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## HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action

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### Abstract

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 programmes 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.

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### Introduction

For nearly two decades, as countries all over the world have struggled to respond to the HIV/AIDS epidemic, issues of stigma, discrimination and denial have been poorly understood and often marginalized within national and international programmes and responses. In some ways this is paradoxical, since concern about the deleterious effects of HIV and AIDS-related stigma has been voiced since the mid-1980s. In 1987, for example, Jonathan Mann, the founding Director of the World Health Organization's former Global Programme on AIDS, addressed the United Nations General Assembly. In what would soon become a widely accepted conceptualization, he distinguished between three phases of the AIDS epidemic in

any community. The first of these phases was the epidemic of HIV infection—an epidemic that typically enters every community silently and unnoticed, and often develops over many years without being widely perceived or understood. The second phase was the epidemic of AIDS itself—the syndrome of infectious diseases that can occur because of HIV infection, but typically only after a delay of a number of years. Finally, he described the third epidemic, potentially the most explosive—the epidemic of social, cultural, economic and political responses to AIDS. This was characterized, above all, by exceptionally high levels of stigma, discrimination and, at times, collective denial that, to use Mann's words, "are as central to the global AIDS challenge as the disease itself" (Mann, 1987).

By 1995, WHO/GPA had been superseded by the Joint United Nations Programme on HIV/AIDS (UNAIDS), bringing together six different United Nations agencies with the explicit goal of recognizing the

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multiple social dimensions of the epidemic. Yet when Peter Piot, the Executive Director of UNAIDS, addressed the 10th meeting of the agency's Programme Coordinating Board in December of 2000, he turned in his concluding remarks to outline what he described as "the continuing challenge". Top of his list of "the five most pressing items on this agenda for the world community" was the need for a "renewed effort to combat stigma". He went on to emphasize, "this calls for an all out effort, by leaders and by each of us personally. Effectively addressing stigma removes what still stands as a roadblock to concerted action, whether at local community, national or global level" (Piot, 2000). More recently still, HIV and AIDS-related stigma and discrimination have been chosen as the theme for the 2002–3 World AIDS Campaign, highlighting the continuing pertinence of these concerns both conceptually and programmatically.

At least in part, our collective inability to more adequately confront stigmatization, discrimination and denial in relation to HIV and AIDS is linked to the relatively limited theoretical and methodological tools available to us. It is important, therefore, to critically evaluate the available literature on the study of stigma and discrimination, both independent of HIV/AIDS and more specifically in relation to it, in order to develop a more adequate conceptual framework for thinking about the nature of these processes, for analyzing the ways in which they work in relation to HIV and AIDS, and for pointing to possible interventions that might minimize their impact and their prejudicial effects in relation to the epidemic.

#### Stigmatization and discrimination as social processes

Much of what has been written about stigma and discrimination in the context of HIV and AIDS has emphasized the complexity of these phenomena, and has attributed our inability to respond to them more effectively to both their complex nature and their high degree of diversity in different cultural settings. As a recent USAID Concept Paper put it: "The problem is a difficult one, because underlying the apparent universality of the problem of HIV/AIDS-related [stigma, discrimination and denial] there appears to be a diversity and complexity that makes it difficult to grasp in a programmatically useful way" (USAID, 2000).

While it is important to recognize that stigma and discrimination are characterized by cross-cultural diversity and complexity, one of the major factors limiting our understanding of these phenomena may well be less their inherent complexity than the relative simplicity of existing conceptual frameworks. To make serious progress in analyzing and responding to these phenomena, it may therefore be necessary not only to attend to

their cross-cultural complexity and specificity, but to re-think some of the taken for granted frameworks within which we are encouraged to understand them.

Typically, discussions of stigma, particularly in relation to HIV and AIDS, have taken as their point of departure the now classic work of Goffman (1963), defining stigma as "an attribute that is significantly discrediting" which, in the eyes of society, serves to reduce the person who possesses it. Drawing on research experience with people suffering from mental illness, possessing physical deformities, or practicing what were perceived to be socially deviant behaviours such as homosexuality or criminal behaviour, Goffman (1963) argued that the stigmatized individual is thus seen to be a person who possesses "an undesirable difference". He argued that stigma is conceptualized by society on the basis of what constitutes "difference" or "deviance", and that it is applied by society through rules and sanctions resulting in what he described as a kind of "spoiled identity" for the person concerned (Goffman, 1963).

