborhood; I don’t want anyone to know that I am sick’, she said, wiping away her tears.”

#### *Managing disclosure to fellow association members and the outside world*

Disclosure of status is not systematic within associations attached to health facilities (anonymous screening and testing centers, maternal and infant health clinics, hospitals). It is easier to reveal the information in the context of a personal relationship – having first assessed the risk of stigmatization. However, other criteria justify the use of strategies for retaining information on a person’s seropositive status.

Corinne, 35 years old, is single and mother of a small boy. She is an active member of an association. At a charity run held in Bobo-Dioulasso on 7 April 2001, she appeared in public and made a tearful speech. While the words left no doubt about her precise seropositivity, her tears raised some questions about her precise serological status.

“So everyone was left in doubt; people said that I had gone public, others said I hadn’t and that I cried out of pity, each one had their opinion, and ... I believe that two weeks after the charity run, B.D. (television presenter), who invited me to Ouaga, during a broadcast on AIDS with Doctor P.T.S. and S.M. (*the first person to reveal AIDS publicly in Burkina Faso*) and other members who are involved in the struggle were there. And during the questions, she showed the charity event and asked me whether or not there had been criticisms, what impact that had on me, afterwards she wanted to know my serostatus and I couldn’t, I told her no! I wasn’t going to answer that.”

When she is questioned about her reluctance to make an explicit public disclosure, she explains:

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<sup>13</sup> As reported by the counsellor.

“A public disclosure. Well! I often ask myself the question. Most often what stops me, the thing that stops me from going public is the fact that I come from a rather poor family, I have a child who is not recognized by his father, so the child is my responsibility, then I had a boyfriend who helped me a little, just a little, well I tried to persuade him, to convince him to take the test, but he didn’t want to. He didn’t want to and, well, he left. He always used to come and hassle me, he wanted to know why I am in the AIDS movement, why I didn’t look for other work. Myself, I don’t work, I have to live, if it happens that ... I have had two or three boyfriends in Bobo here, and sexual relations at least with a few who didn’t use any protection. So I tell myself that if I went public just now, then I might make an enemy. Really, I don’t know; what I have in mind are all those constraints.”

The spheres in which individuals are willing to go public are therefore limited. A charity run is a restricted social venue whereas a television program is broadcast to a wide audience. For another woman, belonging to the association and being involved in the combat against HIV/AIDS also means worrying about protecting the reputation of her seropositive husband, who has a profession of some social standing. Membership in a PLWHA association does not rule out strategies for controlling information in the various social spheres.

The cooperation between PLWHA associations and health workers pursued in Bobo-Dioulasso since 1995 has led to a significant improvement in medical and psychosocial care for PLWHA.<sup>14</sup> The almost daily presence of members of PLWHA associations within some clinics – in this case, the medicine and pneumonology unit of the national hospital center of Bobo-Dioulasso – helps to lighten the heavy burden shouldered by health workers dealing with HIV patients.

Given the difficulty of disclosing seropositive status, the presence of associations within the hospitals is a means of overcoming the problem of “unregulated screening”, in which the results are not divulged to the patient. The involvement of associations has helped forge a chain of confidentiality between patients, caregivers and association members, enabling an effective screening, disclosure and treatment strategy to be put in place. Yet family members are hardly ever involved in the chain. How is it possible to combat HIV/AIDS and its social consequences effectively if the patient’s family is excluded?

## Conclusion

AIDS is rife in contexts beset with economic difficulties. Access to antiretroviral drugs remains problematic for most sufferers. The way HIV/AIDS patients are looked after from the standpoint of the social environment reveals a growing trend of individualism in African societies, a consequence of the economic crisis affecting many African countries: “People are searching for themselves; families do not want to invest in a sick person who, as they see it, is going to die”. The stigmatization of seropositive individuals can thus be seen as a mark that disqualifies them with respect to social solidarity. As regards family relations, the seropositivity crystallizes family tensions pre-dating the disclosure of serostatus (due to the behaviour of the seropositive individual in anticipation of rejection). For women who remain in the family household, relations with their brothers often become strained.

Associations are not without their social constraints either and must cope with the problem of stigmatization. Their members are daily confronted with the spectre of shame and develop reflexes that anticipate stigmatization. Widows, whose property has often been looted by the families of their

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<sup>14</sup> In an article (1999), N. Meda emphasizes that of a total of 400 physicians in Burkina Faso, less than 10% are involved in counselling or the disclosure of serology results.

deceased spouse, join associations but do not bring charges for fear of the consequences. The future of children is a permanent concern in a time of AIDS. Dealing with the serological status of children is still problematic, even for members of associations. It is difficult to get a screening test done on a child, and this is hardly foremost among the concerns of PLWHA. On the contrary, an almost total silence continues to reign, almost certainly reflecting a reluctance to know the serological status of the children of PLWHA.

“I don’t really want to know the serological status of my children. I have AIDS, that’s already an enormous burden, I don’t want to think about the idea that my children might be infected, I prefer not to know” (35 years old and father of two children).

Interactions do not take place between, on the one hand, individuals “shameful” of their HIV infection and, on the other, those who are “without shame”. Stigma is a social construction, shaped in a context of social relations:

“... the notion of stigma does not so much imply the existence of a set of particular individuals who can be separated into two columns, the stigmatized and the normal; but rather the effect of an omnipresent social process that causes everyone to have two roles, at least in some respects and at some phases of life. The normal and the stigmatized are not persons but points of view. These points of view are socially generated interactions in contacts between mixed groups, as a result of unsatisfied norms that influence the encounter.” (Goffman, 1968, p. 163)

In short, the internalization of fragility (in relation to sexuality, power, and gender) is present within associations. It is important here to stress that the social consequences of discovering seropositivity vary depending on whether the infected individual is well or ill. It seems that shame of the family is greater when it learns of the seropositivity of one of its members if that person is already ill. In this case, it is as if they were confronted by a failure: “people lose hope”; some people come to visit out of curiosity, just to see the physiological effects of AIDS. Out of shame for their appearance, some AIDS patients do not want to be seen by other people: “Others will laugh at me!”.

The shame arising from the discovery of seropositivity is governed by a process of communication (direct and indirect<sup>15</sup>) that is instrumental in the social degradation of the individual. Associations are scarcely exempt from this phenomenon.

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<sup>15</sup> Rumours play an important role in the communication process. As a female patient belonging to an association put it: “people are looking at me, they are whispering ... people have been criticizing me ...”.

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# HIV/AIDS-related Stigmatization in Chinese Society: Bridging the Gap between Official Responses and Civil Society<sup>1</sup>

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To understand the contradictions in Chinese society with regard to the prevention of HIV/AIDS, one has to be aware that three systems of representation and practice coexist within this society. It is in a paradigmatic context of pluralism that values, behaviour and action are negotiated: the first system derives from Chinese tradition; the second system was introduced by Marxist ideology and nurtured the ambition of constructing a socialist society; while the third system may be associated with the global – “globalizing” or “globalized” – model with which China, like the rest of the world, is today confronted. Denial of the epidemic for over a decade was the product of a silence imposed by Chinese tradition and by socialist ideology. These consensual silences – motivated by the desire to “save face”,<sup>2</sup> and by the vision of a socialist Utopia – were finally broken by the mounting “global” pressure as the epidemic came to assume crisis proportions. In everyday life, the resulting tensions find expression in the stigmatization not only of HIV-infected individuals and their families and communities, but also of sympathizers and activists, whether acting independently or within social organizations.

In China, as in most regions of the world, stigmatization may be seen as one of the major obstacles to the prevention of the HIV/AIDS epidemic. It has perceptively been noted (Goldin, 1994) that the AIDS-related stigma epidemic ultimately has a greater impact on society and population at large than the disease itself. Moreover, although China has adopted strict laws forbidding discrimination against people living with HIV, the severe stigma attaching to patients – rather than to the illness – remains the most urgent problem they face at the stage of asymptomatic seropositivity (E. Rosenthal, *The New York Times*, 14 January 2003).

To grasp the phenomenon of stigmatization in Chinese society, it is necessary to refer to the social and political context and to the ways in which civil society is organized in relation to the State. I shall make particular reference to the network of local associations constituted by the “Government-Organized Non-Governmental Organizations” (GONGOs), the way they function, and their cooperation with international organizations and NGOs. The GONGOs – a term initially proposed by G. White et al. (1996) – may be regarded as institutions mediating between national and international institutions. We shall also focus on the relations between national and local authorities, which can explain some of the barriers to the implementation of prevention policies.

My article begins with an overview of the context of the epidemic and of the epidemiological data in China, based on the latest UNAIDS country report (2002). It then focuses on three themes: firstly, the notions of stigma, deviance and discrimination are discussed in order to provide a theoretical framework for analyzing the forms of stigmatization affecting people living with HIV (PLWHA). I go on to highlight the importance of cultural factors, beyond the impact of social and political factors, that need to be taken into account in drawing up national prevention policies. Two

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<sup>1</sup> I wish to thank Alice Desclaux for reviewing this article.

<sup>2</sup> A notion fundamental to the social psychology of individuals of Chinese origin: the principle underlying behaviour in face-to-face interactions aimed at gaining social approval. A shared awareness of the risk entailed by social contact, which prompts individuals to support each other in order to preserve the public image of all parties involved. See Zheng Li-Hua, 1995, *Les Chinois de Paris et leurs jeux de face* [*The Paris Chinese and their face-saving games*]. Paris, L’Harmattan (“Logiques sociales” coll.).

examples will illustrate the vulnerability of certain social groups: sex workers<sup>3</sup> and poor “blood-selling” farmers. Finally, I examine the means that exist to combat stigmatization, ranging from national laws to local regulations and including action by local organizations.

## Context of the epidemic

In Asia and the Pacific, 7.1 million people are estimated to be infected with HIV, with a 70% increase between 1996 and 1998. The Mekong River Basin (continental South-East Asia) displays the highest increase. The low seroprevalence rates in many countries of the region are misleading: they mask localized epidemics in certain regions, particularly in the most highly populated countries of the world, China and India.

According to the Chinese Ministry of Health, China has entered a phase of rapid expansion of the epidemic since 1998. In December 2001, the number of HIV-infected people was estimated at 600,000 whereas only 30,736 people were officially registered as HIV-positive – and this official figure had increased by 70% during the first half of 2001. In April 2002, official Chinese estimates were revised upwards, bringing the number of people likely to be infected to 850,000. Most national and international experts, however, consider that over one million people (up to 1.5 million) are probably infected. By 2010, according to the Chinese Ministry of Health, 10 million people – some experts speak of 20 million – could be HIV-positive if effective prevention measures are not implemented (UNAIDS, 2002). Ten per cent of registered HIV carriers are teenagers. A national survey conducted by the health authorities indicates that 60% of young people are uninformed or ill-informed about the disease, and that approximately 21% have absolutely no knowledge of prevention methods.

