
HIV and AIDS-Related Stigma and Discrimination: a conceptual framework and implications for action

Richard Parker and Peter Aggleton

ABIA

Brazilian Interdisciplinary AIDS Association

T C R U
THOMAS CORAM RESEARCH UNIT
Institute of Education, University of London

HIV and AIDS-Related Stigma and Discrimination: a conceptual framework and implications for action

Richard Parker and Peter Aggleton

ABIA

Brazilian Interdisciplinary AIDS Association

TCRU

THOMAS CORAM RESEARCH UNIT
Institute of Education, University of London

Copyrights © 2002, ABIA and TCRU

Associação Brasileira Interdisciplinar de AIDS - ABIA

Brazilian Interdisciplinary AIDS Association

Address: Rua da Candelária, 79/10º andar - Centro

CEP: 20091-020 - Rio de Janeiro, RJ - Brazil

Telephone: (+55) (21) 2223-1040 Fax: (+55) (21) 2253-8495

E-mail: abia@abiaids.org.br <http://www.abiaids.org.br>

DIRECTORS - President: Richard Parker

Vice-President: Sonia Corrêa

Secretary-General: Otávio Cruz Neto

Treasurer: José Loureiro

Executive Coordinator: Veriano Terto Jr.

Deputy Coordinator: Maria Cristina Pimenta

Thomas Coram Research Unit - TCRU

Institute of Education, University of London

27-28 Woburn Square - London WC1H 0AA - UK

DIRECTOR - Peter Aggleton

COPY EDITING - Ivia Maksud

DIAGRAM, LAYOUT AND ART - Wilma Ferraz and Juan Carlos Raxach

SUPPORT - Horizons Project/The Population Council

Ford Foundation

John D. and Catherine T. MacArthur Foundation

EDITION - 2.000 copies

Printed in Brazil

Catalogue Card

Departamento Nacional do Livro

Fundação Biblioteca Nacional (National Library Foundation). Rio de Janeiro/RJ, Brazil

P242h Parker, Richard

HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action / Richard Parker, Peter Aggleton. - Rio de Janeiro: ABIA, 2002.

42p.; 21 x 28cm

ISBN: 85-88684-05-5

1. AIDS (Illness) - Social Aspects. I. Aggleton, Peter. II. Título.

CDD: 616.798

*Partial or total reproduction of this publication is permitted,
provided the source and authors are mentioned.*

SUMMARY

I. INTRODUCTION	5
II. STIGMATIZATION AND DISCRIMINATION AS SOCIAL PROCESSES	7
II.1 - CULTURE, POWER AND DIFFERENCE	10
II.2 - STIGMA AND THE PRODUCTION AND REPRODUCTION OF SOCIAL INEQUALITY	12
II.3 - TOWARD A POLITICAL ECONOMY OF STIGMATIZATION AND SOCIAL EXCLUSION	14
III. SOURCES OF HIV AND AIDS-RELATED STIGMATIZATION AND DISCRIMINATION	16
III.1 - PRIOR TO HIV/AIDS	17
III.2 - SPECIFIC TO HIV/AIDS	20
III.3 - SYNERGY BETWEEN DIFFERENT SOURCES OF STIGMATIZATION	21
IV. FORMS OF HIV AND AIDS-RELATED STIGMATIZATION AND DISCRIMINATION	22
IV.1 - COLLECTIVE (SOCIETAL/COMMUNITY)	22
IV.2 - INDIVIDUAL EXPERIENCE	24
V. KEY CONTEXTS OF HIV AND AIDS-RELATED STIGMATIZATION AND DISCRIMINATION	26
V.1 - FAMILIES AND COMMUNITIES	26
V.2 - EDUCATION AND SCHOOLS	27
V.3 - EMPLOYMENT AND THE WORKPLACE	28
V.4 - HEALTH CARE SYSTEMS	29
V.5 - TRAVEL, MIGRATION AND IMMIGRATION	29
V.6 - HIV/AIDS PROGRAMS	31
VI. A NEW AGENDA FOR RESEARCH AND ACTION	32
VI.1 - RESEARCH	32
CONCEPTUAL STUDIES	33
NEW INVESTIGATIVE STUDIES	33
STRATEGIC AND POLICY-ORIENTED RESEARCH	34
VI.2 - INTERVENTION	34
VII. REFERENCES	37