Useful and important as Goffman's formulations of this problem were, a fuller understanding of stigmatization, at least as it functions in the context of HIV/AIDS, requires us to unpack this analytic category—and to re-think the directions that it has pushed us in our research and intervention work. Above all, the emphasis placed by Goffman on stigma as a "discrediting attribute" has led to a focus on stigma as though it were *a kind of thing* (in particular, a cultural or even individual value)—a relatively static characteristic or feature, albeit one that is at some level culturally constructed. The emphasis Goffman's work gave to possessing an "undesirable difference" which leads to a "spoiled identity", in turn, has encouraged highly individualized analyses in which words come to characterize people in relatively unmediated fashion. 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.

It is important to recognize that neither of these emphases is in fact drawn directly from Goffman, who, on the contrary, was very much concerned with issues of social change and the social construction of individual realities. Indeed, one reading of Goffman's work might suggest that, as a formal concept, stigmatization *devalues relationships* rather than being a fixed attribute. Yet the fact that Goffman's framework has been appropriated in much research on stigma (whether in relation to HIV/AIDS or other issues), as though stigma were a static attitude rather than a constantly changing (and often resisted) social process has seriously limited the ways in which stigmatization and discrimination have been approached in relation to HIV and AIDS.

In the years that have passed since the publication of Goffman's influential study, the research literature on

stigma has grown rapidly. The concept of stigma has been applied to an exceptionally wide range of different circumstances, particularly in relation to health, ranging from leprosy (Opala & Boillot, 1996), to cancer (Fife & Wright, 2000), urinary incontinence (Sheldon & Caldwell, 1994), and mental illness (Corrigan & Penn, 1999; Phelan, Link, Steuve, & Pescosolido, 2000).<sup>1</sup> This literature has included refinements of Goffman's original formulation, elaborations on the themes that he first raised, and extensive demonstrations of the impacts that stigmatization can have on the lives of those who are affected by it.

Probably, the largest percentage of this rapidly expanding literature has come from social psychologists who have used social-cognitive approaches in order to examine the ways in which individuals construct categories and incorporate these categories in stereotypical beliefs (see Crocker, Major, & Steele, 1998; Link & Phelan, 2001). Yet much of this work too has suffered from serious conceptual limitations—even the definition of stigma has typically been exceptionally vague and highly variable (see Link & Phelan, 2001). Indeed, in much of the existing literature on stigma, investigators provide no definition at all, or seem to refer to something like a dictionary definition—'a mark of disgrace', or some similar aspect such as stereotyping or social rejection. When definitions are offered, they have been relatively limited. Stafford and Scott (1986, p. 80), for example, have written of stigma as 'a characteristic of persons that is contrary to a norm of a social unit'. Crocker et al. (1998, p. 505) argue that people who are stigmatized 'possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context'. Jones et al. (1984) have argued that stigma is a 'mark' that links a person to undesirable characteristics such as stereotypes.

In addition to the problems involved in defining stigma, perhaps in part because of the strong social-cognitive focus adopted, there has been an individualistic emphasis in much of what has been published. The central thrust of much research has been on the perceptions of individuals and the consequences these perceptions for social interactions (see Oliver, 1992; Link & Phelan, 2001). Much work has tended to focus on stereotyping rather than on the structural conditions that produce exclusion from social and economic life, and social psychological analyses have often transformed perceived stigmas into marks or attributes of persons (see Fine & Asch, 1988; Fiske, 1998; Link & Phelan, 2001). In this case, stigma comes to be seen as something *in* the person stigmatized, rather than as a

designation that others attach *to* that individual (Link & Phelan, 2001).

These tendencies have in large part been reproduced and extended in much of the research that has been carried out on stigma in relation to HIV and AIDS.<sup>2</sup> As in the broader literature on stigma, much work on HIV and AIDS-related stigmatization has tended to understand stigma in highly emotional terms—for example, as 'anger and other negative feelings' toward people living with HIV and AIDS, that in turn leads to 'the belief that they deserve their illness, avoidance and ostracism, and support for coercive public policies that threaten their human rights' (see Herek, Capitanio, & Widaman, 2002; see, also, Blendon, Donelan, & Knox, 1992; Crandall, Glor, & Britt, 1997; Crawford, 1996; Goldin, 1994; Green, 1995; Herek, 1990; Herek & Capitanio, 1993, 1997; Kelly, Lawrence, Smith, Hood, & Cook, 1987; Tewksbury & McGaughey, 1997). Other research has focused on 'stigmatizing attitudes' and the extent to which such attitudes are correlated with misunderstandings and misinformation concerning the modes of HIV transmission or the risk of infection through everyday social contact (Herek et al., 2002, p. 371; see, also, Herek & Capitanio, 1994, 1997; Herek & Glunt, 1991; Stipp & Kerr, 1989), or with 'negative attitudes' toward the groups that are believed to be disproportionately affected by the epidemic, such as gay and bisexual men, injecting drug users or sex workers (see Herek et al., 2002, p. 371; see, also, Herek & Capitanio, 1998; Pryor, Reeder, Vinacco, & Kott, 1989; St. Lawrence, Husfeldt, Kelly, & Hood, 1990).