People have tested HIV-positive in all the provinces, autonomous regions and municipalities. Four of the six provinces where the epidemiological situations are most alarming are southern regions (Yunnan, Sichuan, Guangxi, Guangdong), the other two being the province of Xinjiang (North-West China) and that of Henan (central region). In Guangxi, HIV infection rates among sex workers rose from 0% in 1996 to 11% in 2000, suggesting a large increase in sexual transmission of the disease.<sup>4</sup>

The main practices giving rise to contamination are the sharing of infected needles, and unprotected heterosexual and homosexual intercourse. The epidemic is initially spread by sharing needles for drug use, then by heterosexual transmission, following epidemic models identical to those in Thailand, Vietnam, Burma and southern China. In some regions, the transfusion of HIV-infected blood products also results in contamination.

A vulnerability factor for HIV is internal and external (cross-border) mobility, facilitated by the circulation of goods and persons, and by economic integration at the regional level in East and South-East Asia, and by rapid and uneven development at the international level, resulting in the coexistence of prosperous regions with pockets of poverty. The mobility of those involved in the sex industry (sex workers, clients, owners of the various premises where the sex industry develops, procurers, traffickers, transporters, authorities, etc.) is an additional vulnerability factor.

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<sup>3</sup> I shall not use the term “sex professionals” because it is today a well-documented fact that most of those concerned work in the sex industry for a short period of their lives (16-25 years in the contexts in which I researched on the subject in East Asia: China, Taiwan, the Republic of Korea) and that some people engage in prostitution on an occasional basis. The term “sex worker” is much more appropriate. My study does not include data on male sex “workers” although they represent a non-negligible proportion of the sex industry.

<sup>4</sup> Press release: “New UNAIDS Report warns AIDS Epidemic still in early phase and not levelling off in worst affected countries”, July 2002.

With regard to the vulnerability of ethnic minorities, this is now officially recognized, but prevention policies remain ill-adapted to the specificities of these minorities. There is a continuity of cultures – through ethnic, linguistic, cultural and historic links – between the “mountain” populations of southern China and continental South-East Asia. These links facilitate cross-border population mobility. Furthermore, relations between ethnic majorities in the “plains” and minorities in the “mountains” play a part in the construction of national identity. Spatial distribution and space and environmental management have an impact on health policies and epidemic prevention strategies in the fields of education, information, screening and patient care. Yet these factors are still taken into account very little if at all in official responses to the AIDS epidemic risk.

The virus is spreading throughout the population, and China could experience an epidemic disaster that would entail colossal economic losses and social chaos. The government response has so far been rather ineffective: following a period of denial, the authorities are showing a lack of openness, and a relative absence of political will.

The June 2002 UNAIDS report previously mentioned identified other vulnerability factors: a crumbling public health system – which in practice means the exclusion of many people from the health care and prevention system – and severe stigmatization of AIDS patients. Despite the rehabilitation measures taken by the Chinese Ministry of Health at the end of the 1980s, the rural health system has deteriorated inexorably in poorer regions. The Peking health authorities are aware of the problem and are trying to put forward solutions aimed at restoring universal access to quality health care. Unfortunately, such instructions often go unheeded in the regions. Indeed, the central State has less coercive power in the regions because they are self-financed and do not always have the means of implementing high-cost measures (Cailliez, 1998). From a more global perspective, White (1998) attempted to model social protection reform in China and questions the existence of a specific state assistance model in East Asia.

## **Stigmatization and social vulnerability of PLWHA**

*The notions of stigma, discrimination and deviance: a theoretical framework for the analysis of stigmatization phenomena*

I will begin by referring to the ordinary definitions of these notions found in a dictionary (Larousse, 1991): “A stigma is a lasting mark left by a wound, a disease”; “To stigmatize is to condemn, to reprimand severely and publicly. Literally, it is a trace, a mark that reveals a degradation”; “Discrimination is the action of isolating and treating certain individuals or an entire group differently from the others”; “To discriminate is to establish a difference, a distinction between individuals or things”.

Carrying a stigma or adopting behaviour perceived as “deviant” gives rise to discrimination against an individual or a group, which itself generates forms of marginalization. Indeed, being marginalized means “being placed on the margin, set apart”. Marginalization processes tend to exclude from society, thereby posing a threat to the social integration of certain individuals or groups. Deviance – which is suggestive of hostility, punishment and stigma – is another term used to marginalize certain groups. Persons perceived as “deviant” might become scapegoats in the context of epidemics experienced as social afflictions.

E. Goffman (1975) was the first to develop a theoretical framework for the study of stigma from a social science perspective and to conduct research on the social functions of disability. Before

acquiring its current meaning, “stigma” was originally used by the Greeks to designate marks inscribed on a person’s body in order to expose something unusual and reprehensible about their moral status (Goffman, 1975, p.11). Three types of stigma may thus be distinguished:

“First there are abominations of the body – the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior. Finally, there are the tribal stigma of race, nation, and religion, these being stigma that can be transmitted through lineages and equally contaminate all members of a family.” (Goffman, 1975, p. 14/p. 4 in “Stigma: Notes on the Management of a Spoiled Identity”, latest edition – 1986 (first edition – 1963).

Stigma and deviance are qualifications that involve questions of degree: they are not categories *per se*. From an interactionist perspective, the stigmatized individual is not a person but a point of view, which is a social construct. That is why the status of the “stigmatized person” may change. Applying this to the issue in question, the stigma attached to people living with HIV and their relatives can be transformed and even eliminated through appropriate information and educational measures – that is to say, measures that take into account the findings of research on the interactions between normal and stigmatized individuals (character stigma) and between normal and stigmatized groups (tribal stigma), and which endeavor to bring about changes of viewpoint. These changes could help to deconstruct stigmatization.

It must however be stressed that stigmatization processes appear to have a more general social function: to induce those not having the support of society to adhere to social standards. These processes are thus structurally resistant to change. They may also have other social functions depending on the type of stigma: for instance, the stigmatization of certain individuals who become scapegoats may be an instrument of official social control (Goffman, 1975, p. 161).

#### *The facts of discrimination, screening and HIV patient care*

Looking beyond the local representations and constructions of disease that underlie discrimination, our intention here is to refer to specific examples of discrimination in everyday life and their consequences for prevention. I have dealt elsewhere with the theme of the Other as the main vector of HIV/AIDS at the symbolic level and as a fundamental category of the social construction of disease, in both the Chinese context and other cultural contexts.<sup>5</sup> The aim is also to identify emerging structural trends in institutions and certain social groups that may strengthen HIV-related discriminatory practices. These trends can be observed within the selfsame official institutions and social organizations involved in the fight against AIDS.

For instance, “high-risk groups” are consistently singled out in informational and educational materials, and also by individuals involved in the fight against HIV/AIDS, whether working for associations, official organizations or health facilities. Epidemiological studies may thus encourage

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<sup>5</sup> The term “Other” was used in a generic sense, to include all strangers and “those who are strange” from the standpoint of the social and cultural representations of Chinese populations (Han), and thus referred to ethnic, sexual and social minorities. E. Micollier. 1999. L’Autre porteur originel et/ou vecteur privilégié du VIH/SIDA (Chine populaire-Taiwan) [The Other: Original Carrier and/or Main Vector of HIV/AIDS in the Cultural Representations of the Chinese World (The People’s Republic of China – Taiwan)]. Journal *Autrepart*, No. 12, “Le SIDA des autres. Constructions locales et internationales de la maladie” [Other People’s AIDS. Local and International Constructions of the Illness], directed by C. Fay. Éditions de l’Aube/IRD, pp. 73-86.



discriminatory discourse with regard to HIV-vulnerable populations by the mere fact of distinguishing them from the rest of the general population (Farmer, 1996; Dozon and Fassin, 1989).

Instances of stigmatization have been reported in the international and Chinese press since the publication of an article by Elizabeth Rosenthal in the *New York Times*,<sup>6</sup> raising for the first time the problem of the Henan villagers infected by blood-borne HIV transmission. Such phenomena are recognized as a vulnerability factor in the official reports of UNAIDS-China. Fear and discrimination are major obstacles to the implementation of prevention policies. At the beginning of the national prevention campaign launched in the 1990s, messages addressed to the general public exploited the fear factor to encourage preventive behaviour. Today, the risk of discrimination and stigmatization directed at HIV-infected people, compounded by fear of the disease, is acknowledged by the authorities. Official regulations condemn discriminatory behaviour and language.

However, information remains scarce, and counseling and healthcare provision is still unavailable to the vast majority of the population. In such a context, “high-risk groups” easily become scapegoats. The essential objective must therefore be to raise awareness among the population so that it comes to perceive “the self as contaminating” rather than always seeing “the other as contaminating”. In practical terms, screening tests should be perceived as relevant for the future of the individual and his or her relatives. Unfortunately, a number of press articles (mentioned in the UNAIDS report) have reported that people testing HIV-positive run the risk of losing their jobs,<sup>7</sup> being excluded from school,<sup>8</sup> being rejected by their social community, being banned from their village or town,<sup>9</sup> not being allowed to marry, and not receiving any treatment into the bargain.<sup>10</sup> It is therefore understandable that nobody volunteers for testing.

These examples and my own field observations point to a considerable gap between official policies and actual practices – which is neither something new nor specifically Chinese. Laws against AIDS discrimination are applied unevenly depending on the localities, and have had a number of untoward effects, which are all the more visible since neither the authorities (in particular the local authorities), nor the health personnel, nor the general public are ready to accept so much as the notion of non-discrimination.

In this social context, anti-discrimination laws seem totally inappropriate and meaningless for the vast majority of the population. Each national law prohibiting discrimination is matched by a local regulation that contradicts it: for example, local regulations (provincial laws, and municipal, cantonal or district regulations) prevent HIV-infected persons from getting married, continuing to work or using public swimming pools (Rosenthal, 2003). The police tend to issue warnings to companies run by HIV-positive individuals, and to seize their goods. Since they are not bound by a code of practice protecting patient confidentiality and anonymity, certain doctors disclose their patients’ serological status to their employers. It should be noted that of the 10 principles on which there is consensus in China and which sum up the content of current medical ethics, not a single one concerns patient confidentiality or anonymity.<sup>11</sup> As for medical staff, they refuse to provide patient care for fear of contamination – indicating a lack of information on methods of protection but also the

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<sup>6</sup> 28 May 2001.

<sup>7</sup> M. Liu, M. Meyer. *Newsweek*. 30 November 2000.

<sup>8</sup> L. Chang. *Wall Street Journal*. 23 March 2001.

<sup>9</sup> M. Liu, M. Meyer. *Newsweek*. 30 November 2000.

<sup>10</sup> D. Rennie. *Daily Telegraph*. 7 December 2000.

<sup>11</sup> I.P. McGreal analyses comments and discussions in China concerning the principles that distinguish present-day Chinese bioethics from traditional medical ethics. He refers to the work of Shi Dapu: *Recherche en bioéthique et l'éthique médicale en Chine aujourd'hui* [Bioethics Research and Medical Ethics in Present-day China] and “The Rise and Progress of Chinese Medical Ethics”. See I.P. McGreal. 1991. The New Dimensions of Chinese Medical Ethics. *Journal of Chinese Philosophy*, No. 18, pp. 161-168.

unavailability of these methods. For instance, some surgeons refuse to operate on HIV-positive patients.