FIGURES SUMMARY

FIGURE 1 - Three epidemics	6
FIGURE 2 - Our goals	6
FIGURE 3 - Structure of the paper	7
FIGURE 4 - The nature of stigma	10
FIGURE 5 - Knowledge/Power and the production of stigma	11
FIGURE 6 - Stigma and stigmatization	12
FIGURE 7 - Power and culture	13
FIGURE 8 - Stigmatization	14
FIGURE 9 - Different kinds of identity	16
FIGURE 10 - Some metaphor of AIDS	16
FIGURE 11 - The production of HIV/AIDS-related stigma	18
FIGURE 12 - Key determinants to AIDS-related stigma (after de Bruyn, 1999)	21
FIGURE 13 - A vicious circle	22
FIGURE 14 - Key contexts for HIV and AIDS stigmatization and discrimination	26
FIGURE 15 - A framework for action	35

HIV AND AIDS-RELATED STIGMA AND DISCRIMINATION: A CONCEPTUAL FRAMEWORK AND IMPLICATIONS FOR ACTION

RICHARD PARKER¹ AND PETER AGGLETON²

I. INTRODUCTION

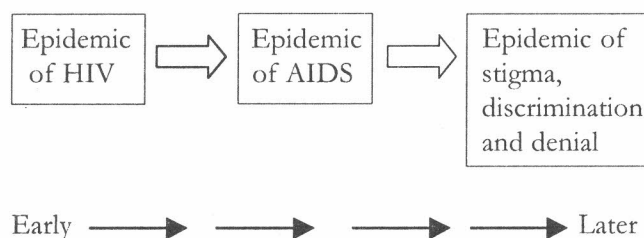
For nearly two decades, as countries all over the world have struggled to respond to the HIV/AIDS epidemic, issues of stigma, discrimination and denial have been among the most poorly understood, yet most unyielding, dilemmas facing the development of public health and education programs. Indeed, very early in the organized global response to the epidemic, when Jonathan Mann, in his role as the founding Director of the World Health Organization's Global Programme on AIDS, addressed the United Nations General Assembly in 1987, it was perhaps above all in relation to stigmatization and discrimination that he sought to characterize the rapidly spreading AIDS pandemic (Mann, 1987). In what would soon become a widely accepted conceptualization,

Mann stressed that it is possible to identify at least three phases of the AIDS epidemic in any community—phases that are so distinct that they can be described as three different epidemics. He described the first of these phases as 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. He described the second phase as the epidemic of AIDS itself, the syndrome of infectious diseases that can occur because of HIV infection, but typically (due to the peculiar workings of the virus in the human immune system) only after a delay of a number of years. Finally, he identified what he described as the third epidemic, potentially the most explosive, as the epidemic of social, cultural, economic and political responses to AIDS—reactions that have been 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) (Figure 1).

¹ Associação Brasileira Interdisciplinar de AIDS; Instituto de Medicina Social, Universidade do Estado do Rio de Janeiro; Mailman School of Public Health, Columbia University.

² Thomas Coram Research Unit, Institute of Education, University of London.

Figure 1 - Three epidemics



Nearly 15 years later, the World Health Organization's Global Programme on AIDS (WHO/GPA) no longer exists. 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 multiple social dimensions of the epidemic. Yet when Peter Piot, the Executive Director of UNAIDS since its creation, 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" (Piot, 2000). 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, so action against stigma ramifies across every single aspect of HIV work" (Piot, 2000).

In spite of the years that separate these two important statements, and despite the immense resources that have been mobilized to control the epidemic, the issue of stigma continues to stand at the center of the fight against the global AIDS pandemic. While major victories have clearly been won—particularly in the

development of new, more effective treatments and therapies for people living with HIV in resource rich settings—much less has been achieved in seeking to overcome the impact of stigma and discrimination on the lives of those affected by the epidemic. As biologically complex as the Human Immunodeficiency Virus is, this complexity pales in comparison to the complexity of the social forces involved in the production and reproduction of stigma in relation to HIV and AIDS (see Malcolm *et al.*, 1998; UNAIDS, 2000).

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. The key goal of this review therefore is to examine 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 intervention activities that might minimize their impact and their prejudicial effects in relation to the epidemic (Figure 2).