Given this point of departure, it is perhaps not surprising that much of the empirical research that has been carried out on stigma in relation to HIV and AIDS thus far has tended to focus heavily on the beliefs and attitudes of those who are perceived to stigmatize others. Public opinion polls and surveys of knowledge, attitudes and beliefs about HIV and AIDS, those affected by the epidemic, or those perceived to be at risk of HIV infection have dominated the research literature (see, for example, Blendon & Donelan, 1988; Blendon et al., 1992; Herek, 1999; Herek & Capitanio, 1993, 1994, 1997, 1999; Herek & Glunt, 1991; Herek et al., 2002; Price & Hsu, 1992; Singer, Rogers, & Corcoran, 1987; Stipp & Kerr, 1989). Both randomized samples and convenience samples have been used in such research, but almost always with the intent of investigating the emotional responses of the target population groups: 'negative feelings toward PWAs'; 'responsibility and blame'; 'discomfort'; and similar emotional responses are among the frequently investigated categories in seeking to assess levels of stigma existing in different population groups (see, for example, Herek et al., 2002).

<sup>1</sup>For an excellent overview of the literature on stigma in sociology, see Link and Phelan (2001).

<sup>2</sup>For an overview of this literature, see, in particular, Malcolm et al. (1998).

These emotional responses, in turn, are often linked to beliefs concerning the facts of HIV transmission—understandings of how the virus is transmitted, and, typically, misunderstandings about how it is not (see Herek et al., 2002). ‘Correct’ as opposed to ‘incorrect’ beliefs thus become the defining cause of stigmatization in relation to people living with HIV and AIDS, as well as of those perceived to be associated with the epidemic in a variety of different ways.

This basic approach to conceptualizing and investigating stigma in relation to HIV and AIDS has had important consequences, in turn, for the primary forms of intervening in response to stigma and stigmatization. The vast majority of the interventions that have been developed and evaluated in the research literature in order to respond to stigma related to HIV and AIDS have been aimed at increasing ‘tolerance’ of people with AIDS on the part of different segments of the ‘general population’. While the specific segments of the amorphous general population that have been targeted for intervention have varied significantly—ranging from psychology or nursing students in North America (Batson et al., 1997; Wyness, Goldstone, & Trussler, 1996) to pregnant women in Scotland (Simpson et al., 1998), immigrants in Israel (Soskolne et al., 1993), or commercial farmers and their employers in Zimbabwe (Kerry & Margie, 1996)—the key approaches have been remarkably similar. Strategies have been developed to ‘increase empathy and altruism’ and to ‘reduce anxiety and fear’ primarily 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 and AIDS as encountered by these different population groups (see Ashworth et al., 1994; Hue & Kauffman, 1998; Mwambu, 1998; Soskolne et al., 1993). Different interventions have thus focused on psychological counseling approaches (Kaleeba et al., 1997; Kerry & Margie, 1996; Kikonyogo et al., 1996; Simpson et al., 1998) and increasing contact with people living with HIV and AIDS on the part of those with little direct experience of the epidemic (Batson et al., 1997; Bean, Keller, Newburg, & Brown, 1989; Herek & Capitanio, 1997)—and on acquiring ‘coping skills’ in order to better manage the effects of stigmatization on the part of those living with HIV and AIDS (see Brown, Trujillo, & Macintyre, 2001).

Interestingly, while references to stigma and stigmatization in work on HIV and AIDS typically acknowledge Goffman and his work as intellectual precursors, discussions of discrimination are rarely framed in relation to any theoretical tradition whatsoever (even when discussed, as is often the case, in tandem with the discussion of stigma). The meaning of discrimination is normally taken almost for granted, as though it were given or obvious on the basis of simple common usage.

As the *Oxford Dictionary of Sociology* stipulates, however, “[t]his concept—which in common usage means simply “treating unfairly”—occurs most commonly in sociology in the context of theories of ethnic and race relations. Early sociologists...viewed discrimination as an expression of ethnocentrism—in other words a cultural phenomenon of “dislike of the unlike” (Marshall, 1998). More recent sociological analyses of discrimination, however, “concentrate on patterns of dominance and oppression, viewed as expressions of a struggle for power and privilege” (Marshall, 1998).<sup>3</sup>

This sociological emphasis on the structural dimensions of discrimination is particularly useful in helping us think more sensibly about HIV and AIDS-related stigmatization and discrimination. To move beyond the limitations of current thinking in this area, we need to reframe our understandings of stigmatization and discrimination to conceptualize them as social processes that can only be understood in relation to broader notions of *power* and *domination*. In our view, stigma plays a key role in producing and reproducing relations of power and control. It causes some groups to be devalued and others to feel that they are superior in some way. Ultimately, therefore, stigma is linked to the workings of *social inequality* and to properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings.

