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Outsider status: Stigma and discrimination experienced by gay men and African people with HIV

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Outsider status

Stigma and discrimination experienced by Gay men and African people with HIV

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Research Report

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Contents

1 Introduction

1.1 BACKGROUND

In recent years there has been an increasing amount of international-level policy and research about the negative impact that HIV-related stigma and discrimination have on the well-being of people with HIV and on prevention (Aggleton & Parker 2002, DeBruyn 2002, Nyblade 2003, UNAIDS/WHO 2003, United Nations 2001). It is clear that stigma and discrimination relating to HIV infection are persistent problems for those who have been diagnosed. Evidence gathered in the UK demonstrates that the majority of people living with HIV report the effects of stigma and discrimination in a range of settings (see Scott 2001 for a detailed review). Sigma's own work investigating the experiences of people living with HIV in the UK has found that just under a quarter experienced discrimination within the previous year while accessing services, social settings, and in public (Weatherburn *et al*. 2002). Moreover, a study focussing on African people living with HIV in the UK (Weatherburn *et al*. 2003) revealed that over one third had experienced problems with discrimination in the previous year. This same study revealed that just under half of African people with HIV had not revealed their diagnosis to anyone they lived with, two thirds had not told their employers and a quarter had not told their GP. There is little question that people's concern about disclosure of their diagnosis bears a direct relationship to their concern that doing so will bring about damaging consequences.

Although the prevalence and impact of stigma and discrimination relating to HIV in the UK is clear, there is little qualitative research that explores the operation of stigma and discrimination as *processes* and seeks to describe the *nature* of the relationship between stigma, discrimination and reduced health outcomes (although see Elam, 2004). Case studies and policy reports point to the role of government policy, political leadership and social environments in either worsening or ameliorating the negative effects of stigma and discrimination (Atrill *et al*. 2001, Kinniburgh *et al*. 2001, Fortier 2003). This report presents the findings of a study which explores how stigma and discrimination contribute to reduced health and well-being for the two largest groups of people living with HIV in the UK: African migrants and Gay and Bisexual men. In order to do so, it is necessary to critically consider the ways in which stigma and discrimination are theorised and described.

1.1.1 Stigma, discrimination and their social functions

Typically, academic literature and policy work on stigma concentrates on Goffman's (1963) renowned investigation on the topic, which analyses the ways in which blame and guilt affect the way that people act. Goffman describes stigma as a negative effect for those who do not match social expectations of normality (in terms of health, social behaviour, appearance, *etc*.). Such individuals are subjected to the judgements of others and are often blamed for their own misfortune. Goffman explains how individuals with this 'spoiled identity' seek to avoid the negative reactions of others by trying to conceal their stigmatising condition ('passing'). This strategy perpetuates the illusion of normality while simultaneously compounding the individual's own social isolation.

Parker and Aggleton (2003) develop and further expand upon Goffman's interpretation of stigma in order to account for the role that stigma plays in preserving or undermining social structures. Stigma and discrimination are functional practices within a cultural system which aims to maintain boundaries between those with power, and those without. And it is this crucial connection to broader issues of inequality which offers us a deeper understanding of how and why stigma operates, and how it can be successfully challenged and resisted.

Parker and Aggleton's analysis of stigma is based in a tradition of social theory in which cultural practices are understood to contribute to the perpetuation and demarcation of power. The implications of this tradition for our understanding of stigma and discrimination are profound. Established social inequalities consolidate power along the lines of socio-economic status, gender, age, sexuality, illness, *etc*. Social norms ensure that people in different social categories know how they are 'meant' to behave in specific contexts, and those who violate these norms become the focus of public attention through mechanisms such as shame, disapproval, blame and guilt (Becker 1973, Foucault 1967). In most societies, these mechanisms of control are central to the collective enforcement of social norms which govern individual modes of behaviour and reinforce power structures (DeToqueville 1840, Foucault 1977, Gramsci 2001). Norms are often backed up by a type of reasoning that asserts that negative consequences will result from behaviours judged to be immoral and irresponsible; therefore those caught up in adversity are seen to have done something wrong to bring it about. One of the central ways in which these norms are enforced is through discriminatory social practices which can range from overt abuse to subtle demonstrations of inequality, which ultimately serve to isolate those regarded as 'outsiders'.

