Stigma, Discrimination
and HIV/AIDS in Latin America
and the Caribbean

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Foreword

In 2002, it was estimated that 1.9 million adults and children were living with HIV/AIDS in Latin America and the Caribbean. Of these, an estimated 1.5 million were in Latin America and 470,000 in the Caribbean. Prevalence rates at 2% are the second fastest growing in the world. Prevalence rates in high risk groups can reach 5%, and there is a sharp rise in the case of women infected with HIV/AIDS. These speak to the urgent need to give concerted attention to the HIV/AIDS situation in all countries of the region.

In response, the IDB is undertaking efforts to help countries combat this epidemic and has launched a series on HIV/AIDS. As part of this series, this paper was prepared as a background document for a seminar entitled *HIV/AIDS and Development: Challenges and Responses in Latin America and the Caribbean* held at the Annual Meeting of the Boards of Governors of the Inter-American Development Bank and Inter-American Investment Corporation in March 2002.

It focuses on a rather unexplored dimension to date of the epidemic: the resulting stigma and discrimination and its impact on the effectiveness of HIV/AIDS programs. This paper presents a conceptual framework that explains the interplay between stigma, discrimination and human rights. The paper also provides guidelines for developing programmatic activities that situate HIV/AIDS-related stigma and discrimination within the broader social context where a variety of stigmas related to class, race, gender and ethnicity exist. Thus, the framework and the paper can be useful both to those fighting the spread of HIV/AIDS as well as to those fighting exclusion in other social contexts.

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Introduction

All over the world and throughout the Americas, HIV and AIDS have shown themselves capable of bringing out the best and the worst in people. They trigger the best when, in solidarity, individuals group together to combat denial and to offer support and care to individuals infected and affected by the epidemic. They bring out the worst when people are stigmatized, ostracized and treated badly by their loved ones, their family and their communities. Such actions not infrequently result in discrimination and the abuse of human rights (see, for example, Daniel and Parker, 1993; Altman, 1994).

The Declaration of Commitment published after the 2001 United Nations General Assembly Special Session (UNGASS) on HIV/AIDS highlighted how the realization of human rights is an essential element in the global response to the HIV/AIDS pandemic. Protecting and promoting human rights reduces vulnerability to HIV/AIDS and prevents stigma and related discrimination against people living with or at risk of HIV/AIDS. Governments were called upon to develop strategies to combat stigma and social exclusion, and to develop legal and policy frameworks that protect in the workplace the rights and dignity of persons living with and affected by HIV/AIDS. The Declaration of Commitment also sets out targets for monitoring achievement.

More recently, Peter Piot, Executive Director of UNAIDS, has drawn attention to the ways in which HIV/AIDS-related stigmatization and discrimination make prevention difficult by forcing the epidemic out of sight and underground. In a statement to the Plenary of the World Conference Against Racism held in Durban, South Africa, in September 2001, he said:

> HIV stigma comes from the powerful combination of shame and fear. Shame because the sex or drug injecting that transmit HIV are surrounded by taboo and moral judgement, and fear because AIDS is relatively new, and deadly. Responding to AIDS with blame, or abuse for people living with AIDS, simply forces the epidemic underground, creating the ideal conditions for HIV to spread. The only way of making progress against the epidemic is to replace shame with solidarity and fear with hope.

And in the Americas too, the importance of combating HIV/AIDS-related stigma and discrimination has been highlighted in numerous conferences and meetings. As Mirta Roses Periago, Director of the Pan American Health Organization, recently put it,

> Important gains in child health and life expectancy in the continent are being swept back by AIDS, destroying the efforts and investments of past decades. The poor get infected, and those infected become poor and iso-

> lated by stigma and sickness, rejected from schools and jobs.

But what is HIV- and AIDS-related stigma? Where does it come from and what does it do? Clear answers to these questions are important if we are to make progress in challenging the destructive and negative responses that HIV/AIDS can give rise to.

Understanding HIV/AIDS-related Stigma and Discrimination

HIV/AIDS plays to some deep-seated fears and anxieties—fear of germs and disease, fear of death, and anxieties about sex (Patton, 1985). There are major similarities between HIV/AIDS-related stigma and discrimination and some of the negative social reactions triggered by diseases such as leprosy, tuberculosis and cancer (Sontag, 1988).

But the stigma and discrimination that HIV/AIDS has given rise to is much more than this. All over the world, and especially in Latin America and the Caribbean, it has systematically played to, and reinforced, existing prejudices and anxieties—about homo- and bisexuality, about prostitution and sex work, and about injecting drug use.