Much work exists within the social and political sciences that is directly relevant to this task, but so far little of this has been utilized in HIV/AIDS research.<sup>4</sup> This, we suspect, is the result of stigma and discrimination being conceived as individual processes—or as what some individuals *do* to other individuals. While such approaches may seem logical in highly individualized cultures (such as the modern-day USA and parts of

<sup>3</sup> Interestingly, in the *Oxford Dictionary of Sociology*, the entry for discrimination is linked (through the cross-associations typical throughout the dictionary entries), not to stigma but to prejudice and sexism. Prejudice, in turn, is described as “an unfavorable attitude towards a group or its individual members” (p. 522). In HIV/AIDS research, while stigma has been used extensively to describe AIDS-related attitudes, the term prejudice seems to have been much less frequently employed. As we will try to explain throughout this text, we are convinced that these issues of linguistic usage are not simply inconsequential. They have important implications for the ways in which societies have responded to HIV/AIDS-related stigmatization and discrimination.

<sup>4</sup> In particular, the work of writers such as Michel Foucault, Pierre Bourdieu, Antonio Gramsci, and Manuel Castells, described later.

Europe) where people are taught to believe they are nominally free agents, they make little sense in other environments. Throughout much of the developing world, for example, bonds and allegiances to family, village, neighbourhood and community make it obvious that stigma and discrimination, when and where they appear, are social and cultural phenomena linked to the actions of whole groups of people, and are not simply the consequences of individual behaviour (UNAIDS, 2000).

It is vitally important to recognize that stigma arises and stigmatization takes shape in specific contexts of culture and power. Stigma always has a history which influences when it appears and the form it takes. Understanding this history and its likely consequences for affected individuals and communities can help us develop better measures for combating it and reducing its effects. Beyond this though, it is important to better understand how stigma is used by individuals, communities and the state to produce and reproduce social inequality. It is also important to recognize how understanding of stigma and discrimination in these terms encourages a focus on the political economy of stigmatization and its links to social exclusion.

#### Culture, power and difference

Michel Foucault's work concerning the relation between culture or knowledge, power, and notions of difference is particularly helpful in engaging with these issues. Although Foucault's work was carried out at roughly the same time as Goffman's (mainly during the course of the 1960s and the 1970s) and focused on a number of similar concerns—issues such as mental illness, crime and punishment, and the social construction of deviance more generally—it had quite different cultural, intellectual and disciplinary origins. While Goffman's work was heavily influenced by the US sociology of the time and focused on the social construction of meanings through interaction, Foucault's work took shape in a very different context. In particular, and in line with the contemporary projects of European social philosophy, he wanted to better understand how different forms of knowledge come to be constituted in distinct historical periods.

For Foucault, fields such as psychiatry and biomedicine are best understood as 'cultural systems' that offer different claims to truth. The evidence they amass, and the understandings they promote are not 'facts' or 'truths' in any simple sense, but social products linked to the power of the professions. This more radical view of knowledge encourages a level of humility in the face of 'evidence' about the world—understandings are contextual and provisional (and this applies even to the

'hard' sciences and biomedicine), and must always be understood as such. As his work evolved, however, Foucault began to focus his attention not only on knowledge in and of itself, but also on the relationship between knowledge and power. He was particularly interested in what he called the regimes of power embedded in different knowledge systems, and the forms of control exercised by such systems over individual, as well as social, bodies.

Foucault's most influential studies of power, *Discipline and Punish* and *The History of Sexuality, Volume I: An Introduction*, placed emphasis on what he defined as a new regime of knowledge/power that characterized modern European societies during the late-nineteenth and early twentieth centuries (and much of the world thereafter) (Foucault, 1977, 1978). Within this regime, physical violence or coercion increasingly gave way to what he described as 'subjectification', or social control exercised not through physical force, but through the production of conforming subjects and docile bodies. He highlighted how the social production of difference (what Goffman and the US sociological tradition more typically defined as deviance) is linked to established regimes of knowledge and power. The so-called unnatural is necessary for the definition of the natural, the abnormal is necessary for the definition of normality, and so on.