Foucault has argued that by tracing the development of rules regarding acceptable versus unacceptable behaviour, and included versus excluded groups of people, it is possible to determine precisely where the heart of the power structure resides at a particular time and place in history (1977, 1978). Taking Foucault's line of argument together with Goffman and others helps us to recognise that stigma and discrimination do not simply reside in the realms of ignorant attitudes or lack of clear information – they provide a complex means of producing and reproducing the power structures at the core of modern society.

1.1.2   HIV-related stigma and discrimination

If we apply such a model of stigma to people with HIV, we can understand HIV-related stigma as having a broader social and political function: to maintain power inequalities (most likely between those infected and those not, but possibly also between people of different ethnicities or different sexual orientations). Moreover, we would see HIV-related stigma as heavily reliant on other forms of discrimination (such as racism, homophobia, misogyny *etc*.). Finally, we would understand HIV-related stigma as a process which implicates both the stigmatiser and the stigmatised. It is not merely an isolated act of exclusion that one person does to another.

Jonathan Mann, founder of what is now UNAIDS, consistently argued for this more complex (but ultimately more useful) understanding of stigma. He insisted that those populations most heavily affected by HIV infection suffered from a severe lack of human rights reinforced by fundamental social, political and economic inequality (Mann *et al*. 1996). Stigma relies on existing prejudices and patterns of exclusion in order to further marginalise those who are already more vulnerable to HIV. It stems from the association of HIV with sex, disease and death, and with behaviours that may be illegal, forbidden or taboo. Moreover, stigma is harmful in itself because it leads to feelings of shame, guilt and isolation of people living with HIV, and because it prompts people to act in ways that directly harm others and deny them services or entitlements — actions that should be considered as HIV-related discrimination (UNAIDS/WHO 2003).

The prevalent understanding that HIV-related stigma and discrimination is simply carried out by individuals against other individuals fails to grasp the larger issues at play. Within an ongoing social system that continues to uphold fundamental inequalities, efforts that simply aim to change HIV-related attitudes and tolerance levels, or provide correct information among the general public or even among specific sub-populations will have little impact. Instead, interventions to counter stigma must engage with the legislative, policy and social environment within which individuals live. Such interventions must also seek to identify the social role of stigma in any given situation. Unless we can describe what purpose stigma serves, we cannot hope to counter it effectively.

1.1.3 The policy environment

This is the right time for such a theoretically informed, broad investigation of HIV-related stigma in the UK. For example, the policy of dispersing asylum seekers to detention centres located outside large urban environments often means that asylum seekers living with HIV are moved away from specialist HIV treatment and care centres (Creighton *et al.* 2004) as well as being moved to a setting where support and contact within expatriate groups is unlikely. Home Office changes to immigration policy implemented in April 2003 also mean that a person with HIV who is on treatment will be unlikely to be granted leave to remain on medical grounds under humanitarian protection provisions. If that person is granted discretionary leave to remain it will only be for three years (THT 2003). Although particularly harmul changes to immigration legislation which attempted to ban failed asylum applicants from accessing social care and benefits (HMSO 2002: Sec 55), have been successfully challenged in the courts by refugee agencies (Refugee Council 2004b), the government is likely to appeal this ruling at some point in the future.

In addition to this, changes made earlier this year to the provision of NHS services for overseas visitors impose strict limitations on access to hospital care for non-residents and those whose asylum applications have failed (Department of Health 2004). Broadly speaking, this means that while short-term visitors, including students and failed asylum seekers, will be allowed to access HIV testing and other STI screening, long-term treatment for infection will not be provided unless it is paid for privately.

Pending changes to the Disability Discrimination Act 1995 due to come into force late in 2005 (Disability Rights Commission 2004) mean that the definition of disability will be extended to include more people with HIV from the point of diagnosis. This legislative amendment has been lauded by those seeking to improve employment, public access, provision of services, transport and housing that is free from discrimination, and draws attention to the stigma and discrimination that affects non-symptomatic HIV infection. However, as some exchanges among respondents in this report demonstrate (see section 2.2.3) there is a degree of possible confusion around the implications of discrimination legislation. Rather than understanding the Disability Discrimination Act as a means of protection, some people may have uncertainties about whether the new amendments impose a duty to declare their disability when applying for a new job or council flat. In an atmosphere of ongoing policy and legislative flux, it is imperative that those affected by such change are clearly informed of the implications.