E. Rosenthal relates the story of a group of seven people living with AIDS who simply wished to share accommodation. She describes their forced wanderings: evicted from legally rented temporary accommodation, the individuals were, on each occasion, compelled to leave the district in which they lived. They were not welcomed in any district, and no landlord would agree to accommodate them, even in a town as dynamic and cosmopolitan as Canton. In the course of my field studies in Taipei in 1997, it emerged that HIV-positive people wishing to live together faced the same problems as in Canton. From the moment their serological status was known, they were hounded from their accommodation and district. All the inhabitants questioned in the area spoke in similar terms of the risk of lowering the value of the property. They placed the emphasis on financial and economic loss rather than the moral stigmatization of the Other. Might this not simply be a cover – an argument that, in the context of the globalization of Asian societies, passes as being more “politically correct” than a moral and moralizing discourse?

Whatever the case, if we are to believe official policies pursued in Canton against discrimination towards HIV-infected people, this group of seven HIV-positive individuals, representing a model of mutual help, should have been encouraged in its approach: the Guangdong province “Medium- to long-term plan for AIDS prevention and control” stipulates that private associations and organizations should be supported because they have a role to play in reducing the discrimination experienced by AIDS sufferers, HIV-positive individuals, their families and relatives. In practice, these measures – prescribed in administrative documents that are often vague as regards ways and means of implementation – remain a dead letter.

On the basis of case studies conducted in West Africa, particularly Burkina Faso, Alice Desclaux (1996) has shown that discrimination – when the problem is recognized and taken on board by the institutions involved in the fight against AIDS – is addressed in exclusively ethical terms, which seriously limits the possibility of changing discriminatory behaviour and language. Indeed, the same ideas concerning infection persist, such as the preconceived idea – very widespread, including in medical circles and among associations involved in combating AIDS – that the cause of infection has to do with individual behaviour and is therefore a matter of individual responsibility (Desclaux, 1996, p. 271). This idea helps reinforce guilt feelings among HIV-positive individuals. The same observation can be made concerning the treatment of discrimination by Chinese institutions. A. Desclaux has looked into the role that anthropological research could play in combating HIV-related discrimination: anthropology can help to expand our thinking on discrimination by taking it beyond the confines of ethics. What is needed then is to refocus analysis of discrimination and stigmatization, and the way in which they are dealt with, on the realm of social and human reality in its complexity – in the direction of an analysis of social relationships that takes account of all the actors and their interactions, gender and power relations, and institutional and political factors.

Concerning access to antiretroviral drugs, China still refuses to declare a health emergency, which is an essential precondition for obtaining authorization to produce generic drugs. Indeed, China is one of the developing countries that have the technological capacity and industrial infrastructure to produce generic drugs locally. Yet the authorities continue to favor direct negotiation with patent-holding multinationals to obtain cheaper drugs.<sup>12</sup> In the meantime, whether declared or not, the health emergency on the ground remains very real for sufferers and their relatives.

Care facilities and programs for PLWHA are almost non-existent in China. They still take the form of small pilot projects launched by international NGOs active since the beginning of the epidemic, such as Save the Children Fund and the Australian Red Cross. The majority of HIV-infected people

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<sup>12</sup> Situation in January 2003.

are treated by the medical personnel of the Epidemic Prevention Stations, and by hospital staff treating infectious diseases assigned by the national health authorities to look after HIV. It should be stressed that psychosocial care is neglected, that there are still only very few networks for HIV-positive people and no home healthcare facilities.<sup>13</sup>

In Beijing, two support structures for HIV-positive people were set up in 1998. The Home of the Red Ribbon is part of Ditan Hospital, which was designated as the referral hospital in China for HIV/AIDS treatment and research. Clinical research carried out both on biomedical antiretroviral drugs and traditional Chinese medicine – and in particular pharmacopeia – are conducted there in cooperation with the Ministry of Health Center for AIDS Prevention and Control.

The other support structure is the Home of Loving Care within You'an Hospital: this home provides medical care and psychological support to hospitalized or outpatient people living with AIDS. To the extent possible, it also fulfils an information role with regard to patients' relatives and families. It has the status of a GONGO, dependent on the Chinese Association of STD and AIDS Prevention. This social organization plays an active role in combating HIV-related discrimination.<sup>14</sup>

### **Vulnerability to HIV in two social groups: sex workers and poor “blood-selling” peasants**

#### *Management of the sex trade*

The sex trade forms an amorphous informal sector and those involved in the sex industry are mobile as regards the way they enter and leave the sector. Perceptions of the commercial exchange of sex and of the people participating in it vary according to social group, region and the local dynamics of social, economic and political relations. The way society is stratified is reproduced in particular in encounters between sex workers and their clients: at the two extremes of the broad spectrum of the sex trade, well-off clients meet high-class prostitutes in urban areas, or keep “second wives” or “concubines”, whilst poor migrant peasants live with a woman, often a migrant herself, “recruited” by and for a group of men, who provide her with board and lodging but not a wage in exchange for a number of services including sexual services (Pan, 2003).

The sex trade seems to be at the heart of the “sexual cultures”, a traditional model still widespread in China, a country which is moreover experiencing revitalization with the emergence of a comfortably-off middle class and the reappearance of an economic elite (Micollier, 2003). Throughout the history of Chinese civilization up to the present time, one finds that paid sexual exchanges have increased as men have become richer.

The concept of “sexual culture” refers to a complex configuration of ideas, behaviour and affects linked to sexuality. It is a social construct that takes shape in an open and dynamic set of social, political and economic relations. Within a given community, it is an affective model of emotional states and a consensual model of ideas associated with sexual conduct, underpinned by values and moral principles concerning the nature and purpose of sexual relations, which institutionalizes what is felt by the group to be “normal, natural, necessary or approved” (Herdt, 1997, p. 10).

This “contextualization and conceptualization” is a tool enabling the HIV risk faced by certain categories of the population and by the population as a whole to be more accurately assessed. I will take as an example the “sex worker” category, which was initially described as an “at risk group” and is now described as “a group with increased vulnerability to HIV”, according to the international

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<sup>13</sup> UNAIDS Report, *op. cit.*, p. 22.

<sup>14</sup> *Ibid.*

terminology adopted by international bodies and NGOs. At the beginning of the Chinese national AIDS-prevention campaign in the 1990s, sex workers were called “women in crisis” in brochures and information sheets aimed at them. The use of discriminatory language thus came from official Chinese agencies.

Such language was tolerated in silence by the official international agencies working with them to set up the national campaign to combat AIDS. The information brochures were designed and distributed with the backing of international donors, and they were even translated into English. At that stage in the campaign, at a time when the risk of an epidemic was denied by the Chinese authorities, it was impossible to criticize this cultural and local re-appropriation of prevention. The risk for the international agencies was that they would no longer be able to work in China in that field if the timid national response was the target of criticism by foreigners.

The official position at the time was that prostitutes should be re-educated. They were never regarded as the victims of an all-embracing system, an attitude which could have led to a change in legislation, as the Dutch example shows. Indeed, the Netherlands is perhaps the only country where recognized sex workers have the same rights as other workers, are organized in trade unions, and ply a trade that was recently completely legalized (2000). In Amsterdam’s red light district they can even call the “condom police” if clients refuse to wear a condom or subject them to violence.

In China, as in most countries, the sex trade is banned by law. The Decision of the Standing Committee of the National People’s Congress Prohibiting Prostitution (1991) stipulates that trafficking in human beings and prostitution are illegal activities. Responsibility for supervising the application of these decisions lies with the police. Sex workers are not registered and are only obliged to undergo health checks when they are arrested. There are a large number of re-education centers for sex workers and their clients in China (Fox, 1997, pp. 6-7).

The discrimination lies in the fact that “sex workers” are not protected by the State, which does not take effective measures to limit their vulnerability. The existence of the re-education centers serves ultimately only to increase their vulnerability by encouraging them to remain underground in order to avoid sanctions. The same problem arises for “blood-selling” peasants, who have not been protected but on the contrary rendered more vulnerable by a State that for many years did not prohibit – are, indeed, tacitly encouraged – “blood smuggling” in certain regions of China by buying up the blood for official health structures and drug production.

#### *Management of blood donation: blood-related representations and practices*

Representations of the body, and in particular of body fluids including blood and sperm, and the practices associated with them go some way to explaining the scale of the “blood donation scandal” in China. These practices and representations are cultural factors that must be taken into consideration in managing the HIV/AIDS epidemic risk.

Hundreds of thousands of peasants in the impoverished regions of central China such as Henan have been infected with HIV by the practice, widespread in China, of selling blood. According to estimates by UNAIDS and experts from various national and international organizations, between 100,000 and 500,000 people from Henan Province have been contaminated after selling their blood in ways that disregard the basic rules of hygiene.

The illegal trade in blood in China is controlled by mafia-style groups called “bloodheads” and is still rife despite the sanctions of the Chinese authorities: selling one’s own blood has been a criminal offence for five years now. Nevertheless, the chronic shortage of blood products in hospitals and

pharmaceutical laboratories producing drugs using blood products forces them to carry on buying blood on the black market. Poverty has prompted many peasants in the central regions of China, in particular Henan and Hebei Provinces, to sell their blood illegally in deplorable hygienic conditions: the use of contaminated syringes is widespread and the blood, stripped of therapeutically useful substances, is injected back into the donors. Blood donors are thus highly vulnerable to the spread of HIV and to other infectious diseases passed on through contaminated blood, such as hepatitis C. The risk of an epidemic has been ignored by the health authorities: the transmission of HIV through blood is a taboo subject in China even though for a few years now UNAIDS and the Ministry of Health have identified pockets of blood-transmitted HIV infection and consider that they should one day be acknowledged in order to control them. The issue is now recognized as a public health problem, but is substantially downplayed and thus still denied to some extent. The Law on Blood Donation of 1 October 1998 stipulates that blood for clinical transfusions must come exclusively from unpaid volunteer donors.

The ban on the donation of body fluids, substances and parts is a permanent taboo in Chinese societies. The majority of the Chinese population would refuse to give blood, an indicator of the power of traditional representations of blood stemming from Confucian or Taoist conceptions of the body. Respect for the integrity of the body is a key notion in these representations. Blood is considered to be a substance obtained by the transformation of matter from sperm (*jing*) and life force (*qi*). Blood is thus associated with biological reproduction, with all that that implies and the emotions that crystallize around it.

Furthermore, the donation or sale of blood is a gender-linked practice associated with representations that are likewise subject to categorization by “social gender”: one finds that women are more often delegated by families to give blood. I will suggest two possible reasons why, which are still at the hypothetical stage and might be confirmed by specific surveys and analyses of the subject: (1) men’s blood is considered to be more precious, given the widely held idea that their blood is obtained from the transformation of sperm; (2) in any event, women lose blood during menstruation and so their bodies are ineluctably and inherently in a state of “unstable or ephemeral integrity”, according to a local essentialist perception.

Moreover, once the blood has been stripped of substances used in drug production, it is injected back into the “vendors”, a practice, as I have already stated, with serious implications for the spread of HIV, but which is linked to a local conceptualization of the body: it is “restored” to people, possibly also out of a residual respect for the integrity of the body.