Understanding these links is vital if we are to develop effective responses. For HIV/AIDS-related stigma is not something that resides in the minds of individuals. Instead, as we shall see, it is a *social product* with deep societal origins. Therefore, tackling stigma and the discrimination to which it gives rise calls for strong measures—interventions that go beneath the surface of things to deal with underlying structures and root causes.

The Nature of Stigma

The origins of the word stigma can be traced to the classical Greek where the term was used to describe the branding of outcast groups as a permanent mark of their status. More recent discussions of stigma, particularly in relation to HIV and AIDS, have their point of departure in the now classic work of Goffman (1963), which defined stigma as "an attribute that is significantly discrediting" and which, in the eyes of society, serves to reduce the person who possesses it.

Drawing on research with people suffering from mental illness, possessing physical deformities, or practicing what were perceived to be socially deviant behaviors such as homosexuality or criminal activity, Goffman (1963) argued that the stigmatized individual is a person who possesses "an undesirable difference." Stigma is conceptualized by society on the basis of what constitutes *difference* or *deviance*, and is applied through rules and sanctions resulting in a *spoiled identity* for the person concerned.

Important as Goffman's formulation of this problem was, for an adequate understanding of stigmatization in the context of HIV/AIDS, it is necessary to think carefully about this analytic category and to re-think some of the directions that it has pushed us in. Above all, Goffman's emphasis on stigma as a *discrediting attribute* has led many people to think of stigma as though it were a "thing"—a cultural or individual value. The emphasis given to possessing an *undesirable difference* that leads to a *spoiled identity*, in turn, has encouraged highly individualistic analyses. Thus stigma, understood as a negative attribute, is mapped onto people, who in turn by virtue of their difference, are understood to be negatively valued in society.

Since the publication of Goffman's influential study, the research literature on stigma has grown rapidly. Probably, the largest percentage of this has come from social psychologists who have examined how individuals construct categories and incorporate these categories in stereotypical beliefs (see, for example, Crocker, Major and Steele, 1998; Link and Phelan, 2001). The central thrust of much of this research has been on the perceptions of individuals and the consequences of these perceptions for social interactions (see Oliver, 1992; Link and Phelan, 2001). Much work too has tended to focus on stereotyping as something that individuals do to others. All too often, stigma comes to be seen as something that resides within the person stigmatized, rather than a *designation that others attach* to that individual (Link and Phelan, 2001).

This has important programmatic consequences on numerous interventions that aim to increase levels of *tolerance* toward people with HIV/AIDS by different segments of the general population. Efforts have been made, for example, to *increase empathy and altruism* and to *reduce anxiety and fear* by providing what is perceived to be correct information and by developing psychological skills thought to be essential to more effective management of the emotional responses that are thought to be unleashed by HIV/AIDS (see, for example Ashworth *et al.*, 1994; Hue and Kauffman, 1998; Mwambu, 1998; Soskolne *et al.*, 1993).

Such analyses, and the interventions that follow from them, have a number of significant weaknesses. Beyond their failure to recognize stigmatization as a *process* with which individuals and communities engage, they fail to account for (or intervene around) the *social structures* that give HIV- and AIDS-related stigma its meaning. Within a particular culture or setting, certain attributes are seized upon and defined as discreditable or not worthy within the context of HIV/AIDS. *Undesirable differences* and *spoiled identities* do not naturally exist, they are actively created by individuals and by communities. Stigmatization therefore describes a *systematic process of devaluation* rather than a "thing."

Importantly, much HIV- and AIDS-related stigma builds upon and reinforces prejudices. In countries throughout the Americas, people with HIV/AIDS are often believed to have deserved their illness because they have done something "wrong." Most usually, these "wrongs" are linked to sex or to illegal and socially frowned upon activities, such as injecting drug use. Men who become infected may be seen as homosexual, bisexual or as having had sex with sex workers. Women with HIV/AIDS are viewed as having been promiscuous, despite clear evidence to suggest that in the majority of cases they have acquired the infection from husbands and regular male partners.

Media images of HIV/AIDS as a *woman's disease*, a disease of '*prostitutes*, an *African disease* or a *gay plague* reinforce these stereotypes and beliefs. Although these images are varied, they are not random. In fact, they are patterned in a way that ensures that HIV-and AIDS-related stigma plays into, and reinforces, existing social inequalities. These include inequalities of wealth, inequalities that make women inferior to men, inequalities of nationality and ethnicity, and inequalities linked to sexuality and different forms of sexual expression (figure 1).