The National Strategy for Sexual Health and HIV (Department of Health 2001) outlines a national commitment to create an HIV stigma action plan within the UN framework (United Nations 2001). It also prioritises the support and development of practical ways of tackling HIV-related stigma and discrimination. In order to meet the obligation of addressing HIV-related stigma and discrimination (United Nations 2001: para 37), a successful plan of action in the UK will demand a detailed theoretical understanding of the social structures of inequality that underlie and are reinforced by stigmatising practices (Parker & Aggleton 2003). It will also require evidence of the specific ways in which diverse individuals and groups affected by HIV are impacted. In this way it will be possible to determine practicable interventions that will: a) strengthen the human rights of those living with and affected by HIV, b) address and introduce change in the settings which produce the most harmful types of stigma and discrimination by tackling social inequality directly, and c) generate environments where those living with and affected by HIV are more able to manage and/or resist the ongoing power imbalances that persist in relation to the epidemic. An example of a national plan of action which incorporates these factors has already been drafted in Canada (Canadian Legal HIV/ AIDS Network 2003).

This report will describe the ways in which systemic and widespread homophobia, racism and xenophobia (coalesced with a wide range of other detrimental attitudes such as misogyny and the tendency to discriminate on the basis of age or disability), constitute the stigmatising responses

associated with HIV. Without acknowledging and addressing the social inequalities that underlie and are essentially the rationale for HIV-related stigma and discrimination, there will be little possibility of a successful response. In doing so, we aim to make a significant contribution both to the development of the action plan and the activities of the Department of Health and of HIV organisations. By presenting the experiences and opinions of people living with HIV in the light of the social and institutional inequalities that pervade those experiences, we aim to produce a resource which will be relevant to the development of imminent policy. We also expect that this work serve as a longer-term resource for those investigating the detailed and complex realities of stigma and discrimination as they affect those living with diagnosed HIV.

The remainder of this chapter describes our methods and our sample. Chapter two examines the experiences of African people with HIV in the UK. Chapter three critically analyses the response to the difficulties described in chapter two. Chapter four moves on to describe the experiences of Gay and Bisexual men and chapter five, in turn, outlines responses to HIV-related stigma within this group. Chapter six considers the possibility and utility of an integrated response to stigma among people living with HIV. Chapter seven closes the report with a detailed discussion and a list of practical recommendations on a range of levels.

1.2 METHODS

In view of the limited resources available to carry out this research, we restricted our area of enquiry to the following groups: Gay and Bisexual men with HIV, African women with HIV and African men with HIV. Together these two groups account for the vast majority of people living with diagnosed HIV in the UK. We are aware, however, that the experiences of other groups could and should be explored (such as intravenous drug users with HIV or sex workers with HIV). In order to facilitate richer comparison between Gay and Bisexual men and African people, we weighted recruitment among Gay and Bisexual men to include Gay and Bisexual immigrants from South America and Southern Europe.

A panel of one-hundred-and-twenty-five participants was recruited using a range of methods. Banners were placed at various commercial and non-commercial websites aimed at our target groups. Poster advertisements and recruitment cards were placed in various AIDS service organisations and African and Gay community organisations in London, Brighton and Manchester. In addition, advertisements were placed in a range of community newsletters. Workers at specific agencies were approached to proactively recruit certain groups. For example, NAZ Project London recruited a group of South American migrant Gay and Bisexual men, OPAM recruited a group of African men and Positively Women recruited a group of African women. Recruitment cards were distributed to group participants in order to aid snowball recruitment. Response was made as easy as possible by maximising the range of ways an individual could apply to take part in research – they could apply by telephone, email or mobile text. On-line respondents completed screening questionnaires on our website, the results of which were automatically emailed to Sigma. Other respondents were screened by telephone questionnaire.