### **Means of combating stigmatization: Chinese social organizations, civil society and responses to AIDS**

I shall begin by outlining the nature, legal status and functioning of social organizations in China, and their activities and ties with official agencies, taking as my reference a study by Michaela Raab (1997), based on field surveys of these organizations and describing the actual situation in society, rather than Tony Saich’s analysis, which attempts to provide a conceptual model of the nature and functioning of social organizations in China (a perceptive study that deserves to be mentioned but whose critical analysis goes beyond the framework of this paper).

Ms Raab’s study was carried out in 1996-1997 among 60 urban groups involved in social development. One of the main findings was that the structural links of social organizations with the government did not impede their operational autonomy. On the contrary, they can have a mediating role that may go as far as calling government action into question:

“Most of the groups studied seemed to owe their existence mainly to their ability to get through to the marginal social groups that government agencies have considerable difficulty reaching. In 1996, some 200,000 social organizations were registered at the Ministry of Civil Affairs at all administrative levels. Of these, only a few dozen – most of them not registered as social organizations – had a style of activism characteristic of NGOs.” (Raab, 1997).

Many groups have filled gaps left by bureaucracy and have sought innovative ways of narrowing the divide separating the State from society. The trend emerged in the 1990s but the number of social organizations stopped growing in 1996 when an official measure was adopted at the national level aimed at halting the movement, a sign that the authorities perceived it as a potential risk.

Social organizations may be divided into five categories with sometimes imprecise boundaries: private clubs and salons; service-oriented associations (GONGO); research centers; networks and forums (GONGO), and activist, informational or educational institutions. It should be noted that these categories are used above all heuristically for the sake of analysis and may unfortunately be less relevant in the field as one organization can fit two or three categories.

GONGOs operate as a sort of “government charity” that goes beyond fund-raising for government services. For instance, young volunteers are asked to look after impoverished senior citizens by visiting them on a regular basis. Rural development groups based in an urban setting provide other services. They have received funding from abroad to alleviate poverty in China and can override administrative divisions by working directly with the canton or municipal authorities whilst maintaining links with official decision-makers at a higher level. University lecturers and other academics have also created non-governmental groups working in the public service sector: they provide services and at the same time conduct “research-actions”, whose results are often used for activist, informational and educational purposes.

Chinese networks provide a link between State employees and, to a certain extent, the work units (*danwei*) to which the members of the network belong and informal popular organizations that are not registered as GONGOs. They are well placed to circulate information to a variety of organizations and to train young people. The networks play an important role in areas of development that benefit from relatively easy access to foreign funding – for instance, HIV/AIDS prevention and environmental protection. They can be highly effective in building consensus around the promotion of certain measures, but they do not represent mass movements.

Lastly, activist, informational and educational agencies aim to work with the media. Although their methods differ from the more conflictual approach adopted by NGOs in other countries, they can be highly effective in achieving their objectives.

Despite the leveling-off in the number of GONGOs, the development of social organizations in China from the 1980s to the mid-1990s led many official agencies to work with these “satellite organizations”, also referred to by some observers as “less governmental organizations”.

The level of autonomy and social commitment of Chinese social organizations varies considerably. They refer to their relationship with the government in terms of cooperation. Activist groups stress that their main aim is to raise awareness of problems through information and education and not to put pressure on the government. International donors support many voluntary organizations of this type – for instance, those contributing to HIV/AIDS prevention under the auspices of the health authorities, and those involved in social assistance in cooperation with the Ministries of Civil Affairs, Public Health and Education. My own observations in the field, and the findings of Raab’s study confirm that the degree of operational emancipation depends on financial autonomy.

Despite the results achieved, links with the “mother” administration are not weakened: GONGO staff are paid by the government, and files on them (including information on the curriculum vitae of employees relating to work and their social and political involvement in mass organizations and neighborhood committees) are available to the administration. They even attend the same political meetings as their civil service counterparts.

However, forums tackle the awkward problems that have emerged with economic liberalization, such as migrant workers and urban unemployment, which the government would find hard to acknowledge and deal with officially. “In this way, pilot projects” in the field of social assistance have been launched by these voluntary groups. Let us take the sex trade as an example: whereas the sex industry is subject to frequent government measures aimed particularly at sanctioning sex workers, who are arrested and re-educated in detention centers, an association involved in HIV/AIDS prevention can very well enjoy a measure of tolerance from the authorities with regard to the promotion of condom-wearing by women, who should be denounced by a government agency for the illegal exercise of the sex trade.

Government organizations, GONGOs and other categories of Chinese NGOs are involved in the struggle against AIDS. Together with official international organizations (bilateral and multilateral donors) and international NGOs, they endeavor to put in place coherent national responses to the spread of HIV/AIDS. It is possible to identify three categories of social organization involved in this struggle:

- International NGOs such as the Ford Foundation, the Save the Children Fund, AusAIDS, Médecins Sans Frontières and Médecins du Monde are active in China. As the present article deals with Chinese organizations, I will not elaborate on the modes of operation and activities of these organizations.
- The “GONGOs”, which operate at three administrative levels: local, regional and national. Their specificity lies in the fact that they are linked to a government body organization acting as an umbrella-organization, and thereby have no legal status. For instance, the Jinglun Family Center of the China Association of Social Workers, a GONGO financially supported by the Ford Foundation, has introduced sex-education programs in colleges and universities in the six provinces and training courses for teachers and parents, in cooperation with the local education authorities and the local sections of the “National Women’s Federation”.
- Finally, academic NGOs play a particularly active role in combating AIDS. In China, they are referred to as “secondary organizations” (*erji danwei*) and are the result of individual initiatives. Examples include the China AIDS Network, the Beijing Preventive Medical Association, and the Institute for Research on Sexuality and Gender at Beijing People’s University. This institute is directed by sociologist Pan Suiming. Pan and his colleagues have conducted studies on ideas associated with sexuality and sexual practices among groups vulnerable to HIV infection and among the population at large (for instance, Pan, 1999; Pan, 2003).

The China AIDS Network is an academic organization which was set up following the mobilization of a medical faculty in the capital (Beijing Union Medical College). Research in the social and behavioural sciences has been carried out by teams or members of the network, who have studied, for example, practices among lorry drivers and the sex trade in hotels located along major highways in Hainan and Guangxi in South China (Liao Susu, 1998, 2000) and, again, the social and economic

impact of HIV infection in Ruili, in Yunnan, near the Burmese border, a well-known crossroads for drug trafficking (Micollier, 1998).

The Yunnan Provincial HIV/AIDS Network initiated a project by the “Yunnan Province Society for the Promotion of Cooperation with International Non-Governmental Organizations”. It publishes a newsletter, educational and information materials, and conducts information, education and communication (IEC) activities relating to AIDS.

Relatively independent initiatives related to AIDS education, often in association with health departments and academic institutions, have successfully mobilized the male homosexual community in China’s major towns. Such associative groups lead a marginal existence. Some of them have had to cease their activities, thus being forced into illegality after short periods of formal existence. The leaders and coordinators of such associations can end up on a sort of black list: they may face difficulties in finding a job as a result of their commitment to the fight against AIDS and their connection with homosexual groups (*A Human Rights in China Report*, 1997).

A program focusing on bioethical issues implemented under the aegis of the “Chinese Academy of Social Sciences” (Qiu, 1996) and funded by the Ford Foundation, covered the ethical aspects of AIDS, with the ultimate aim of providing guidelines for government policy. The program was coordinated by Professor Qiu Renzong, who is a philosopher by training. Qiu came out strongly against authoritarian methods: “If we cannot safeguard people’s rights, there will be no guarantee of protection in the sphere of public health”. Stigmatizing people infected with HIV or those belonging to vulnerable groups, or restricting their rights, will indeed drive the disease and its litany of problems underground, thus invalidating any attempt to introduce preventive and treatment measures.

It should be borne in mind that a series of contradictions, not to say oppositions, leads to conflictual situations between global international policies and local policies, on the one hand, and between national and local policies, on the other, with regard to regulations and practice. Such contradictions have to do with the relations between national and local power structures. They reflect the hierarchy of Chinese administrative units at national, provincial, municipal, cantonal, and district levels.

Nevertheless, it is important in the Chinese context, given the political and institutional factors we have mentioned, that international governmental and non-governmental organizations, Chinese national governmental, provincial and local organizations, and “Government-Organized Non-Governmental Organizations” (GONGOs) should work together. In spite of all the predictable obstacles, negotiations between all parties are indispensable upstream and downstream of the design and implementation of development projects. If no consensus is reached, external organizations run the risk of not being able to continue working in China for lack of the necessary authorization. Such a mode of operation may seem frustrating, restrictive and slow, but in the long term it may produce more results than in contexts where external organizations are seemingly subject to less restrictions on action.

Account should also be taken of the fact that resistance to the implementation of certain measures, and to certain ideas and methods in AIDS-prevention strategies, stems not only from the institutional and political sphere but also from civil society itself. At the base, it derives from families, from teachers who sometimes do not cooperate in sex-education programs for young people and from medical personnel, which itself has an information, educational and management role. Thus stigmatization phenomena must be managed within associations involved in the fight against AIDS. All these sites of resistance must be identified, understood, analyzed and taken into account in drawing up and introducing AIDS programs so as to discover appropriate means of reducing the discrimination affecting persons living with AIDS.



True, this “Chinese-style” operational model presupposes a structurally determined gradualism, and the validity of all these negotiations is questionable where the epidemic assumes emergency proportions. However, while a more brutal and less consensual adoption of development policies advocated by “politically correct” decision-makers (subscribing to the “global” system of practices and representations mentioned in my introduction), may lead to success in the short term, it does not necessarily do so in the medium or long term, even where such policies are initially taken up and supported by local stakeholders. In the end it may even prove counter-productive when subjected to critical scrutiny by the same or by other local stakeholders. Groups representing sites of resistance may feel manipulated by external forces. They then tend to find solutions corresponding to a literally applied traditionalist or fundamentalist model, whether religious or political. Social science research on AIDS in Africa has observed, demonstrated and denounced pernicious effects of this kind produced by AIDS campaigns, which are sometimes exclusively aimed at changing behaviour and ideas as rapidly as possible by enlisting the support of civil society stakeholders or the representatives of local authorities. In that connection, African examples have much to offer Asia region decision-makers, since the two continents are not at the same stage of the epidemic.

As regards prospects for the application of social science research in the health sphere, I have tried to show through this article that, in the case of AIDS prevention strategies, social science research tends to provide a more comprehensive understanding and knowledge of human and social reality since it does not separate the health field from other aspects of human and social reality. It endeavors in particular to take account of the complexity and diversity of economic, social and cultural contexts. In that connection, the field of health and sickness afford access to the social dimension in its totality. The contextualization of development projects is a prerequisite for their implementation in the field and increases the chances of realizing, in part at least, the goals being pursued.

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## **Annexes**

## ANNEX I

### Bibliography of participants (Recent publications related to the theme of the round table)

Alice Desclaux

- **Articles**

“Et si la pandémie de VIH/SIDA était une opportunité pour améliorer la pertinence des programmes de promotion de l’allaitement en Afrique” [What if the HIV/AIDS Pandemic Was an Opportunity to Improve the Relevance of Breastfeeding Campaigns in Africa]. *Cahiers Santé* 12, pp. 73-75. 2002.