While it focuses on issues similar to those examined by Goffman in his work on stigma (e.g., psychiatry and the mentally ill; prisons and criminals; sexology and sexual deviants or 'perverts', etc.), Foucault's work more clearly emphasizes the cultural production of difference in the service of power. While Goffman's work on stigma hardly even mentions the notion of power, and Foucault's work on power seems altogether unconcerned with stigma in and of itself, when read together their two bodies of work offer a compelling case for the role of culturally constituted stigmatization (i.e., the production of negatively valued difference) as central to the establishment and maintenance of the social order.

Within such a framework, the construction of stigma (or, more simply, stigmatization) involves the marking of significant differences between categories of people, and through such marking, their insertion in systems or structures of power. Stigma and stigmatization function, quite literally, at the point of intersection between *culture, power and difference*—and it is only by exploring the relationships between these different categories that it becomes possible to understand stigma and stigmatization not merely as an isolated phenomenon, or expressions of individual attitudes or of cultural values, but as central to the constitution of the social order. This new understanding has major implications for the ways in which we might investigate and respond to the specific

issues involved in HIV and AIDS-related stigma, stigmatization and discrimination.

### The strategic deployment of stigma

Placing culture, power and difference centre stage with respect to stigma, stigmatization and discrimination opens up new possibilities for research and intervention. But first we need to understand the ways in which these social processes function and operate.

In this respect, notions of *symbolic violence* (associated, in particular, with the sociological work of Pierre Bourdieu) and *hegemony* (initially elaborated in Antonio Gramsci's political theory, but more recently employed usefully in cultural analysis by writers such as Raymond Williams, Stuart Hall and others) are particularly useful. They highlight not only the functions of stigmatization in relation to the establishment of social order and control, but also the disabling effects of stigmatization on the minds and bodies of those who are stigmatized.

Like that of Foucault, Pierre Bourdieu's work has been concerned with the relations between culture and power (Bourdieu, 1977, 1984; Bourdieu & Passeron, 1977).<sup>5</sup> It aimed to examine how social systems of hierarchy and domination persist and reproduce themselves over time, without generating strong resistance from those who are subject to domination and, indeed, often without conscious recognition by their members. For Bourdieu, *all* cultural meanings and practices embody interests and function to enhance social distinctions among individuals, groups and institutions. Power therefore stands at the heart of social life and is used to legitimize inequalities of status within the social structure. Cultural socialization thereby places individuals as well as groups in positions of competition for status and valued resources, and helps to explain how social actors struggle and pursue strategies aimed at achieving their specific interests.

'Symbolic violence' describes the process whereby symbolic systems (words, images and practices) promote the interests of dominant groups as well as distinctions and hierarchies of ranking between them, while legitimating that ranking by convincing the dominated to accept existing hierarchies through processes of hegemony. While 'rule' is based on direct coercion, 'hegemony' is achieved via a complex interlocking of political, social and cultural forces which organize dominant meanings and values across the social field

<sup>5</sup>While Foucault tended to prioritize the relationship between culture, power and difference in relatively static ways (albeit marked by radical shifts or disjunctures from one historical period to another), however, Bourdieu has focused much more clearly on the relations between culture, power, social structure and social action.

X) in order to legitimize the structures of social inequality, even to those who are the objects of domination (Gramsci, 1970; Williams, 1977, 1982).

With respect to stigmatization and discrimination, such insights are important for several reasons. First, if as Bourdieu argues, all cultural meanings and practices embody interests and signal social distinctions among individuals, groups and institutions, then few meanings and practices do so as clearly and as profoundly as stigma, stigmatization and discrimination. Stigma and discrimination therefore operate not merely in relation to difference (as our readings of both Goffman and Foucault would tend to emphasize), but even more clearly in relation to social and structural inequalities. Second, and even more importantly, stigmatization does not simply happen in some abstract manner. On the contrary, it is part of complex struggles for power that lie at the heart of social life. Put even more concretely, stigma is deployed by concrete and identifiable social actors seeking to legitimize their own dominant status within existing structures of social inequality. X X

Beyond helping us to understand that stigmatization is part of a complex social struggle in relation to structures of inequality, notions of symbolic violence and hegemony also help us to understand how it is that those who are stigmatized and discriminated against in society so often accept and even internalize the stigma that they are subjected to. Precisely because they are subjected to an overwhelmingly powerful symbolic apparatus whose function is to legitimize inequalities of power based upon differential understandings of value and worth, the ability of oppressed, marginalized and stigmatized individuals or groups to resist the forces that discriminate against them is limited. To untie the threads of stigmatization and discrimination that bind those who are subjected to it, is to call into question the very structures of equality and inequality in any social setting—and to the extent that all known societies are structured on the basis of multiple (though not necessarily the same) forms of hierarchy and inequality, to call this structure into question is to call into question the most basic principles of social life. 2