The study consisted of a series of twenty focussed group interviews which took the form of a guided discussion lasting between one and two hours. In order to ensure cultural appropriateness and aid disclosure, a team of seven facilitators was used which included four African and two Gay male peer facilitators/researchers. Groups were co-facilitated, and in groups with African men and/or women, at least one of the facilitators was African. In one group (migrant Gay men), professional interpreters were employed. In the remaining groups, we found that we could rely on other group participants to (informally) translate the contributions of members who did not feel able to express themselves fully in English. All groups were audio-tape recorded and detailed annotations were made. A reflexive thematic analysis was conducted on audio-tapes and notes by the two lead researchers working in collaboration. Substantial on-going analysis was conducted while the project was under

way, in order to ensure that the results of previous groups informed the design of subsequent groups. In addition, fieldwork was staged in order to allow time for interim analysis to take place at three points throughout the course of the study. In order to guide discussion, a range of interactive aids were used including flashcards, press articles and health promotion advertisements.

The composition of groups changed over time. The first ten groups consisted of five groups of Gay and Bisexual men, three groups of African women and two groups of African men. When we use quotes from participants of these initial groups in the text of the report, they are specifically identified as one of the following: 'Gay men's group', 'migrant Gay men's group', 'African women's group', and 'African men's group'. The next six were composed of African men and African women together in the same groups. Those who took part in these groups and who are quoted in the text are identified as participants in a 'mixed African group'. Here we are referring to the mixed gender of the African people taking part in these groups. All African people taking part in this study were born in a range of different countries (see section 1.3 under 'Country of Birth'), and to that extent there were no 'nationality specific' groups in this project. The final four groups in this project were fully mixed, comprising of African women, African men, and Gay and Bisexual men. Participants from these final groups are said to have taken part in 'mixed African and Gay men's groups'. Depending on the location and nature of the group (and their willingness to do so), individuals could take part in more than one group. Thirty people returned to do so. Individuals were paid £20 expenses per group attendance and in extreme cases, additional travelling/childcare expenses were paid.

We are aware that adopting these three target groups (African men, African women and Gay and Bisexual men) we may be seen to create an entirely arbitrary and artificial distinction between Gay and Bisexual men and African men which may lead to an assumption that the men in the latter group are entirely heterosexual and the men in the former group all non-African. Of course, in reality, this is not the case and we are aware that there are homosexually active and Gay and Bisexually-identified Black African men. In anonymous self-complete questionnaires, all the African men in our sample reported a heterosexual identity and were free to join any group they felt they identified with most. Although two Gay-identified African men contacted us and expressed an interest in taking part in Gay and Bisexual groups, neither followed up their interest with an attendance. We are aware that the experiences of homosexually active African men both here and in Africa are worthy of investigation, however, we could not have done these experiences justice within the remit of this study.

1.3 SAMPLE DESCRIPTION

One-hundred-and-twenty-five people took part in the twenty focus groups. Of these, thirty (about one quarter) took part in more than one group (eight Gay and Bisexual men; twelve African heterosexual men; and ten African heterosexual women). Demographic data is unavailable for six respondents who did not fill in the short self-complete questionnaire. A further three respondents partially completed the questionnaire. Demographics are presented below for those one-hundred-and-nineteen participants who fully or partially completed questionnaires.

Target group

Gay and Bisexual Men: 44

Heterosexual African Men: 34

Heterosexual African Women: 41

Age	All Respondents	Gay and Bisexual men	Heterosexual African men	Heterosexual African women
Range	22-66	25-48	26-66	22-63
Mean	39	35	39	40
Median	37	34	40	40

Ethnicity	All Respondents	Gay and Bisexual men	Heterosexual African men	Heterosexual African women
Black African	75	0	34	41
White British	29	29	na	na
White European	6	6	na	na
South American	8	8	na	na
Black Caribbean	1	1	na	na

Country of Birth	All Respondents	Gay and Bisexual men	Heterosexual African men	Heterosexual African women
Africa				
Uganda	20		7	13
Zimbabwe	18		6	12
Zambia	11		8	3
Kenya	4		3	1
Nigeria	7		3	4
Rwanda	7		3	4
South Africa	2		0	2
D.R.Congo	1		1	0
Liberia	1		1	0
Malawi	1		1	0
Sierra Leone	1		0	1
Tanzania	1		0	1
Europe				
UK	30	29	1	
Spain	4	4		
Italy	1	1		
Portugal	1	1		
The Americas				
Brazil	5	5		
Argentina	1	1		
Chile	1	1		
Colombia	1	1		
Trinidad & Tobago	1	1		