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## Évelyne Micollier

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## Fatoumata Ouattara

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## Claude Raynaut

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## Laurent Vidal

- **Articles**

With K. Delaunay. “Le sujet de l'observance. L'expérience de l'accès aux traitements antirétroviraux de l'infection à VIH en Côte-d'Ivoire” [The Subject of Observance. The Experience of Access to Antiretroviral Treatment of HIV Infection in Côte-d'Ivoire]. *Sciences Sociales et Santé*, 20, 2, pp. 5-29. 2002.

“Évolution de la recherche sur le SIDA au cours de l'années 1990” [Evolution of AIDS Research During the 1990s]. *Transcriptase*, 98, pp. 20-21. 2002.

With P. Msellati. “Le SIDA dans les pays en développement: l'exemple de l'Afrique” [AIDS in Developing Countries: the Example of Africa]. *Actualités et Dossiers en Santé Publique*. 2002.

“De l'universalisme au relativisme en éthique: inévitables échanges (l'exemple du SIDA)” [From Ethical Universalism to Relativism: the Inevitable Trade-Offs (the case of AIDS)]. *Ethnologes Comparées*, <http://www.alor.univ-montp3.fr/cerce/r3/n.3.htm>. 2001.

With A. Desgrées du Loû. “SIDA et situations sociales des femmes en Afrique. Des notions aux méthodes de recherché” [AIDS and the Social Situation of Women in Africa: From Notions to Research Methods]. *Cahiers Santé*, 11, pp. 265-272. 2001.

With P. Msellati. “Qu'est ce que traiter le SIDA en Afrique?” [What Does It Mean to Treat AIDS in Africa?]. *Afrique Contemporaine*, 195, pp. 91-104. 2000.

“Sexualité et SIDA en Afrique (entretien avec L. Bazin)” [Sexuality and AIDS in Africa (conversation with L. Bazin)]. *Journal des anthropologies*, 82-83, pp. 309-323. 2000.

“La transmission. Le SIDA et ses savoirs” [Transmission. AIDS and Knowledge of AIDS]. *L'Homme*, 150, pp. 59-84. 1999.

“Anthropologie d'une distance. Le SIDA, de réalités multiples en discours uniformes” [Anthropology of Distance. AIDS, Multiple Realities and Standard Discourse]. *Autrepart*, 12, pp. 19-36. 1999.

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- With D. Coulibaly-Traoré: “L'accès aux traitements des patients vivant avec le VIH/SIDA en Côte d'Ivoire: une enquête qualitative” [Access to Treatment by Patients Living with HIV/AIDS in Côte d'Ivoire: a Qualitative Survey], pp. 159-177.
- With C. Esse; D. Gadou; G. Kponhassia. “Les professionnels de santé d'Abidjan et Bouaké face à l'Initiative: une enquête qualitative” [The Response of Health Professionals in Abidjan and Bouaké to the Initiative: a Qualitative Survey], pp. 229-251.

“Le lien. De connaissances en pratiques, évaluer les risques du SIDA” [The Link: From Knowledge to Practice, Evaluating the Risks of AIDS]. In: J.P. Dozon; D. Fassin (ed.). *Critique de la santé publique. Une approche anthropologique* [A Critique of Public Health. An Anthropological Approach], pp. 233-235. Paris, Balland (coll. “Voix et regards”). 2001.

“Penser le risque de transmission: transmission de la mère à l'enfant et allaitement maternel” [Reflecting on the Risk of Transmission: Transmission from Mother to Child and Maternal Breastfeeding]. In: A. Desclaux, B. Taverne (eds.). *L'allaitement dans le contexte de l'Afrique de l'Ouest: de l'anthropologie à la santé publique* [Breastfeeding in the Context of West Africa: from Anthropology to Public Health], pp. 411-432. Paris, Karthala. 2000.

“De quelques lieux de rencontre de disciplines et concepts communément mobilisés par la recherche sur le SIDA” [On Convergences of Disciplines and Concepts Commonly Enlisted by AIDS Research]. In: C. Becker; J.-P. Dozon; C. Obbo; M. Touré (ed.). *Vivre et penser le SIDA en Afrique/Experiencing and Understanding AIDS in Africa*, pp. 79-97. Paris, Codesria/IRD/Karthala. 707 pp. 1999.

With A.-D. Blibolo and B.T. Nguessan. “Structures sanitaires et malades confrontés à la prise en charge du SIDA à Abidjan (Côte d'Ivoire)” [Health Structures and the Challenge of Caring for AIDS Patients in Abidjan (Côte d'Ivoire)]. In: *Le SIDA en Afrique. Recherches en sciences de l'homme et de la société* [AIDS in Africa. Research in the Human and Social Sciences], pp. 153-159. ANRS/ORSTOM, April (coll. Sciences sociales et SIDA). 1997.

With G. Seidel. “The Implications of ‘Medical’, ‘Gender in Development’ and ‘Culturalist’ Discourses for HIV/AIDS Policy in Africa”. In: C. Shore; S. Wright (ed.). *Anthropology of Policy. Critical Perspectives on Governance and Power*, pp. 59-87. London/New York, Routledge. 1997.

In A. Desclaux; C. Raynaud (ed.). *Le dépistage VIH et le conseil en Afrique au sud du Sahara, aspects médicaux et sociaux* [HIV Screening and Counselling in Sub-Saharan Africa, Medical and Social Aspects]. Paris, Karthala (coll. Économie et Développement). 1997.

- “L'annonce aux malades. Contextes et significations à partir d'exemples ivoiriens” [Disclosure to Patients. Contexts and Implications Based on Examples from Côte d'Ivoire], pp. 27-33.
- “Le rôle des associations” [The Role of Associations], pp. 245-250.



“Méthode et éthique: l’anthropologie et la recherche confrontées au SIDA” [Method and Ethics: Anthropology and Research Confronted by AIDS]. In: M. Agier (ed.). *Anthropologies en dangers* [*Anthropologies in Danger*], pp. 99-107. Paris, Éditions Jean-Michel Place. 1997.

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With P. Msellati and J.-P. Moatti (ed.). *L’accès aux traitements du VIH/SIDA en Côte d’Ivoire. Évaluation de l’Initiative ONUSIDA/Ministère de la santé publique. Aspects économiques, sociaux et comportementaux* [Access to HIV/AIDS Treatment in Côte d’Ivoire. Evaluation of the UNAIDS/Ministry of Public Health Initiative. Economic, Social and Behavioural Aspects]. Paris, ANRS (coll. Sciences sociales et SIDA). 327 pp. 2001.

*Femmes en temps de SIDA. Expériences d’Afrique* [*Women in a Time of AIDS. African Experiences*]. Paris, PUF (coll. Politique d’aujourd’hui). 195 pp. 2000.

*Le silence et le sens. Essai d’anthropologie du SIDA en Afrique* [Silence and Sense. Towards an Anthropology of AIDS in Africa]. Paris, Anthropos-Economica. 217 pp. 1996.

With J.P. Dozon (ed.). *Les Sciences sociales face au SIDA: cas africains autour de l’exemple ivoirien* [The Social Sciences and the AIDS Challenge: African Examples from Côte d’Ivoire]. Actes de l’Atelier, Bingerville (Côte d’Ivoire); 15-17 March 1993. Éditions ORSTOM (coll. Colloques et séminaires). 301 pp. 1995.

## ANNEX II

### Indicative Bibliography “HIV/AIDS: Stigma and Discrimination”

This bibliography has been compiled by the Ile-de-France Centre Régional d'Information et de Prévention du SIDA (CRIPS) on the basis of the Docsida database belonging to the French CRIPS network, consisting of eight CRIPS in France, all of which provide inputs to the database. Most of the documents included in this bibliographic selection can be consulted in the documentary resources centre of the Ile-de-France **Centre Régional d'Information et de Prévention du SIDA (CRIPS Ile-de-France, France)**.

#### *CRIPS Ile-de-France*

Tour Maine-Montparnasse  
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75755 Paris cedex 15  
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Tel: 01 56 80 33 33  
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e-mail: [info@lecrips.net](mailto:info@lecrips.net)  
<http://www.lecrips.net> and [www.vihinternet.org](http://www.vihinternet.org)

All the documents published under the project “A Cultural Approach to HIV-AIDS Prevention and Care” are available on the project’s webpage:  
<http://www.unesco.org/aids>

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ABRIOL, S.; LOUX, F.

**Stigmatisation et discrimination des personnes atteintes: pour des recherches qualitatives sur les phénomènes d'exclusion [Stigmatization and Discrimination against Infected Persons: The Case for Qualitative Research on the Phenomena of Exclusion]**

Article; French; Review: Transcriptase; 2000/05; No. 83; ISN: 1166 5300; pp. 6-8

Main theme: DISCRIMINATION

DISCRIMINATION; EUROPE; CENTRAL AND EASTERN EUROPE

Reference IDF: Transcriptase, No. 83

AGGLETON, P.

UNAIDS, Geneva

**Comparative Analysis: Research Studies from India and Uganda – HIV and AIDS-related Discrimination, Stigmatization and Denial**

Study; French; Geneva: UNAIDS; 2002/05; UNAIDS Best Practice Collection; ISN: 92-9173-147-1; 42 pp.

Main theme: DISCRIMINATION

DISCRIMINATION; STIGMATIZATION; DENIAL; SURVEY; COMPARISON; UGANDA; INDIA

Abstract: This survey presents the comparative findings of two studies on the nature, determinants and consequences of HIV and AIDS-related discrimination, stigmatization and denial in India and Uganda. This document is part of a collection entitled: UNAIDS Best Practice Collection relating to discrimination, stigmatization and rejection.

Location: RA

AGGLETON, P.; PARKER, R.

UNAIDS, Geneva

**A Conceptual Framework and Basis for Action**

**HIV/AIDS Stigma and Discrimination**

Report; French; Geneva: UNAIDS; 2002/06; ISBN: 92 9173 209 5; 22 pp.

Main theme: DISCRIMINATION

DISCRIMINATION; STIGMATIZATION; CONCEPT; HUMAN RIGHTS; FIELD WORK; INTERNATIONAL

Abstract: This document provides a definition of stigmatization and discrimination together with examples relating to HIV (Human Immunodeficiency Virus) infection. It restates fundamental human rights, reports on actions to combat discrimination against infected people, and finally proposes strategies for undertaking such actions.

Reference IDF: 0606, A/0059

BARLERIN, R.; BOCHENT, S.; COQUET RAVISY, C.

Université Blaise Pascal, Clermont-Ferrand

**Erreur fondamentale et SIDA [Fundamental Error and AIDS]**

Report; French; 1994; 14 pp.

Main theme: STIGMATIZATION

STIGMATIZATION; REPRESENTATION OF THE ILLNESS; BELIEFS

Abstract: This document shows how and why HIV-sufferers are declared more responsible for their illness than other patients

BOUJENAH, P.; Frouma Films International; HENRY, M.; NIEDA, J.

**3,000 scénarios contre un virus: L'exclusion [3,000 Scenarios against a Virus: Exclusion]**

Video; Short film; French; 1994; 2.35 mins.