HIV/AIDS-related stigma is, therefore, linked to power and domination throughout society as a whole, and the stigmatization of individuals and groups as a result of HIV/AIDS plays a key role in producing and reproducing relations of power and control. Importantly, it causes some groups to be devalued and others to feel that they are superior in some way. Ultimately, HIV/AIDS-related stigma creates, and is reinforced by, *social inequality.*

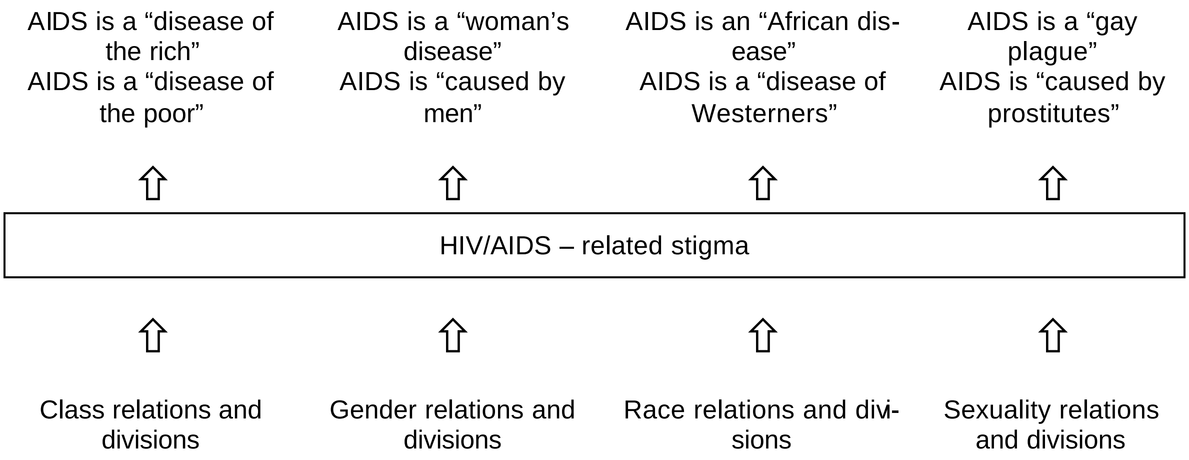
Discrimination

While references to HIV/AIDS-related stigmatization typically acknowledge Goffman and his work as intellectual precursors, discussions of discrimination are rarely framed in relation to any clear-cut theoretical tradition. This is true even when they are discussed, as is often the case, in tandem with stigma. The meaning of discrimination is taken almost for granted, as though it were obvious on the basis of simple common usage.

Importantly, while many writers have tended to view discrimination as an expression of ethnocentrism, or a *dislike of the unlike*, more recent analyses have concentrated on patterns of dominance and oppression, viewed as expressions of a struggle for power and privilege (Marshall, 1998). This emphasis is useful in helping us think about HIV/AIDS-related discrimination, and the manner in which it contributes to processes of social exclusion and inclusion.

Stigma is harmful not only in itself (since it can lead to feelings of shame, guilt and isolation), but also because of its larger societal impact. The enactment of prejudiced ideas can lead individuals to do things (or not do things) that harm others or deny them services or entitlements. Hospital or prison staff, for example, may seek to deny health services

Figure 1
The Production of HIV/AIDS-related Stigma



to a person living with HIV/AIDS. Or, employers may seek to terminate workers' employment on the grounds of HIV status. Such acts constitute discrimination. Put succinctly, discrimination occurs when a distinction is made against a person that results in their being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group. Discrimination can, of course, occur at many different levels: at the level of the individual, or at the level of the community or society as a whole.

Across the world, there have been numerous instances of HIV/AIDS-related discrimination. People with HIV/AIDS (or who are believed to have HIV/AIDS) have been segregated in schools and hospitals, refused employment, denied the right to marry and form lasting relationships, required to submit themselves to HIV tests in connection with travel or even to return to their home country, and attacked or even killed because of their sero-positive status (see Maluwa, Aggleton and Parker, 2002) for a discussion of these issues).

Throughout the Americas, there have been numerous cases of discrimination on the grounds of HIV/AIDS (box 1).

Because of HIV/AIDS-related discrimination, the rights of people living with HIV/AIDS and their families are often violated, simply because they are known or presumed to have HIV/AIDS. This violation of rights increases the negative impact of the epidemic at many levels.

At the level of the *individual*, for example, it causes undue anxiety and distress—factors that in themselves contribute to ill health. At the level of the *community*, it causes whole families and groups to feel ashamed, to conceal their association with the epidemic, and to withdraw from participation in more positive social responses. And at the level of *society as whole*, discrimination against people with HIV/AIDS and human rights abuses reinforce the mistaken belief that it is acceptable that those infected with HIV/AIDS should be ostracized and blamed. A vicious cycle exists between stigma, discrimination and human rights violations (figure 2).