This new emphasis on stigmatization as a process linked to competition for power and the legitimization of social hierarchy and inequality, highlights what is often at stake in challenging HIV and AIDS-related stigmatization and discrimination. It encourages a move beyond the kinds of psychological models and approaches that have tended to dominate much of the work carried out in this field to date—models which all too frequently see stigma as a thing which individuals impose on others. It gives new emphasis to the broader social, cultural, political and economic forces that structure stigma, stigmatization

and discrimination as social processes inherently linked to the production and reproduction of structural inequalities.<sup>6</sup>

### Toward a political economy of stigmatization and social exclusion

Focusing on the relations between culture, power and difference in the determination of stigmatization, encourages an understanding of HIV and AIDS-related stigmatization and discrimination as part of the political economy of social exclusion present in the contemporary world. Greater attention to this broader political economy of social exclusion could potentially help us to think about contexts and functions of HIV and AIDS-related stigma, as well as more adequate strategies for responding to it.

In order to do this, it is imperative to situate the analysis of HIV/AIDS historically, and to remember that 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, 1996, 1997, 1998). These transformations have been characterized by rapidly accelerating processes of social exclusion, together with an intensified interaction between what might be described as ‘traditional’ and ‘modern’ forms of exclusion. Among the most vivid processes described by recent research has been the rapidly increasing feminization of poverty together with the increasing polarization between rich and poor in both the so-called developed as well as the so-called developing worlds.

Yet the new forms of exclusion associated with economic restructuring and global transformations have almost everywhere reinforced pre-existing inequalities and exclusions, such as racism, ethnic discrimination, and religious conflict. This intensifying interaction between multiple forms of inequality and exclusion offers a general model for an analysis of the interaction between multiple forms of stigma that has typified the history of the HIV and AIDS epidemics. By examining the synergy between diverse forms of inequality and stigma, we may be better able to untangle the complex

<sup>6</sup>An extensive theoretical and empirical research literature exists that deals with the mechanisms and consequences of social exclusion cross-culturally and cross-nationally. See, for example, the review in relation to health (Purdy & Banks, 1999). On the particular impact of poverty on health generally and on HIV/AIDS in particular, see, also, World Bank (1993, 1997). Unfortunately, with only a few exceptions this literature has for the most part not been employed to address issues relating to HIV and AIDS, and has almost never been used to examine and respond to HIV and AIDS-related stigmatization and discrimination (Farmer, Connors, & Simmons, 1996; Parker & Camargo, 2000; Singer, 1998).

webs of meaning and power that are at work in HIV and AIDS-related stigma, stigmatization and discrimination.

Second, and equally important, recent work on the transformation of the global system and the political economy of informationalism has called attention to the growing importance of identity (or, often, identities) as central to contemporary experience. This is particularly helpful in seeking to confront issues of stigmatization precisely because attending to it enables us to recoup, and indeed reposition, Goffman’s original insight, nearly 40 years ago, concerning the impact of stigma in the construction of a kind of spoiled identity (Goffman, 1963). Much recent work on the nature of identity has emphasized its constructed and constantly changing character (Hall, 1990). This, in turn, has made it possible to begin to theorize changing constructions of identity in relation to both the experience of oppression and stigmatization, as well as resistance to it (Castells, 1997, p. 8). Such a view has been most clearly articulated by Castells (1997), who has distinguished between *legitimizing identities*, which are ‘introduced by the dominant institutions of society to extend and rationalize their domination *vis à vis* social actors’, *resistance identities*, which are ‘generated by those actors that are in positions/conditions devalued and/or stigmatized by the logic of domination’, and *project identities*, which 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 ideas offer important insights and avenues for responding more effectively to HIV and AIDS-related stigmatization and discrimination in the future—but only to the extent that we are able to reconceptualize issues of stigmatization and discrimination within a broader political economy of social exclusion as it functions in the contemporary world. It is within this broader context that a new agenda for research and action in response to HIV and AIDS-related stigma, stigmatization and discrimination must ultimately be developed.

### A new agenda for research and action

To take seriously the notion that stigmatization and discrimination must be understood as social processes linked to the reproduction of inequality and exclusion pushes us to move well beyond the kind of behavioural and psychological models that have tended to dominate work thus far. While the latter have provided some insights and will continue to play a role in a broader research and programmatic response to the epidemic, they need to be complemented by new ways of

understanding and overcoming HIV and AIDS-related stigma, stigmatization and discrimination.