Figure 2 - Our goals

- Review relevant literature on stigma, stigmatization and discrimination
- Develop a conceptual framework for understanding these processes in relation to HIV and AIDS
- Identify suitable options for intervention

With this in mind, our review has been divided into six major sections. Following this introduction, we turn to a discussion of stigmatization and discrimination understood not

so much as things or psychological dispositions on the part of individuals, but as **social processes** linked to the structures and workings of power that can only be fully understood and responded to through equally social models of analysis and intervention. In the third section, based on this understanding of stigmatization and discrimination as social processes, we will examine the social sources of such processes, paying particular attention to the sources of stigma that existed prior to the emergence of HIV and AIDS; new sources which seem to have emerged or been adapted specifically in relation to HIV/AIDS epidemics; and the powerful synergy between both of these sources throughout the development of the epidemic. In the fourth section of the review, we will look in detail at the forms that HIV and AIDS-related stigmatization and discrimination have taken, both at the collective level of societies and communities, as well as at the level of individual subjectivities and practices. In the fifth section, we will explore some of the key contexts of HIV and AIDS-related stigmatization—including schools, the workplace, and the health care system. And finally, in the sixth and concluding section of the document, we offer a new agenda for research and action in response to HIV/AIDS-related stigma and discrimination—an agenda aimed at interrupting the disturbing continuity of these social processes from the mid-1980s to the present, and at responding to what both Jonathan Mann and Peter Piot correctly identified as perhaps the single most important impediment to effective social and public health responses in the global epidemic (Figure 3).

Figure 3 - Structure of the paper

- Background
- Stigma and discrimination as social processes

- Sources of stigma and discrimination
- Forms of stigma and discrimination
- Contexts of stigma and discrimination
- An agenda for research and action

II. STIGMATIZATION AND DISCRIMINATION AS SOCIAL PROCESSES

Much of what has been written about stigma, discrimination and denial 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 both to 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 SD&D [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, discrimination and denial are far from unitary constructs, and are characterized by a high degree of cross-cultural diversity, one of the major factors limiting our understanding of these phenomena to date 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 rethink some of the taken for granted frameworks within which we are encouraged to understand them.

As a first step in this direction, and for the purposes of this review we will prioritize the discussion of stigmatization and discrimination. Indeed, our analysis suggests that the social origins of stigmatization and discrimination may

in fact be quite different from those of denial, which is a far more psychological construct (unless analyzed distinctly as collective denial). It is striking to note, for example, that while the *Oxford Dictionary of Sociology* contains significant entries on both stigma and discrimination, recognizing their long history in social analysis, it contains no entry referring to denial (see Marshall, 1998).³

Typically, discussions of stigma, particularly in relation to HIV and AIDS, have taken as their point of departure the now classic work of Erving Goffman, and have defined stigma as “an attribute that is significantly discrediting” which, in the eyes of society, serves to reduce the person who possesses it (Goffman, 1963). While the term itself has a long history (that can be traced to Classical Greece in which it referred to a brand placed on outcast groups), it entered sociological analysis largely through Goffman’s work (see Marshall, 1998:642). 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 behavior, Goffman argued that the stigmatized individual is seen to be a person who possesses “an undesirable

difference” (Goffman, 1963). 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 early 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 rethink 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 tended to encourage a highly individualized analysis in which words come 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 are in fact drawn directly from Goffman, who, on the contrary, was much

³ Although stigmatization, discrimination and denial have typically been linguistically linked as a seemingly unified trio in writings related to HIV and AIDS—and even potentially reified through the use of abbreviated designations such as “DSD”, “SD&D”, etc., in many programmatic documents—this linkage has always been implicitly assumed rather than investigated or analyzed. This assumption may well be counter-productive and that in light of the current state of knowledge and debate it is more productive to examine stigmatization, discrimination and denial as analytically separate concepts which merit distinct theoretical frameworks. While denial may ultimately prove to have important links to stigmatization and discrimination, there is no *a priori* reason to conclude that this will be so, just as there is no reason to conclude that denial in relation to HIV and AIDS may not have quite different social and historical causes than do stigmatization and discrimination. In short, we would suggest that collective denial in response to HIV and AIDS,

much like the forms of “moral panic” that have received rather more research attention in relation to the epidemic (see Weeks, 1989; Watney, 2000), deserves detailed analysis and conceptual development in order to overcome its largely unsystematic usage in current discourse. Such analysis would take us well beyond the space and available resources for the current review, and for this reason we have chosen to focus the majority of our discussion here on the more clearly (and more systematically) inter-related concepts of stigmatization and discrimination as related to the HIV/AIDS epidemics.