Box 1

Some recent cases of HIV- and AIDS-related Discrimination in the Americas

In ***Trinidad and Tobago***, children with HIV/AIDS have been denied access to primary school because of parental fears and anxieties. "I totally disagree with children with HIV being in schools with our children," a mother was reported as saying on a recent television talk show. Another caller, responding to the news that two HIV positive children were about to enter primary school, called on the authorities to "build a (special) school for those children."

In ***Chile***, there have been numerous reports of people having lost their jobs once their HIV status is known. Machismo, homophobia, family honor and sexual silence are among the many factors said to have contributed to this. The existence of a name-based system of national reporting further compounds the problem.

In ***Peru***, soccer-player Eduardo Esidio was removed from the University Sports Club professional team in January 1999 when it was discovered that he was HIV positive. The directors of the club argued that his presence in the locker room endangered the rest of the players, and that other teams would refuse to play against them.

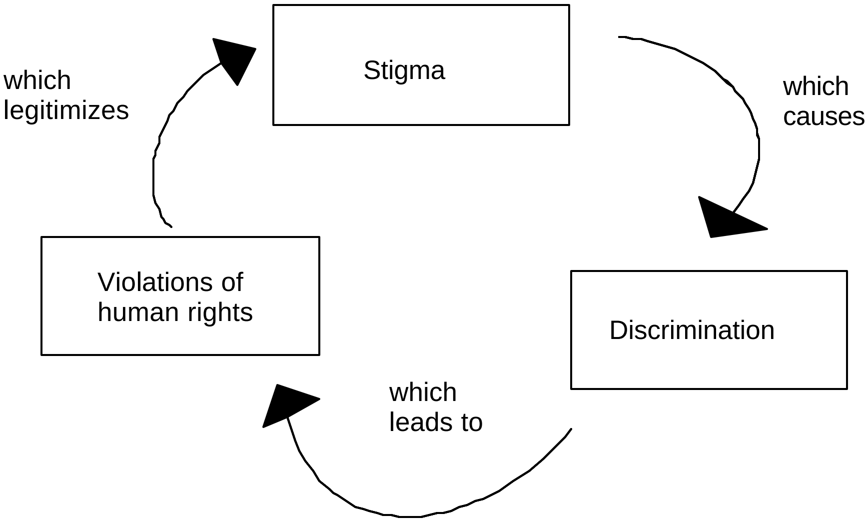
In ***Mexico***, the Human Rights Commission recently castigated staff at O'Horán Hospital in Mérida, Yucatan, for serious irregularities in the medical care afforded to people with HIV/AIDS, including grave lack of medical care, breach of confidentiality and lack of respect for human rights.

In ***Costa Rica***, efforts were made to transfer Minor Navarro, a school teacher in a small community near San José, to a new posting after his serostatus became known. Navarro declined the transfer and took his case directly to the Education Ministry, which at first declined to act. After protests from a variety of groups, the country's ombudsman ("Defensoría de los Habitantes'') intervened requiring the transfer decision to be reversed.

In ***Brazil***, in spite of the widely acknowledged quality of the Ministry of Health's national STI/AIDS program, discrimination continues to be felt not only by people living with HIV and AIDS, but also by groups perceived to be affected by the epidemic. Some civil service entry procedures continue to require HIV tests as part of the medical examinations.

Sources: http://www.aegis.com/news.

Figure 2
The 'Vicious Cycle' of Stigma, Discrimination and the Violation of Rights



A Rights-based Response

Freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal and perpetual. Human rights inhere in individuals because they are human and apply to people everywhere in the world. The core existing human rights instruments and the American Convention on Human Rights prohibit discrimination based on race, color, sex, language, religion, political or other opinion, national or social origin, economic status, birth, or any other social status.[1]

Recent UN Commission on Human Rights resolutions (1999/49 and 2001/51), have stated quite unequivocally that the term "or other status" in nondiscrimination provisions in international human rights texts should be interpreted to cover health status, including HIV/AIDS. They have, moreover, confirmed that "discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards." Discrimination against people living with HIV/AIDS, or those thought to be infected, is therefore a clear violation of their human rights.

Why is this important, and why should the links between stigma, discrimination and human rights be more clearly recognized and acted upon? There are several reasons. First, because since freedom from discrimination is a human right, there is an existing framework for responsibility and accountability of action. This need not be created afresh within the context of HIV/AIDS. National governments are responsible and accountable not only for not directly violating rights, but also for ensuring the conditions that enable individuals to realize their rights as fully as possible. Whether they openly acknowledge it or not, nations have the obligation to respect protect and fulfil human rights.