### *Research*

While it is impossible to elaborate a fully developed research agenda on HIV and AIDS-related stigmatization within the space of this review, in this concluding section we will outline some of the directions that such an agenda might explore. At least three lines of social enquiry might help us to more fully develop the kind of perspective on HIV and AIDS-related stigmatization and discrimination that we have sought to advance in this review: (1) conceptual studies; (2) new investigative studies; and (3) strategic and policy-oriented research.

### *Conceptual studies*

Conceptual studies are perhaps most obviously linked to the kind of work that took place within the context of the current review. Such studies aim to identify and work with concepts, ideas and new understandings of greatest relevance to national and international programmes and activities focusing on HIV and AIDS-related stigma. They seek to interrogate the adequacy of existing ways of explaining things against the available evidence. They contribute to the development of new concepts and ideas of relevance to HIV and AIDS-related stigmatization and discrimination. They also offer new ways of understanding processes of change, social movements and cultural transformation in response to HIV and AIDS-related stigmatization and discrimination.

Conceptual studies have a crucial role to play in ensuring that existing knowledge is constantly reviewed for its adequacy and appropriateness in the light of changing needs and circumstances as they impact upon HIV and AIDS-related stigma. They ensure that new categories of thinking are developed, together with new ways for identifying priorities. They allow for new vision and for a new role of theory. While they must continue to include work focusing on the psychological dimensions of HIV and AIDS-related stigma, they must also move beyond this framework to examine the social, cultural, political and economic determinants and consequences of stigmatization and discrimination.

### *New investigative studies*

New investigative studies aim to take new patterns of thought and explanation and to identify the essentially social processes at work in HIV and AIDS-related stigma, the ways in which such processes contribute to HIV/AIDS vulnerability, and the possibilities for positive community participation and response in reducing stigmatization and discrimination. Context-

specific empirical investigations of this kind, which examine the contributions already made, are likely to better account for past failures and successes, identify present opportunities and point to future priorities, thereby contributing in turn to the development of new theory. Ideally, however, such investigations should be conducted alongside broader comparative work in order to enable us to better understand those aspects of HIV and AIDS-related stigmatization and discrimination that are local, as well as those aspects that may cross national and cultural boundaries.

There are any number of well-developed models, even in the existing record of HIV/AIDS social research, for such a balance between concern with specificity as well as with comparability. The programme of research developed by the International Center for Research on Women focusing on women and AIDS, or the WHO/GPA/UNAIDS studies of sexual risk among young people, the acceptability of the female condom or household and community responses to HIV and AIDS, all provide useful models in this regard (Rao Gupta & Weiss, 1995; Aggleton, Dowsett, Rivers, & Warwick, 1999). Moreover, studies of HIV and AIDS-related stigmatization and discrimination in India and Uganda recently sponsored by UNAIDS provide an important point of departure for thinking about the potential for more integrated, comparative work in the future (UNAIDS, 2000).

### *Strategic and policy-oriented research*

In contrast to conceptual enquiry and new investigative studies, strategic and policy-oriented research on HIV and AIDS-related stigmatization and discrimination aims to identify and describe the combinations of programme elements that contribute to success in responding to these phenomena, the circumstances in which these programme elements are best operationalized (along with the actors involved), and the likely outcomes of specific kinds of programme implementation. It is essential that strategic and policy-oriented research be sensitive to the broader policy context. Programmes to address HIV and AIDS-related stigma and discrimination are rarely, if ever, implemented in an ideologically neutral context. Understanding the relationship between programme development and implementation and the broader social context is central to the success of efforts to disseminate and/or scale up existing successes.

### *Intervention*

Ultimately, of course, the key goal of all such research should be to contribute to the development of programmes and policies aimed at effectively reducing the human suffering (both in terms of new infections and in

terms of the quality of life for people with HIV disease as well as those considered to be at risk of infection) that is a direct result of unmitigated HIV and AIDS-related stigmatization and discrimination. While there is surely an important role for basic research that is not necessarily directly linked to intervention, even conceptual and descriptive studies on HIV and AIDS-related stigma and discrimination need to be framed in ways that will ultimately feed into and nurture the development of advocacy and intervention aimed at reducing levels of stigmatization and the effects that discrimination has on both individuals and groups.

Our ability to achieve greater success in this regard, however, is directly linked to our willingness to move beyond the conceptual frameworks and intervention models that have largely dominated the field thus far. Both the theories that have been used in much intervention research focusing on HIV and AIDS-related stigmatization, and the research designs used to test such interventions, have rarely broken the mould that dominates the vast majority of HIV/AIDS intervention research more generally: Cognitive-behavioural and social-cognitive models (such as 'empathy induction') have predominated in the theoretical frameworks employed, and experimental or quasi-experimental evaluation designs have been the norm (see Brown et al., 2001). Yet even a moment's thought should demonstrate that such individual level interventions, while possibly useful in themselves, could never be scaled up in the manner required for an efficacious response throughout Africa, Asia, Central and Southern America. The resources do not exist. Besides, the individual framework with which they operate is simply alien to perhaps the majority of the world's cultures. They must be complemented by actions that have as their starting point the deeper social, political and economic causes of stigma and stigmatization, and which engage with the lives of collectivities and communities—for this is the level at which the great majority of HIV and AIDS-related stigma operates.