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 captures a *relationship* of devaluation rather than a fixed attribute. Yet the fact that Goffman's framework has been used in much HIV/AIDS research 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.

Interestingly, while references to stigma and stigmatization in work on HIV and AIDS typically acknowledge Goffman and his work as intellectual precursors, the closely related discussion of discrimination is rarely framed in relation to any theoretical tradition whatsoever. 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, 1998:163) It goes on, however, to suggest that most recent sociological analyses of discrimination “concentrate on patterns of dominance and oppression, viewed as expressions of a struggle for power and privilege” (Marshall, 1998:163).⁴

⁴ Interesting, 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 (Marshall, 1998:522). In HIV/AIDS research, while stigma has been used extensively to describe AIDS-related attitudes, the term prejudice

This sociological emphasis on the structural dimensions of discrimination is particularly useful in helping us think more sensibly about stigmatization and discrimination in relation to HIV and AIDS. In order to move beyond the limitations of current thinking in this area, we need to reframe our understandings of stigmatization and discrimination in order to conceptualize them as social processes. Above all, we need to emphasize that these processes can only be understood in relation to *power* and *domination*. In our view, stigma plays a key role in producing and reproducing relations of power and control in all social systems. It causes some groups to be devalued and others to feel that they are superior in some way. Ultimately, therefore, it is linked to the workings of *social inequality*. To confront and properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, therefore necessarily 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.

Fortunately, much work exists within the social and political sciences that is directly relevant to this task,⁵ but so far little of this has been utilized in HIV/AIDS research. 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

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 in fact important implications for the ways in which societies have responded to HIV/AIDS-related stigmatization and discrimination.

⁵ In particular, the work of writers such as Michel Foucault, Pierre Bourdieu, Antonio Gramsci, and Manuel Castells described later.

USA and parts of Europe) where people are taught to believe they are free agents, they make little sense in other settings. Throughout much of the developing world, for example, bonds and allegiances to family, village, neighborhood 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, not the consequences of individual behavior (UNAIDS, 2000).

One of our key goals, therefore, is to demonstrate how such work may be relevant for the analysis of HIV and AIDS-related stigmatization and discrimination. We will do so by focusing on three key sets of issues. First, it is important to recognize that stigma arises and stigmatization takes shape in specific contexts of culture and power. Stigma never arises in a social vacuum. It 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 may help us develop better measures for combating it and reducing its effects. Second, it is important to better understand how stigma is used by individuals, communities and the state to produce and reproduce social inequality. Third it is 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 (Figure 4).

Figure 4 - The nature of stigma

- Stigma is contextual
- Stigma is historical
- Stigma is strategically deployed
- Stigma produces and reproduces social relations and inequalities

II.1. CULTURE, POWER AND DIFFERENCE

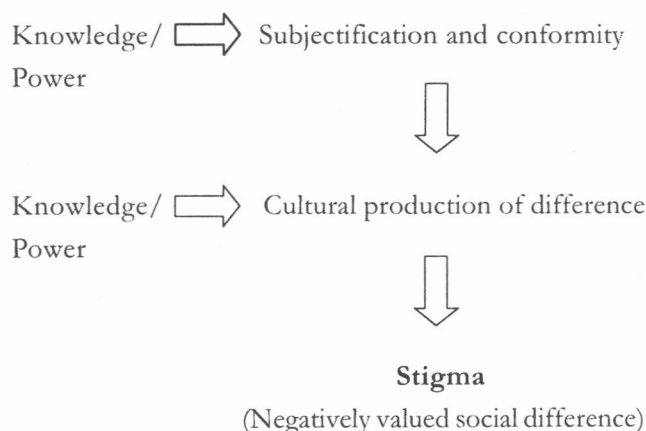
In moving beyond the insights offered by Goffman's work, it is useful to draw on some of the broader theoretical insights of writers such as Michel Foucault concerning the relation between culture or knowledge, power, and notions of difference. Although Foucault's work was carried out at roughly the 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 different cultural, intellectual and disciplinary origins.

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 radical view of knowledge and human understanding 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 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* (Foucault, 1977) and *The History of Sexuality, Volume I: An Introduction* (Foucault, 1978), 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). 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 (Figure 5).