In relation to discrimination, for example, the obligation to *respect* requires countries not to directly or indirectly discriminate in law, policy or practice. The obligation to *protect* requires them to take measures that prevent third parties from discriminating,[2] and the obligation to *fulfil* requires them to adopt appropriate legislative, budgetary, judicial, promotional and other measures to ensure that strategies, policies and programs are developed that address discrimination and ensure that compensation is paid to those who suffer discrimination.

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[1] The right to nondiscrimination is enshrined in Article 2 of the Universal Declaration on Human Rights; International Covenant on Civil and Political Rights; International Covenant on Economic Social and Cultural Rights; Convention on Elimination of All Forms of Discrimination Against Women; Convention on the Rights of the Child; the African Charter.

[2] For example, the adoption of legislation to ensure equal access to health care and health related services provided by third parties, to control the marketing of medicines and medical equipment, and to ensure that medical practitioners and other health professionals meet appropriate standards of education, skill and ethical codes of conduct.

Second, a human rights framework enables access to procedural, institutional and other monitoring mechanisms for enforcing the rights of people living with HIV and AIDS, and for countering and redressing discrimination. Since HIV/AIDS-related discrimination leads to the commission of legal offences, persons who discriminate can be made accountable by law and redress can be provided, where appropriate. Relevant procedural, institutional and other monitoring mechanisms exist at national, regional and international levels. At the national level these include the judicial system (courts of law), national human rights commissions, ombudsmen, law commissions and other administrative tribunals.

This is not to suggest, however, that a focus on discrimination will inevitably lead to an improved situation. Gaps exist in people's awareness of the fact that discrimination is unlawful. Legal services are normally neither affordable nor close to the most vulnerable communities. And there may be problems in obtaining redress for the infringement of rights. However, one thing is absolutely clear: a focus on discrimination provides a useful entry point to hold accountable those whose actions lead to discrimination and the violation of human rights.

The Power of Community

Beyond the use of law, there are other social processes and mechanisms that can be productively utilized in efforts to challenge HIV/AIDS-related stigma and discrimination. Some of these derive from the power of individuals and communities to *resist* and fight back against inequality and oppression. The history of HIV/AIDS throughout the Americas contains numerous instances of successful community struggle to educate and challenge stereotypes and divisive beliefs, to tackle inequities, discrimination and human rights violations and, more recently, to widen access to treatment drugs.

To understand the power of resistance as it relates to HIV/AIDS, it is important to situate our analysis of HIV/AIDS both socially and historically. The epidemic has developed during a period of rapid globalization linked to a radical restructuring of the world economy and the growth of *informational capitalism* (Castells, 1997a, 1997b). These changes have been characterized by rapidly accelerating processes of social exclusion, together with an intensified interaction between what might be described as traditional and more modern forms of exclusion.

Recent work on the transformation of the global system and the political economy of *informationalism* has highlighted the importance of social identity (or, often, identities) as central to contemporary experience. There can be few people or groups who do not possess a social identity, either self-constructed or ascribed to them by others: as *old*, *middle-aged* or *young*; as *Black*, *Latinos* or *whites*; as *lesbians*, *gay men*, *bisexuals* or *straight*; as *progressive*s, *middle-of-the-roaders* or *conservatives*; as *healthy people* or as *people living with HIV/AIDS*, to offer but a few examples.

Importantly, in addition to enabling self-understanding, such identities provide the basis for social action on the basis of a common position in life. Such insight is helpful in seeking to understand how people respond to the process of stigmatization. Recent work on identity (be it self constructed or imposed), for example, has emphasized its constantly changing character. Not infrequently, experiences of oppression trigger resistance and the formation of identities that seek to transform existing social relations (Hall, 1990).[3] Such a process is no less likely to occur in relation to HIV/AIDS-related stigmatization and discrimination than other contemporary forms of oppression.

Manuel Castells (1997a, 1997b) has distinguished between the types of identity possible within relations of inequality. *Legitimizing identities* are those introduced by the dominant institutions of society to extend and rationalize their domination vis-à-vis social actors. *Resistance identities*, on the other hand, are