Main theme: DISCRIMINATION

DISCRIMINATION; CHILDREN; EDUCATION SYSTEM; PARENTS; FRANCE

Public: PUBLIC AT LARGE; CHILDREN; PARENTS

Abstract: Short film from the competition "3 000 scénarios contre un virus". A ring of children in a playground. A mother informs other parents that little Pierre is seropositive. Reactions by mothers and other children, and so forth.

Production: Paris: Médecins du Monde; Paris: CRIPS Ile-de-France; Paris: AESSA

Diffusion: CRIPS Ile de France – VHS SECAM; Beta; 35 mm – 15 euros for the complete videocassette;

Rental upon request

Reference IDF: B01, V/0203

CARAEL, M. dir.; CURRAN, L.; GACAD, E.; GNAORE, E.; HARDING, R.; MANDOFIA, B.M.; STAHLHÖFER, M.; TIMBERLAKE, S.; UMMEL, M.; MURPHY, T.

UNAIDS, Geneva

**Protocol for the Identification of Discrimination against People Living with HIV**

Report; French; Geneva: UNAIDS; 2001/09; UNAIDS Best Practice Collection; ISBN: 92 9173 118 8; 40 pp.; questionnaire

Main theme: DISCRIMINATION

DISCRIMINATION; HUMAN RIGHTS; CONCEPT; EVALUATION; SURVEY; METHODOLOGY; ACCESS TO HEALTH CARE; CONFIDENTIALITY; COMPULSORY SCREENING; EMPLOYMENT; JUSTICE; LEGISLATION; LAW ON FOREIGNERS; INSURANCE; INTERNATIONAL; DEVELOPING COUNTRIES

Abstract: This document is designed to help decision-makers in drawing up surveys to identify VARIOUS forms of arbitrary discrimination. After defining arbitrary discrimination (basic concepts, criteria for assessing its existence, main sources), this document sets out the precise methodology for the survey to be conducted: fields to be covered, proposed indicators, selection and training of interviewers and interviewees, data collection, verification of information. A table is appended summarizing the basic forms of discrimination in

key areas (health, employment, justice and legal procedures, administration, social rights, insurance and other financial services).

Reference IDF: 0606, A/0048

CHAUVIN, I.

**Inadmissible Forms of Discrimination**

Article; French; Review: *Journal du SIDA (Le)*; 2001/07; No. 136-137; ISN: 1153 0863; 29 pp.

Main theme: DISCRIMINATION

DISCRIMINATION; MIGRANTS; SOCIAL INTEGRATION; ACCESS TO HEALTH CARE; REINTEGRATION IN THE WORK FORCE

Abstract: Isabelle Chauvin, in charge of integration at Arcat-SIDA, attests to the difficulties encountered in France by HIV-infected foreigners in gaining access to health care and employment. The increasingly rigid legislative and regulatory framework is here revealed.

Reference IDF: *Journal du SIDA*, No. 136-137

DESCLAUX, A.

**La recherche anthropologique peut-elle contribuer à la lutte contre la discrimination envers les personnes atteintes par le VIH? [Can Anthropological Research Help in Combating Discrimination against HIV-infected Persons?]**

in: *Anthropologie et SIDA: bilan et perspectives [Anthropology and AIDS: Situation and Prospects]*

Extract; French; 1996; pp. 267-286

Main theme: DISCRIMINATION

DISCRIMINATION; ANTHROPOLOGY; RESEARCH; ETHICS; AFRICA; BURKINA FASO

Reference IDF: 12, A/0055

DIJKER, A.

ANRS (Agence Nationale de Recherches sur le SIDA), France

**Aspects socio-psychologiques de la stigmatisation des personnes atteintes [Socio-psychological Aspects of the Stigmatization of Infected Persons]**

in: *Le SIDA en Europe, nouveaux enjeux pour les sciences sociales: 2e conférence européenne sur les méthodes et les résultats des recherches en sciences sociales sur le SIDA [AIDS in Europe, New Challenges for the Social Sciences: Second European Conference on the Methods and Findings of Social Science Research on AIDS]*

Extract; French; Paris: Agence Nationale de Recherches sur le SIDA; 1998/07; Coll.: *Sciences sociales et SIDA*; ISN: 2 910143 12 0; pp. 125-132

Congress: Le SIDA en Europe: nouveaux enjeux pour les sciences sociales, Paris, 1998/01/12-15

Main theme: STIGMATIZATION

SOCIAL PSYCHOLOGY; SOCIAL NORMS; BEHAVIOURAL CHANGE; REPRESENTATION OF THE ILLNESS; SUFFERING; STIGMATIZATION; INTERNATIONAL

Abstract: The author, drawing on a study of the literature, shows that AIDS-infected persons belong to one of the most stigmatized groups in society as compared with other people suffering from chronic illnesses and disabilities. The stigmatization of this group by their entourage and the medical service staff is expressed by the refusal of social contact and by negative emotional reactions, such as fear, disgust and anger.

Reference IDF: 12, A/0073

DUBOIS-ARBER, F., ed.; HAOUR-KNIPE, M., ed.

**Identification des discriminations institutionnelles à l'encontre des personnes vivant avec le VIH en Suisse [Identification of Institutional Forms of Discrimination against People Living with HIV in Switzerland]**

Special issue; French; Review: *Raisons de santé*, 1998; No. 18; ISN: 1420 2921; 140 pp.; questionnaire

Main theme: DISCRIMINATION

DISCRIMINATION; RESEARCH METHODOLOGY; SURVEY; PERIOD 1995-1999; ACCESS TO HEALTH CARE; MEDICAL SECRECY; INFORMING ONE'S PARTNER; EMPLOYMENT; PRIVATE SECTOR; JUSTICE; SOCIAL AID; ACCOMMODATION; INSURANCE; HUMAN RIGHTS;

RECOMMENDATION; SWITZERLAND

Description: The study is presented in three languages: French, German and English.

Abstract: This study, conducted in accordance with a UNAIDS protocol covering a two-year period (1996-1997), was designed to:

- highlight possible forms of institutional discrimination against HIV-infected persons in Switzerland;
- determine in which areas and in what forms discrimination manifests itself;
- propose, as appropriate, recommendations to put an end to such discrimination.

Reference IDF: 0603, A/0295

GROSSHANS, D.

**L'envers de l'exclusion [The Obverse of Exclusion]**

in: *Psychologues au temps du SIDA – dossier No. 2*

Article; French; Review: *Psychologues et psychologies*; 1995/10; No. 126-127; ISN: 0297 6234; pp. 37-38

Main theme: DISCRIMINATION

DISCRIMINATION; TRAUMA; PSYCHOLOGY; FRANCE

Reference IDF: 0706, A/0181

HAMBLIN, J.

UNDP (United Nations Development Programme), New York

**Personnes vivant avec le VIH: le droit, l'éthique et la discrimination [People Living with HIV: The Law, Ethics and Discrimination]**

Summary; French; 1993/11; 10 pp.

Main theme: DISCRIMINATION

DISCRIMINATION; LEGISLATION; ETHICS; SEROPOSITIVE PERSON; HUMAN RIGHTS

Reference IDF: 0603, A/0031

HANDMAN, M.-E.

**La stigmatisation des femmes à travers les représentations du SIDA véhiculées par les médias [The Stigmatization of Women through Representations of AIDS Conveyed by the Media]**

Article; French; Review: *Transcriptase*; 1997/01; No. 52; pp. 12-13

Main theme: DISCRIMINATION

DISCRIMINATION; WOMEN; PREGNANT WOMEN; MEDIA; REPRESENTATION; SEXUAL ROLE; UNITED STATES

Reference IDF: *Transcriptase*, No. 52

**L'intérêt supérieur de l'enfant, le droit à la non-discrimination et au respect de la vie [Best Interests of the Child: The Right to Non-discrimination and Respect for Life]**

in: *Droits de l'enfant et infection par le VIH [Rights of the child and HIV infection]*

Extract; French; Paris: Institut de l'Enfance et de la Famille; 1994; ISN: 2 11 088396 0; pp. 78-82

Main theme: DISCRIMINATION

DISCRIMINATION; CHILDREN; LEGISLATION; INTERNATIONAL; EUROPE

Reference IDF: 0702, A/0398

LACOSTE-DEGUIRARD, C.; PRATO, F.; FERMAN, I.

Université Blaise Pascal, Clermont Ferrand

**Les stéréotypes et les malades du SIDA [Stereotypes and AIDS Sufferers]**

Report; French; 1994; 21 pp.

Main theme: STIGMATIZATION

STIGMATIZATION; REPRESENTATION OF THE ILLNESS; PSYCHOLOGY

Abstract: This document analyses the stereotypes to which AIDS sufferers are subject and highlights the factors that can cause them to evolve.

**Lutte contre l'exclusion des personnes séropositives [Combating the Exclusion of Seropositive Persons]**

Article; French; Review: *Education santé*, 1995/02; No. 94; ISN: 0776 2623; p. 23

Main theme: DISCRIMINATION

DISCRIMINATION; WORK ENVIRONMENT; ETHICS; BELGIUM

Abstract: This article was prompted by the first collective agreement, signed by a Belgian firm, relating to non-discrimination against seropositive workers. The firm concerned entered into an undertaking to practise and promote non-discrimination at three points in an employee's career: recruitment, while under contract and in the event of separation.

Reference IDF: *Education Santé*, No. 94

MARECHAL, I.

**Le poids du silence: un combat qu'ils vont mener seuls, car personne ne doit savoir [The Weight of Silence: A Struggle They Will Pursue Alone, for no one Must Know]**

Book; French; Paris: Anne Carrière; 1996/02; ISN: 2 910188 73 6; 287 pp.

Main theme: DISCRIMINATION

DISCRIMINATION; THE COUPLE RELATIONSHIP; SOLITUDE; FAMILY SUPPORT; SUPPORTING THE SICK PERSON; TESTIMONY; LIVING WITH HIV/AIDS; DENIAL; BISEXUAL; FRANCE

Abstract: Gilles, a top civil servant and father, died in the prime of life. Cancer? That is what they said. In reality, Gilles was bisexual and died from AIDS. Since that illness is socially taboo and he had feared the unpredictable reactions of his entourage, he had asked his wife to hide the truth: neither their friends nor colleagues or even their children were to know. But where can she turn for support? In this true account, Isabelle Maréchal powerfully describes the terrible in camera fears, hopes and anger but also the love into which the couple retreats. The author has written this first-hand account for all those women who are experiencing the same situation and who feel alone as they dare not speak about it.

Reference IDF: 0603, A/0173

MARTIN, J.