Figure 5 - Knowledge/Power and the production of stigma



While focusing 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 emphasized the cultural production of difference in the service of power. While Goffman’s work on stigma rarely 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 workings of power—and, hence, to the establishment and maintenance of the social order. And while Foucault’s own work was most clearly focused on what might be described as the ‘modern’ world taking shape in the industrialized West, and on the knowledge systems present in this quite specific historical and cultural context, his emphasis on the cultural production of differences can quite easily be expanded to the analysis of very different social settings via a focus on what the anthropologist, Clifford Geertz, has described as systems of ‘local knowledge’ (Geertz, 1983). Just as Foucault demonstrated the way in which elite forms of knowledge (psychiatry, demography, and so on) help constitute differences in complex, modern societies, so too do more localized or popular forms of knowledge (religious beliefs, common-sense, and so on) in more simple, or small-scale, social settings (see Geertz, 1983).

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. Indeed, 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 (Figure 6).

Figure 6 - Stigma and stigmatization

- Stigma helps 'order' society
- Stigma is not an individual attitude or cultural value
- Stigmatization links to 'frameworks of truth'
- Stigmatization links to a social group's 'positioning' in society

II.2. STIGMA AND THE PRODUCTION AND REPRODUCTION OF SOCIAL INEQUALITY

Placing culture, power and difference center stage with respect to stigma, stigmatization and discrimination opens up new possibilities for research and intervention. However, we also need to understand the ways in which these social processes function. As important as Michel Foucault's insights have been for an understanding of the workings of power, one of the key limitations of his work (particularly when we seek to apply it to interventions) is the extent to which it decenters the subject and thus calls into question the possibilities for human agency, making it sometimes difficult to conceptualize the intentionally strategic uses of power or the kinds of social action that might be involved in resisting its negative effects (this being so despite Foucault's repeated adage that wherever we find power we will also find resistance). To build a fuller understanding of stigmatization as a social process, therefore, we must ultimately try to understand how stigma produces and reproduces social inequality.

Seeing stigma as created at the point of intersection of culture, power and difference allows for the use of a wide range of new analytic tools whereby to advance our understanding of the ways in which stigmatization functions or operates. In this respect, notions of *symbolic violence* (associated, in particular, with the sociological

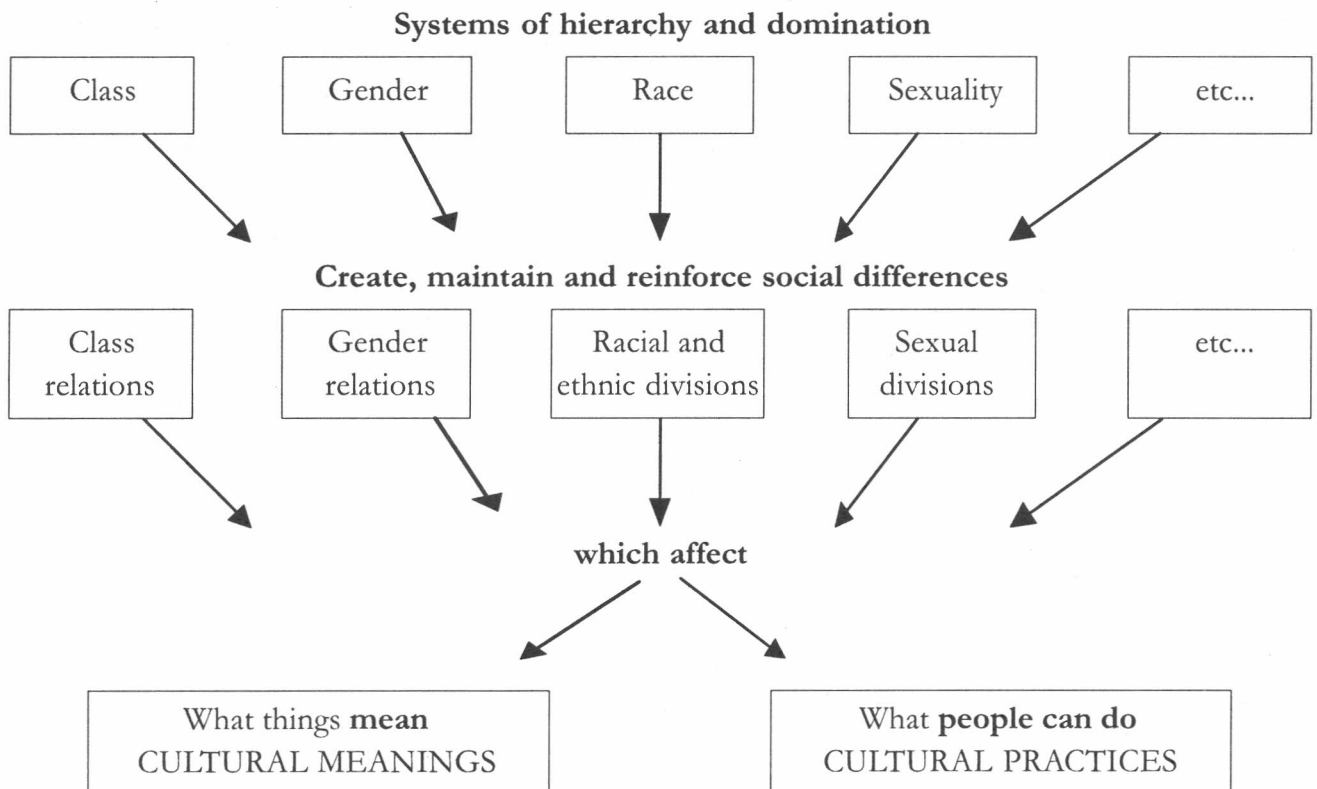
work of Pierre Bourdieu) and *hegemony* (initially elaborated in Antonio Gramsci's political theory, but more recently employed usefully in cultural analysis by writers such as Raymond Williams, Stuart Hall and others) are particularly useful. They highlight not only the functions of stigmatization in relation to the establishment of social order and control, but also the disabling effects of stigmatization in 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.⁶ It aimed to examine how stratified social systems of hierarchy and domination persist and reproduce themselves over generations, most typically without generating strong resistance from those who are subject to domination and, indeed, often without conscious recognition by their members. *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, but is much more clearly deployed 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 (Figure 7).