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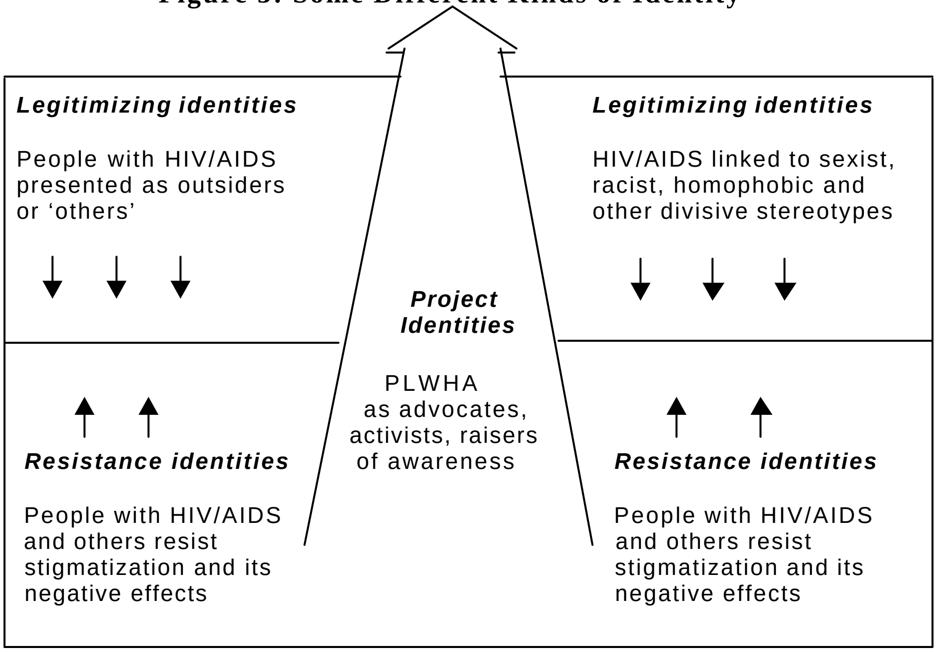
[3] The women's movement, social movements linked to race and sexual equality, and popular political movements all over the world attest to such potential.

those generated by those actors that are in positions/conditions devalued and/or stigmatized by the logic of domination. Finally, *project identities* are formed when social actors, on the basis of whatever cultural materials are available to them, build a new identity that redefines their position in society and, by so doing, seek the transformation of overall social structure.

Such a framework has much to offer when it comes to understanding the effects of HIV/AIDS-related stigmatization and discrimination. As we saw earlier, many of the *legitimizing identities* associated with HIV/AIDS play to social divisions of race, class, gender and sexuality. They construct people with HIV/AIDS as *others*—dangerous people (women, foreigners, poor people, gays, etc) who require to be controlled. But the imposition of such identities is not uncontested, as the experience of organizations of people living with HIV/AIDS all over the world shows.

Figure 3: Some Different Kinds of Identity



Resistance identities quickly arise in response to stigmatization. All over the world, people with HIV/AIDS, both individually and collectively, have been at the forefront of efforts to challenge the negative social identities ascribed to them. They have been joined in their struggles by individuals and groups (including doctors, politicians, health care workers, teachers and academics) disturbed at the near exclusive portrayal of people with HIV/AIDS in negative terms.

In seeking to resist the effects of stigmatization, new *project identities* have been formed through HIV/AIDS activism and involvement. These vary from those that emphasize the centrality of people with HIV/AIDS to work to prevent HIV and mitigate its impact,[4] to those that have

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[4] Through the GIPA principle, for example. See UNAIDS (1999) *From Principle to Practice.*

sought to challenge the actions of governments and multinational drug companies around treatment drug access.[5] Yet other project identities have been forged within families and communities all over the world, as people living with HIV/AIDS have shared their serostatus with relatives and friends, thereby *opening up* the epidemic in new ways.[6]

Such ideas offer important insights and avenues for responding more effectively to HIV- and AIDS-related stigmatization and discrimination. They suggest, for example, that in certain circumstances, stigmatization and discrimination can trigger positive responses of solidarity and inclusion. Numerous examples of this process are apparent across the Americas.

In Mexico, for example, the community group *Michoacanos Unidos por la Salud y Contra el SIDA* (MUSS) has recently been successful in challenging, through the state and national human rights commissions as well as through relevant government ministries, the decision of a school director to prevent the eight year-old daughter of a woman living with HIV/AIDS from attending school. The daughter was said to pose an HIV/AIDS risk because she was losing her baby teeth. Through concerted civil action on a variety of fronts, not only was the case successfully dealt with, but community support and organization were strengthened in the process.

Some of the most dramatic instances of success, however, have occurred when efforts have been made simultaneously to promote the human rights of people living with HIV/AIDS, and to unleash the power of oppressed communities to fight back and take charge of their lives. Nowhere can this process be seen more clearly than in relation to access to antiretroviral medication.