**SIDA et discriminations sociales [AIDS and Social Discrimination]**

Article; French; Review: *Prévenir*; 2000; No. 39; ISN: 0247 2406; pp. 205-207

Main theme: DISCRIMINATION

DISCRIMINATION; POVERTY; SOCIAL EXCLUSION; HEALTH INSURANCE; CMU (universal health coverage)

Reference IDF: 0606, A/0024

Mutuelles de France, Montreuil

**Discriminations sur critères de santé ou de handicap [Discrimination on the Grounds of Health or Disability]**

Report; Seminar proceedings; French; Montreuil: CVM; 2001; ISN: 2 908255 14 6; 72 pp.; table

Congress: *Discriminations sur critères de santé ou de handicap*, Paris, 2001/05/17

Main theme: DISCRIMINATION

DISCRIMINATION; DISABLED PERSONS; HIV-INFECTED PERSONS; WORK ENVIRONMENT; INSURANCE; SURVEY; TESTIMONIES; EMPLOYMENT; LEGISLATION; COMPLEMENTARY INSURANCE; ASSOCIATION; RECOMMENDATION; FRANCE; EUROPE

Abstract: This document is divided into two parts. In the first part, the results of the IFOP survey on discrimination on the grounds of health and disability are presented and analysed. The survey was conducted between 22 March and 6 April 2001 on a sample of 1,986 people, representative of the French population aged 18 and over. The results are accompanied by a series of testimonies, collected on the basis of semi-directive interviews.

The second part is given over to the proceedings of the seminar of 17 May: discrimination and insurance, discrimination and employment, action against discrimination on the grounds of health and disability in the European Community.

Every type of disability is covered. One of the testimonies comes from a seropositive person, and the round

table “Discrimination and employment” was centred on the experience of the association Aides and its information and campaign to prevent discrimination against HIV-infected persons in the work place.  
Reference IDF: 0606, A/0039

NAP+ (Network of African People Living with HIV/AIDS), West and Central Africa; UNAIDS. Inter-Country Team for West and Central Africa

**Situation Analysis of Discrimination and Stigmatization against People Living with HIV/AIDS in West and Central Africa: Ethical and Legal Considerations**

Report; French; Abidjan: UNAIDS. Inter-Country Team for West and Central Africa; 2002/05; 47 pp.; list of addresses

Main theme: DISCRIMINATION

DISCRIMINATION; LIVING WITH HIV/AIDS; HUMAN RIGHTS; ETHICS; MEDICAL SECRECY; PROFESSIONAL ETHICS; STIGMATIZATION; RELATIONS; SITUATION ANALYSIS; CENTRAL AFRICA; WEST AFRICA; BURKINA FASO; CAMEROON; COTE D'IVOIRE; GABON; GHANA; MAURITANIA

Abstract: This analysis, which was carried out from March to July 2001 in six countries of West and Central Africa – Burkina Faso, Cameroon, Côte d'Ivoire, Gabon, Ghana and Mauritania – highlights daily situations of discrimination and stigmatization against people living with HIV in the areas of employment, education, individual freedoms, access to medical care, social security and access to bank loans. After defining the concepts of stigmatization and discrimination and presenting testimonies, it proposes a number of actions that could improve the situation as regards the rights of these persons.

This analysis forms part of the UNAIDS 2002-2003 World AIDS Campaign, aimed at combating stigma and discrimination.

Location: CRIPS Aquitaine (Bordeaux)

NASSI, S.; GRIMAUD, C.; SIMON, K.

Université Blaise Pascal, Clermont-Ferrand

**Stéréotype du sidéen [Stereotype of the AIDS Sufferer]**

Report; French; 1994; 19 pp.

Main theme: STIGMATIZATION

STIGMATIZATION; REPRESENTATION OF THE ILLNESS; SOCIOLOGY; BELIEFS

Abstract: This document focuses on the danger of the kind of stereotype that gives rise to biased judgements conducive to discrimination

Location: CRIPS Auvergne (Clermont-Ferrand)

PECHENY, M.

**Argentina: Discrimination and AIDS Prevention**

in: *Drug Abuse and AIDS Stemming the Epidemic*

Article; English; “Review: Peddro: networking of information in the field of drug abuse prevention through education; 2001/12”; Special issue; pp. 55-57; table

Main theme: DISCRIMINATION

DISCRIMINATION; INJECTIBLE DRUG USERS; EPIDEMIOLOGY; IMPACT; RISK REDUCTION; ARGENTINA

Abstract: The author explains how the confusion between the domain of health and that of social and moral values and the consequent stigmatization of drug users are obstacles to the introduction of risk-reduction measures.

Reference IDF: Peddro, Special issue

PRESTEL, T.

**Aviation: le règne de la discrimination [Aviation: The Realm of Discrimination]**

Article; French; Review: Remaides; 2000/09; No. 37; ISN: 1162 0544; pp. 15

Main theme: DISCRIMINATION

DISCRIMINATION; WORK ENVIRONMENT; EMPLOYABILITY; EMPLOYMENT;

SEROPOSITIVE PERSON; FRANCE

Abstract: This article denounces the decree of 5 July 1994 of the Ministry of Transport, which disqualifies seropositive applicants for air hostess and steward posts in civil aviation.

Reference IDF: Remaides, No. 37

ROBBE, A.; ROBBE, A.; AIDES Fédération Nationale. Mission entreprises, France

**VIH/SIDA et milieu de travail: Sensibilisation formation (2 sketches) [HIV/AIDS and the Workplace: Awareness-raising Training]**

in: *VIH/SIDA et milieu de travail: spots TV et Sketches*

Video; Preventive-education film; French; 2001; 10 [ 2 x 5 ] mins.

Main theme: DISCRIMINATION

DISCRIMINATION; WORK ENVIRONMENT; REINTEGRATION IN THE WORK FORCE; PERSONAL DISCLOSURE OF SEROPOSITIVITY; BELIEFS; RUMOURS; FRANCE

Public: EMPLOYER

Abstract: These sketches are intended to serve as resources for awareness-raising and training in integrating HIV-infected persons in the workplace.

“L’entretien d’embauche” [Job Interview] addresses the question of the access to work by HIV-infected persons under treatment. The attitudes of an applicant and a human resources manager during a job interview are acted out.

“La rumeur” [The Rumour] exposes false beliefs and suspicious attitudes towards other employees. In the restaurant, the rumour spreads as soon as a colleague has a health problem.

Production: Pantin: AIDES Fédération Nationale

Diffusion: AIDES Fédération Nationale – VHS SECAM – Diffusion free of charge

Reference IDF: B01, V/0815

TARABAY, M.

**Les stigmates de la maladie: Représentations sociales de l’épidémie du SIDA [Stigmas of the Illness: Social Representations of the AIDS Epidemic]**

Payot Lausanne, 2000, 217 pp.

Abstract: Through many testimonies, the author is concerned in particular to show that the everyday situation of caregivers, close relatives and AIDS sufferers is sometimes different from that one might think. The book also retraces the way in which the concept of the illness in our society has evolved since the start of the epidemic.

THERY, I.; TASSERIT, S.

**SIDA et exclusion [AIDS and Exclusion]**

in: *L’exclusion, l’état des savoirs [Exclusion, the State of the Art]*

Extract; French; Paris: *La Découverte*, 1996; ISBN: 2 7071 2540 7; pp. 363-373.

Main theme: DISCRIMINATION

DISCRIMINATION; REPRESENTATION; UNDERPRIVILEGED ENVIRONMENTS; SOCIAL EXCLUSION

Reference IDF: 0603, A/0093

VELTER, A.; MOREL, M.

SIDA Info Service, France

**SIDA Info Droit, témoin de l’exclusion et des discriminations: le VIH, un obstacle à l’insertion sociale [SIDA Info Droit, a Witness to Exclusion and Discrimination: HIV: An Obstacle to Social Integration]**

Article; French; English; Review: Enable; 2000/07; No. 4; pp. 11-12

Main theme: DISCRIMINATION

DISCRIMINATION; LEGAL AID; TELEPHONE HOTLINE; SOCIAL EXCLUSION; FRANCE

Description: Review in bilingual inverted format.

Abstract: The calls received on the SIDA Info Droit hotline for legal aid highlight the situations of exclusion



that the HIV infection generates and reinforces in some cases. Extracts from telephone calls illustrate some typical situations.

Reference IDF: Enable, No. 4

WELZER-LANG, D., dir.; DUTEY, P., dir.; DORAIS, M., dir.; GENTAZ, C.; GUILLEMAUT, F.; RYAN, B.; FRAPPIER, J.-Y.; BOCHOW, M.; LESSELIER, C.

**La peur de l'autre en soi: du sexisme à l'homophobie [The Fear of the Other Within: From Sexism to Homophobia]**

Book; French; Montreal: VLB éditeur; 1994; Coll.: *Des hommes en changement*, No. 9; ISBN: 2 89005 587 6; 302 pp.

Main theme: DISCRIMINATION

DISCRIMINATION; REPRESENTATION; HOMOSEXUAL; ADOLESCENT; RESEARCH; METHODOLOGY; ANTHROPOLOGY; LANGUAGE; HOMOSEXUALITY; SEXISM; SOCIAL NORMS; ETHICAL VALUES; BEHAVIOUR; LESBIAN; TAKING A STAND; HOMOPHOBIA; GERMANY; FRANCE

Reference IDF: 0601, A/0349 – out of print

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Manual; English; 1997/05; 300 p.

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in: AIDS reference manual

Manual; Abstract; English; London: NAM Publications; 1997/05; 20 ed.; ISBN: 1 89839771 6; pp. 368-400

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Article; English; Review: *Lancet (The)*; 2002/07/06; vol. 360; ISBN: 0140 6736; pp. 67-72

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**Homosexuals and the AIDS Crisis in France: Assimilation, Denial, Activism**

in: *Acting on aids: sex, drugs and politics*

Abstract; English; London: Serpent's Tail; 1997; ISBN: 1 85242 5539; pp. 346-359

**From Vulnerability to Human Rights**

in: Aids in the world II: global dimensions, social roots and responses  
Abstract; English; 1996; ISN: 0 19 908994 4; pp. 463-476

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in: Acting on aids: sex, drugs and politics  
Abstract; English; London: Serpent's Tail; 1997; ISN: 1 85242 5539; pp. 379-393

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in: Aids in the world II: global dimensions, social roots and responses  
Abstract; English; 1996; ISN: 0 19 508994 4; pp. 326-340

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Abstract; English; New York: the Guilford Press; 1995; ISN: 0 89862 502 5; pp. 270-288

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Abstract; English; London: Serpent's Tail; 1997; ISN: 96 69725; pp. 254-269

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Report; English; 2002/05; 38 p.

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Report; English; 1999/06; 25 p.

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**Declaration of Rights of Persons Living in Israel with HIV/AIDS**

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Report; English; 1998/03; ISN: 1 896735 12 6; 164 [133+31] p.

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**Knowledge and Discrimination: What Kind of Relationship?**

in: Sexual behaviour and HIV/Aids in Europe: comparisons of national surveys

Abstract; English; London: Taylor & Francis; 1998; Coll.: Social Aspects of Aids; ISN: 1 85728 819 X; pp. 375-400

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**The Rights of the Child in the Context of HIV/AIDS**

Flyer; English; 1999/12; 6 [2A4] p.

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Flyer; English; s.d.; 6 [2A4] p.

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Flyer; English; s.d.; 6 [2A4] p.

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**Taking a Rights-base Approach to AIDS Research**

Article; English; Review: IAVI report: the newsletter on international aids vaccine research; 2003/02; vol. 7; n° 1; pp. 10-12, 14

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World Bank, United States; European Commission. Directorate-General for Development, Brussels

**International Law and the Rights of People Living with HIV/AIDS**

in: Confronting AIDS, evidence from the developing world: selected background papers for the World Bank Policy Research Report, "Confronting AIDS: public priorities in a global epidemic"

Abstract; English; 1998; ISN: 92 828 4991 0; pp. 79-92

SACKS V.