If HIV and AIDS-related stigmatization and discrimination must be reconceived as less a matter of individual or even social psychology than as a question of power, inequality and exclusion, it is equally necessary that we re-think the kinds of theoretical bases and evaluation research designs that may be needed to adequately respond to the issues in question. We may be well advised to begin to seek inspiration less in the literature associated with behaviour change than in that on community mobilization and social transformation—a research literature that is surely equally extensive, in spite of the fact that we have for the most part failed to take advantage of it in HIV/AIDS research (Parker, 1996).

In particular, the theorization of resistance and project identities discussed above offers important

insights for re-thinking the development of community mobilization aimed at responding to HIV and AIDS-related stigmatization and discrimination. As we have already suggested in reviewing the research literature in this area, the vast majority of existing interventions have sought to either reduce the incidence of stigmatization on the part of the 'community' or the 'general population', or to reduce the experience of stigma on the part of 'high risk groups' that have been the targets of stigmatization and discrimination (Brown et al., 2001). Yet in both cases, intervention designs seem to have functioned in large part according to what Freire (1970) long ago identified as a 'banking' theory of pedagogy in which the perceived deficit accounts of those being 'educated' are somehow 'filled' by intervention specialists who presume they know the truth about what is needed.

Only more rarely have interventions been designed with the goal of unleashing the power of resistance on the part of stigmatized populations and communities—in spite of the fact that empirical studies of empowerment and social mobilization in response to HIV and AIDS have clearly demonstrated that the most effective and powerful responses to the epidemic (or 'natural experiments' if one prefers the language of much public health research) have taken place precisely when affected communities have mobilized themselves to fight back against stigmatization and oppression in relation to their lives (Altman, 1994; Daniel & Parker, 1993; Epstein, 1996; Parker et al., 1995; Stoller, 1998). The time is therefore ripe to build upon existing empirical evidence, as well as the literature on community organizing and community building, both independent of the specific area of health and directly in relation to it, to begin developing new models for advocacy and social change in response to HIV and AIDS-related stigmatization and discrimination (Delgado, 1994; Minkler, 1998).

If models of community mobilization, advocacy and social change provide one important basis for the development of responses aimed at resisting HIV and AIDS-related stigmatization and discrimination, they must necessarily be conceived as part of a multi-dimensional programme of intervention. Increasingly, it is clear that localized intervention strategies aimed at community mobilization and social change (in this case, in response to HIV and AIDS-related stigmatization and discrimination), must be conceived, whenever possible, in tandem with what have been described as structural or environmental interventions aimed at transforming the context in which both individuals and communities operate as they respond to HIV and AIDS (Sweat & Dennison, 1995; Parker & Camargo, 2000; Parker, Easton, & Klein, 2000).

In few areas are the possibilities for structural intervention as clear as in the case of HIV and AIDS-related stigma and discrimination. Indeed, while

available research on intervention in relation to stigmatization has shown at best very limited results in changing stigmatizing attitudes (whether through 'empathy inducement' or other psychological theories) on the part of dominant sectors of society, judicial and policy interventions in many settings have shown real effectiveness in impeding the worst impact of HIV and AIDS-related stigmatization and discrimination. Legal protections for people living with HIV and AIDS, together with appropriate reporting and enforcement mechanisms (ranging from legal aid services to hotlines for reporting acts of discrimination and violence against people with HIV and AIDS, gay men, women suffering domestic violence, and so on), have provided powerful and rapid means of mitigating the worst effects of the unequal power relations, social inequality and exclusion that lie at the heart of processes of HIV and AIDS-related stigmatization and discrimination.

Ultimately, together with a new emphasis on community mobilization aimed at unleashing resistance to stigmatization and discrimination, structural interventions aimed at developing a rights-based approach to reducing HIV and AIDS-related stigmatization and discrimination should be a high priority in order to create a transformed social climate in which stigmatization and discrimination themselves will no longer be tolerated. Within such a framework, discrimination becomes a clear breach of a basic human rights obligation—a breach that, when concretized in civil rights legislation, can effectively impede and prohibit the exercise of HIV and AIDS-related stigmatization and discrimination.

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