Greater Involvement of People Living with or Affected By HIV/AIDS. Geneva, UNAIDS. Also at http://www.unaids.org/publications/documents/persons/una9943e.pdf

[5] See, for example, http://www.globaltreatmentaccess.org/

[6] See UNAIDS (2001) *Opening Up the HIV Epidemic*. Geneva, UNAIDS. Also at http://www.unaids.org/publications/documents/epidemiology/surveillance/JC485-Opening-E.pdf

Box 2
Some Instances of Success

In ***Costa Rica***, where official resistance to antiretroviral therapy was initially premised on the assumption that it was too expensive to provide, a small group of people living with AIDS –(the Patient Coalition) negotiated for a year with the government. Frustrated, the group appealed to the Supreme Court in 1997 and won its support, forcing the government to begin offering antiretroviral drugs to people with HIV/AIDS. Today, a substantial number of Costa Ricans with AIDS receive combination therapy.

In ***Venezuela***, a combination of activism and commitment to human rights has brought remarkable progress with respect to treatment access. In 1997, Acción Ciudadana Contra el Sida (AC-CSI) filed a suit on behalf of 11 people with HIV/AIDS who were covered by the Social Security System. The claimants were not receiving proper medical attention, thereby their rights to non-discrimination, health, equality, access to science and technology and access to social security, as guaranteed by the national constitution, the American Convention on Human Rights, and other conventions signed and ratified by Venezuela, were being infringed. In May 1997, the court upheld the lawsuit and ordered the Social Security System to provide treatments (including protease inhibitors) on a regular basis at no cost. Numerous successful lawsuits have subsequently been filed, including those against the Ministry of Defence and the Ministry of Health.

In ***Brazil***, the decision to commence local production of antiretroviral medications was triggered in part by community activism and a concern for social justice. In 1996, shortly after the success of a new generation of such medications had been reported at the 11th International Conference on AIDS in Vancouver, Canada, the Brazilian National STD/AIDS Program sought to provide universal access to antiretroviral medications to all Brazilian citizens. The legal right of all Brazilians to receive antiretroviral treatments if necessary was guaranteed in a law approved by the Brazilian Congress. But the ability of the government to provide antiretroviral treatments to all who require them has consistently been threatened by the high cost of purchasing these medications from international companies. As a result, the government, with strong backing from AIDS activists and community-based organizations, has pursued an aggressive policy of locally producing medications that are not protected by international patent restrictions in order to significantly reduce the cost of the government's treatment access program. Despite this success, the risk of discontinuation and interruption of treatment availability continues to be a concern. In many cases, as in the widely publicized treatment access program developed in ***Brazil***, local pressure and political action has succeeded in overcoming frequent threats to antiretroviral distribution.

Source: http://www.aegis.com/news; http://www/aidslaw.com; Rezende, H. and Rey, V. "A vida por um frasco de remédios." *Correio Brasiliense*. 09 September 99. p. 15; Passarelli, C. and Terto Jr. V., "Good medicine: Brazil's Multifront War on AIDS." *NACLA Report on the Americas*, Volume 35, Number 5, March/April 2002, pp. 35-42.

A Multi-faceted Response

Throughout this review, we have argued that in order to successfully challenge HIV/AIDS-related stigmatization and discrimination, we must first understand what these phenomena are, and where they come from. Contrary to popular belief, stigma and discrimination are not "things" or "discrete events," but social processes linked to powerful forces deep within the structure of society. Tackling them successfully, therefore, requires efforts to reduce their surface manifestations together with action to deal with their fundamental root causes.

The use of the law to promote human rights within the context of HIV/AIDS has much to offer. However, any law inevitably remains a dead letter unless supported by the values, expectations and actions of society as a whole. Changes in cultural values and social attitudes, and concrete acts of resistance (on a variety of fronts), are required if we are to move beyond what might be described as a *legalistic* response, unacknowledged and largely un-owned by the population(s) whose rights it is intended to protect.

Too often in the past, efforts to reduce stigma and discrimination have been developed from a model of "liberal enlightenment," in which those who know best intervene to correct the "bad" thoughts and actions of others. This "banking" theory of pedagogy, as the educationalist Paulo Freire (1970) once described it, sees the minds of those who are being educated as empty vessels waiting to be filled with the good ideas of intervention specialists and communications experts. Needless to say, people are rarely taken in by such approaches.

More successful by far are efforts to unleash the power of resistance on the part of stigmatized populations and communities so as to enable them to fight back against stigmatization and oppression in relation to their lives. As Noerine Kaleeba and colleagues (2000) have pointed out, it is the power of community to resist and to *take charge* (not, on the whole, psychological, behavioral interventions) that in many countries has made greatest headway against the epidemic.