'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

⁶ 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 (see, for example, Bourdieu 1977, 1984; Bourdieu and Passeron, 1977).

Figure 7 - Power and culture



ranking between them, while legitimating that ranking by convincing the dominated to accept existing hierarchies. Concepts of symbolic violence therefore have much in common with the notion of hegemony elaborated by Gramsci and cultural theorists such as Raymond Williams. 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 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. Indeed, stigmatization can be seen to play a key role in the transformation of difference into inequality, and can in principle function in relation to virtually any of the key axes of structural inequality present cross-culturally: class, gender, age, race or ethnicity, sexuality or sexual orientation, and so on. 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.**

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 therefore 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 (Figure 8).

Figure 8 - Stigmatization

- Linked to inequalities of power
- Makes social inequalities seem reasonable'
- Creates a social hierarchy (e.g. the stigmatized vs the non-stigmatized)
- Creates and reinforces social exclusion

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 (e.g., Crawford, 1996; Herek, 1990; Herek and Capitano, 1997; Kelley *et al.*, 1987), 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.

II.3. TOWARD A POLITICAL ECONOMY OF STIGMATIZATION AND SOCIAL EXCLUSION

A focus 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 what can perhaps best be described as the **political economy of social exclusion** present in the contemporary world. Importantly, an extensive theoretical and empirical research literature exists dealing with the mechanisms and consequences of social exclusion cross-culturally and cross-nationally (see, for example, the review in relation to health in Purdy and 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 (see, for example, Farmer, Connors and Simmons, 1996; Parker and Camargo Jr., 2000; Singer, 1998), 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. 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 in tandem with globalization. The key characteristic of this period, from roughly the late-1970s to the present, has been a radical restructuring of the world economy linked to the growth of what has been described as informational capitalism (see, for example, 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 and ethnic discrimination, 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 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 in the late-twentieth and early-twenty-first centuries 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 30 years ago, concerning the impact of stigma in the construction of a kind of spoiled identity (see Goffman, 1963). Much recent work on the nature of identity has emphasized its constructed and constantly changing character (see 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.⁷ Such a view has been most clearly articulated by Manuel Castells, who has distinguished between *legitimizing identities*, which are 'introduced by the dominant institutions of society to extend and rationalize their domination *vis á 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' (Castells, 1997, p. 8) (Figure 9).

⁷This includes resistance via the broader mobilization of social movements aimed at projecting social change in response to it (see Castells, 1997).