Length of residency (for those not born in the UK) (N = 3 missing)	All Respondents	Gay and Bisexual men	Heterosexual African men	Heterosexual African women
Range of years	0.5 – 38	0.5 – 13	0.8 – 38	0.5 – 15
Mean # of years	5.5	4.6	6.4	4.6
Median # of years	3.5	3	4	3.5

Educational Qualifications (N = 2 missing)	All Respondents	Gay and Bisexual men	Heterosexual African men	Heterosexual African women
Low 'O' levels or less	35	6	9	20
Medium 'A' levels or equivalent	39	21	6	12
High Degree or higher	43	16	19	8

Number of children (N = 2 missing)	All Respondents	Gay and Bisexual men	Heterosexual African men	Heterosexual African women
No children	58	40	7	11
No children living at home	17	1	9	7
Number of children at home				
One	14	2	3	9
Two to four	25	1	11	12
Five or more	3	0	1	2

Employment (N = 3 missing)	All Respondents	Gay and Bisexual men	Heterosexual African men	Heterosexual African women
Not in paid work	97	35	28	34
Employed	19	8	6	5

Time since HIV diagnosis (N= 3 missing)	All Respondents	Gay and Bisexual men	Heterosexual African men	Heterosexual African women
Less than one year	17	5	5	7
One to three years	50	17	13	20
Three to six years	27	9	12	6
More than six years	22	12	4	6

1.3.1 A note on migration status and on employment

In a policy environment where asylum applications are increasingly rejected, and where those with failed applications face imminent deportation, participants would have been unlikely to take part in the study if we were intent on collecting information on legal migration status. Within the discussions themselves, it was apparent that most African participants had sought asylum, and were either still awaiting a decision, had been granted refugee status, or had been refused. Among those who had migrated from South America, it appeared that work and visitors' visas were the main means of accessing residency. European migrants had automatic residency and rights to access healthcare and benefits in the UK.

For these reasons, we only asked for a yes/no response to the question '*Are you in paid work?*' and did not ask any further detailed questions about types of employment, *etc*. As a result, we can only report responses within this limited framework. Therefore, some of those who appear to be 'unemployed' may be students, retired or medically retired.

2 HIV stigma associated with racism and xenophobia: African people with HIV in England

In this chapter, we first place the experiences of UK-resident, African people with diagnosed HIV within the broader social context of being African in the UK. It is important to preface this with some comments about historical, social and political factors that will impact on both the process of migration and on life in the UK for African people. Like all migrants, African people leave their home country with a set of experiences and beliefs; a sense of a social and political self that is, to a greater or lesser extent, rendered meaningless within the country to which they migrate. They take on a different social meaning as 'an African immigrant', 'an asylum seeker' or 'the African victim of racism and discrimination in the UK'. This very reductive reconstruction of both the individual and the group (which is an almost inevitable facet of the experience of migration) ignores the complex mixture of national, familial, tribal, linguistic, religious, cultural, gendered and sexual aspects which combine to make up an individual's life story or a group's history. Thus, the notion of a singularised 'African identity' has been critiqued as a concept of Western imposition that is confounded by a number of factors including linguistic, cultural, political, historical and gendered difference (Mama 2001, Melber 2002, Owomoyela 2002). On an individual level, the sudden shock of entering a society that has constructed its own negative image of 'the African' often proves to be a heavy burden for migrants; one that is deeply unsettling, inequitable, hostile and in direct conflict with self-awareness and personal identity. Rather than becoming easily acculturated to this new existence, African migrants to the UK are likely to continually find themselves confronted with racist and xenophobic representations, ideologies and images of 'Africanness' which are in direct conflict with who they know themselves to be (Mama, 2001, Anderson 1983).

The historical and political relationship between the home and host country is also central to the experience of the individual migrant and migrant minority groups. In the case of African people in the UK, this relationship is formed by a long and often antagonistic history of colonialism which is likely to influence the social relations, actions and viewpoints of individual African people in the UK and the social and political alliances that African groups forge here. The experiences of the individual, cultural and social norms and practices, as well as the history of colonialism will have a major impact on how individual African people and African groups respond to the social problems they encounter in the UK.