**Women and AIDS: An Analysis of Media Misrepresentations**

Article; English; Review: Social Science and Medicine; 1996; vol. 42; n° 1; pp. 59-73

SHEON A.-R.; WAGNER L.; Mc ELRATH M.-J.; KEEFER M.-C.; ZIMMERMAN E.; ISRAEL H.; BERGER D.; FAST P.

**Preventing Discrimination against Volunteers in Prophylactic HIV Vaccine Trials: Lessons from a Phase II Trial**

Article; English; Review: Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology; 1998/12/15; vol. 19; n° 5; ISN: 1077 9450; pp. 519-526

SHRIVER M.D.; EVERETT C.; MORIN S.F.

**Structural Interventions to Encourage Primary Prevention among People Living with AIDS**

in: Structural factors in HIV prevention

Article; English; Review: AIDS; 2000/06/01; vol. 14; n° Supplement 1; ISN: 0269 9370; pp. S57-S62

Congress: Structural barriers and facilitators in HIV prevention, Atlanta, 1999/02/22-23

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**Charges of Human Immunodeficiency Virus Discrimination in the Workplace: The Americans with Disabilities Act in Action**

Article; English; Review: American Journal of Epidemiology; 2002; vol. 156; n° 3; ISN: 0002 9262; pp. 219-229

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Report; English; 2002/07; ISN: 92 1973 185 4; 226 p.

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Report; English; 2000/06; 56 p.

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**HIV and AIDS-related Stigmatization, Discrimination and Denial: Forms, Contexts and Determinants: Research Studies from Uganda and India**

Report; English; 2000/06; 40 p.

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Guide; English; 2000/05; Coll.: Best Practice; 40 p.

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Report; Legislation; English; 1997; 90 p.

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Report; Proceedings of conference; English; 1996; 35 p.

## ANNEX III

### Selected Articles on Stigma and Discrimination

ALUBO O.; ZWANDOR A.; JOLAYEMI T.; OMUDU E.

**Acceptance and Stigmatization of PLWA in Nigeria.**

AIDS Care. 2002 Feb;14(1):117-26.

There is now an acknowledged burden of AIDS and the HIV in Nigeria. In treatment centers, AIDS-related disorders account for up to 40% of admissions, while many communities have recorded regular losses within the last five years. In December 1999, the federal government announced that 2.9 million people (or 5.4% of the Nigerian population) were already infected by HIV. An important aspect of HIV/AIDS programs is the care of persons living with AIDS (PLWA), both in curative centers and in communities. Based on operations research of a STD/AIDS Management Project, this paper examines acceptance of PLWA in communities in Southern Benue State, an area of high prevalence. From interviews with PLWA, their family members and others in the communities, it was found that the level of stigmatization is high and acceptance of PLWA is low. These reactions stem mainly from the fear of contracting 'the disease that has no cure', believed to be transmittable through any form of physical contact. Based on beliefs, which are further reinforced by the local terms for AIDS, some suggested that PLWA be eliminated before they infect others. These findings suggest that the challenges of AIDS control programs include coming to terms with the epidemic and fostering more acceptance for PLWA and, above all, changing the current perception of HIV/AIDS from a personal to public health problem. The challenges are daunting but urgent, particularly because Nigeria's HIV/AIDS epidemic is reaching an explosion phase and more care will be provided at home.

DUBOIS-ARBER F.; HAOUR-KNIPE M.; Discrimination work group.

**HIV/AIDS Institutional Discrimination in Switzerland.**

Soc Sci Med. 2001 May; 52(10):1525-35.

A UNAIDS protocol designed to identify discrimination against people living with HIV/AIDS was applied in Switzerland, a country where policies against such discrimination had been actively promoted since the beginning of the HIV epidemic. Discrimination, in its strict legal definition, was examined in nine areas of everyday life, and at three levels: legislation, written regulations, and actual practices. Data concerning both expert opinion and subjective experience of discrimination was gathered by members of an interdisciplinary work group by means of: (1) interviews with over 200 key informants and experts, covering each of the areas investigated, and (2) actively seeking testimonies as to experiences of discrimination through local AIDS groups and through informal contacts of work group members. The study revealed little institutional discrimination in the region investigated, attesting to the efficacy of clear and actively promoted anti-discrimination policies. Individual discrimination and stigmatization persist, however. It is in combating individual discrimination and stigmatization that efforts must now concentrate. The UNAIDS protocol was found to be a valuable tool for tracking the sorts of discrimination that can most easily be influenced by policy measures.

FORTENBERRY J.D.; MCFARLANE M.; BLEAKLEY A.; BULL S.; FISHBEIN M.; GRIMLEY D.M.; MALOTTE C.K.; STONER B.P.

**Relationships of Stigma and Shame to Gonorrhoea and HIV Screening.**

Am J Public Health. 2002 Mar; 92(3):378-81.

**OBJECTIVES:** The purpose of this study was to assess the relationships between stigma and shame associated with seeking treatment for sexually transmitted diseases (STDs) and undergoing testing for gonorrhoea and HIV. **METHODS:** Participants were 847 males and 1126 females (mean age: 24.9 years) in 7 cities. Two scales assessed STD-related stigma and STD-related shame. **RESULTS:** Rates of stigma and shame were higher among participants without a gonorrhoea test in the past year and among

those without an HIV test. Sex, age, health service use, previous suspicion of gonorrhea, and low levels of stigma were independently associated with gonorrhea testing. Age, enrollment site, use of health services, gonorrhea testing, and low levels of stigma were independently associated with HIV testing. CONCLUSIONS: Shame is part of the experience of seeking STD-related care, but stigma may be a more powerful barrier to obtaining such care.

HAYES R.A.; VAUGHAN C.; MEDEIROS T.; DUBUQUE E.

**Stigma Directed toward Chronic Illness is Resistant to Change through Education and Exposure.**

Psychol Rep. 2002 Jun; 90(3 Pt 2):1161-73.

In the mid-1980s, research reported that people living with HIV were viewed differently on measures of competence, dependence, morbidity, depression, and moral worth from those living with other chronic illnesses. 443 students were surveyed to evaluate present attitudes in comparison to this earlier research. The usefulness of imaginal exposure, i.e., imagining a loved one living with HIV, in reducing stigma toward people with HIV was also investigated. Analysis indicated no difference in the rating of AIDS and cancer patients on measures of competence, depression, and morbidity and patients with heart disease, the latter being rated significantly less competent and more depressed than AIDS or cancer patients. AIDS patients were rated significantly less dependent than cancer and heart disease patients. While these results suggest that stigma associated with an HIV/AIDS diagnosis, in general, may have decreased over the years, ratings of moral worth were still lower for AIDS patients than for patients with cancer and heart disease. Robustness of this specific aspect of stigma may be associated with sexual prejudice. Also, an imagined loved one who lives with HIV was rated significantly more favorably on all 5 composite scales than a generic person living with HIV, suggesting the usefulness of exposure as an intervention for attitude change. Limitations of the research are discussed.

HEREK G.M.; CAPITANIO J.P.; WIDAMAN K.F.

**HIV-related Stigma and Knowledge in the United States: Prevalence and Trends, 1991-1999.**

Am J Public Health. 2002 Mar; 92(3):371-7.

OBJECTIVES: This study assessed the prevalence of AIDS stigma and misinformation about HIV transmission in 1997 and 1999 and examined trends in stigma in the United States during the 1990s. METHODS: Telephone surveys with national probability samples of English-speaking adults were conducted in the period 1996 to 1997 (n = 1309) and in 1998 to 1999 (n = 669). Findings were compared with results from a similar 1991 survey. RESULTS: Overt expressions of stigma declined throughout the 1990s, with support for its most extreme and coercive forms (e.g., quarantine) at very low levels by 1999. However, inaccurate beliefs about the risks posed by casual social contact increased, as did the belief that people with AIDS (PLWAs) deserve their illness. In 1999, approximately one third of respondents expressed discomfort and negative feelings toward PLWAs. CONCLUSION: Although support for extremely punitive policies toward PLWAs has declined, AIDS remains a stigmatized condition in the United States. The persistence of discomfort with PLWAs, blame directed at PLWAs for their condition, and misapprehensions about casual social contact are cause for continuing concern and should be addressed in HIV prevention and education programs.

PARKER R.; AGGLETON P.

**HIV and AIDS-related Stigma and Discrimination: A Conceptual Framework and Implications for Action.**

Soc Sci Med. 2003 Jul; 57(1):13-24.

Internationally, there has been a recent resurgence of interest in HIV and AIDS-related stigma and discrimination, triggered at least in part by growing recognition that negative social responses to the epidemic remain pervasive even in seriously affected communities. Yet, rarely are existing notions of stigma and discrimination interrogated for their conceptual adequacy and their usefulness in leading to

the design of effective programs and interventions. Taking as its starting point, the classic formulation of stigma as a 'significantly discrediting' attribute, but moving beyond this to conceptualize stigma and stigmatization as intimately linked to the reproduction of social difference, this paper offers a new framework by which to understand HIV and AIDS-related stigma and its effects. It so doing, it highlights the manner in which stigma feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality. It highlights the limitations of individualistic modes of stigma alleviation and calls instead for new programmatic approaches in which the resistance of stigmatized individuals and communities is utilized as a resource for social change.

VALDISERRI R.O.

**HIV/AIDS Stigma: An Impediment to Public Health.**

Am J Public Health. 2002 Mar; 92(3):341-2.

Publication Types: Comment; Editorial.

Terms: Acquired Immunodeficiency Syndrome/prevention & control; Acquired Immunodeficiency Syndrome/transmission; Adult; Attitude of Health Personnel/ethnology; Fear; HIV Infections/prevention & control; HIV Infections/transmission; Health Promotion; Human; Knowledge, Attitudes, Practice; Prejudice; Public Health Practice/standards; Risk-Taking; Sex Behavior/ethnology; Stereotyping; Substance Abuse, Intravenous/virology; United States.

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Professional psychology, research and practice, 1998, vol. 29, no 3, pp. 306-07

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Texte: (Toronto), 1998, no 23-24, pp. 247 - 260

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**HIV/AIDS and Homophobia: Subtle Hatreds, Severe Consequences and the Question of Origins**

Culture, health & sexuality, 2003, vol. 5, no 2, pp. 121 - 136

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Social Science & Medicine, 1994, vol. 39, no 9, pp. 1359-1366

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**Attraction Toward and Nonverbal Stigmatization of Gay Males and Persons with AIDS: Evidence of Symbolic over Instrumental Attitudinal Structures**

Human communication research, 1994, vol. 21, no 2, pp. 241-279

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**Racialized Social System and HIV Infection: The Case of African Americans**

International journal of sociology and social policy, 2002, vol. 22 , no 4-6, pp. 133 - 158

QUAH S.R.

**Ethnicity, HIV/AIDS Prevention and Public Health Education**

International journal of sociology and social policy, 1998, vol. 18, no 7-8, pp. 1-26