The importance of such approaches is well documented, especially in the Americas, where a long tradition of popular education in health and social development has provided a solid basis for the development of programs aimed at consciousness raising, empowerment and community mobilization. One of the key lessons learned from such work has been the importance of directly confronting stigma and discrimination, not only in relation to HIV/AIDS, but also in relation to the other forms of social inequality and exclusion that disempower those most vulnerable to HIV infection.

But what might such approaches look like, and how do they work? In São Paulo, Brazil, for example, recent research has shown that in order to develop effective HIV/AIDS prevention interventions for inner-city youth, it is necessary to first confront issues of poverty and economic marginalization, the stigma and racism associated with the status of many as migrants from the poor, northeastern region of the country, and the unequal power relations and norms associated with gender in Brazilian culture. By focusing not only on HIV/AIDS, but also on these other issues, Brazilian health promotion workers, like those in other parts of the Americas, have demonstrated the potential of what might be described as a kind of community pedagogy, as the key foundation for a more effective response to HIV/AIDS (Paiva, 2000).

The time is ripe to build upon empirical evidence, as well as the conceptual framework articulated here, to develop new models for advocacy and social change in response to HIV/AIDS-related stigmatization and discrimination. What might these be? If human rights advocacy and action, together with community mobilization for social change are an important element of such an approach, then these must take place alongside structural or environmental interventions to transform the broader context in which individuals and communities live as the response to HIV/AIDS (Sweat and Dennison, 1995; Parker, Easton and Klein, 2000).

Importantly, while available research has shown at best very limited results in changing stigmatizing attitudes through "empathy inducement" or other therapeutic and psychological interventions (Parker and Aggleton, 2002), policy interventions across a range of many settings have shown real effectiveness in changing people's actions and behaviors. Legal protections for people living with HIV and AIDS, and appropriate reporting and enforcement mechanisms, are powerful ways of mitigating the worst affects of the unequal power relations, social inequality and exclusion that lie at the heart of HIV- and AIDS-related stigmatization and discrimination.

In countries throughout the Americas, there is a need for greater support for community legal aid centers and/or legal services to tackle instances of discrimination and the abuse of human rights. Given the heavy stigma already associated with HIV/AIDS, these should be able to offer individuals confidentiality and respect. Basing such services in HIV/AIDS service organizations or other community-based organizations working on HIV/AIDS, may be one way of helping to develop trust, especially where such organizations are already valued and respected by those with whom they work.

Beyond this, however, there is an urgent need to train and support existing legal aid institutions in developing their approach to human rights and HIV/AIDS, and in encouraging the creation of lawyers' collectives specializing in HIV/AIDS-related concerns.[7] Training the members of associations of people living with HIV/AIDS in matters relating to human rights and HIV/AIDS is also important, so that these associations can provide in-house paralegal advice, counselling and support.

Again, there is strong evidence of the importance of such programs, particularly from Brazil, where the early legal aid services established in the late 1980s

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[7] For example: *Alter Law* in the Philippines and the *Lawyers Collective HIV/AIDS Unit* in Mumbai, India. These are groups of lawyers specializing in HIV/AIDS related cases and offering free legal service in this area

by community-based organizations such as the Pela VIDDA Group in Rio de Janeiro and GAPA in São Paulo were instrumental not only in protecting the rights of individual clients, but also in influencing jurisprudence more generally in ways that have helped to guarantee access to health care as a fundamental right of all citizens (Ventura, 1999). It is very possibly the case that such work provided the legal foundation for Brazil's highly regarded treatment access program, which is guaranteed by legislation passed by the Brazilian Congress, but rests on the fundamental rights established judicially through more than a decade of legal aid work. These important innovations have subsequently been made concrete within the structure of the state itself, through the establishment of government sponsored rights watch activities, such as Ministry of Health's National Network for Human Rights on HIV/AIDS (Ventura, 1999).

Given the close linkage between stigma, discrimination and human rights, it is important at all times to keep in mind the need for a multi-levelled complementary alleviation strategy that includes two facets. First, efforts to prevent the stigmatization of people and/or communities living with and affected by HIV/AIDS, and second, actions to address or redress the situation when stigma persists and is acted upon in the form of discriminatory actions that lead to negative consequences or the denial of entitlements or services to others, and thus human rights violations.

Together with a new emphasis on community mobilization aimed at unleashing resistance to stigmatization and discrimination, structural interventions aimed at promoting a rights-based approach to reducing HIV- and AIDS-related stigmatization and discrimination should be given high priority in future work. Only in this way can we create a transformed social climate in which stigmatization and discrimination themselves are no longer accepted, or acceptable.

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