Responses to the problem of AIDS inevitably raise questions of social and intimate relationships. We must consider the factors influencing gender relationships and the nature of gender roles as well as account for the modes of sexual expression and the meanings attached to different sexual identities in different cultures. The nature and role of family or kinship networks are also important. In short, an individual's sexual and gender identity, the way they express that identity and the intimate relationships they conduct are heavily culturally and historically mediated.

Instances of the way in which history and culture mediate intimate relationships among African people are manifold. For example, we know that in Africa, HIV is now more widespread among women than men and that practices which subordinate women such as poverty, low levels of schooling, domestic violence, sex work, and inadequate access to condoms, sexual health

information and health care contribute to increased rates of HIV infection among women (UNAIDS 2004). However, a typical Western perspective which positions African men as 'sexual predators' and African women as 'passive victims' with no social power, is a gross simplification (Gupta 2000, Dowsett 2003). This interpretation prohibits an understanding of the ways in which masculine norms of behaviour function as barriers for men themselves, who are also in need of information about how HIV is transmitted (Gupta 2000). It also fails to highlight the ways in which post-colonial African infrastructure and industry, such as mining and migrant labour systems, contribute to a social displacement of men which ultimately contributes to the spread of the epidemic (Chikovore *et al*. 2003). Likewise, gender relationships are influenced by structures such as family and kinship associations, tribal hierarchies and spousal relationships. The notion of 'the subordination of women' takes on a different meaning in contexts where women have traditionally occupied roles as community leaders, land owners and entrepreneurs (Oyewumi 2002) or where women are the heads of households, coordinating finances, delegating tasks and managing small agricultural holdings for the subsistence of the household (Soetan 2001).

Western political or ideological discourses such as feminism and civil rights (which fundamentally inform Western responses to HIV) cannot be transferred automatically or unproblematically onto the situation of African people living with HIV in the UK precisely because they are responses that are appropriate to a Western interpretation of gender relations and kin structures. Continuing to impose Western cultural models onto African contexts means that the negative effects of colonialism will be perpetuated. In addition, such an approach stands in the way of engagement with policies and interventions that will adequately meet the needs of African people living in the UK. Gender is just one of the many areas in which careful attention to culturally appropriate interventions and policy positions relating to African people with HIV living in the UK must be taken into consideration.

In the chapter that follows, we describe everyday racism and exclusion in order to describe the layered inequalities faced by African people with HIV in the UK. They face not only exclusion from wider British society on the basis of race, ethnicity, nationality and immigration status, but also exclusion from personal networks of social and emotional support on the basis of HIV status. Finally, we provide a critical description of the African response to stigma and discrimination.

2.1 BEING AFRICAN IN ENGLAND

We have seen in chapter one how stigma and discrimination function in order to reinforce existing systems of power inequality such as racism, sexism and xenophobia. Therefore, before discussing the specific ways in which HIV-related stigma affects the lives of African people with HIV living in the UK, it is necessary to contextualise day-to-day life in the face of entrenched social, economic and political inequality.

A minority of our respondents moved to the UK for the purpose of career development or study, but the majority did so as a result of persecution, illness, civil conflict, insecurity, genocide and poverty. So for many there is no real option to return 'home' and most describe their existence in the UK as one of necessity rather than choice. Most find themselves on the periphery of British social life, their survival depending on the support of other African people or charitable Britons. Many reported feeling little control over their lives. This situation is most acute for those involved in the asylum application process and even more so for those whose applications have failed. The fundamental role of such structural inequalities in the lives of African people living with HIV in Britain cannot be underestimated. Our examination of these inequalities covers experiences of racism, anti-asylum sentiment, obstacles to accessing services and finally, the experience of accessing welfare benefits and employment.

2.1.1 Racism

African respondents discussed racism and racial segregation in Britain as a matter of routine. Most describe a social life populated mainly by other Black African people and an overwhelming state of inter-cultural ignorance due to the fact that there is little or no interaction with White British people and their culture on a mundane or daily basis.

> **Why would I know what a White family is like, and why would they know anything about me?**
> **African woman: mixed African group, London**

With the exception of those currently studying in the UK (who discussed their experience of the more 'open-minded' multicultural environments of college and university) most respondents felt that in the majority of public settings African people can expect hostile remarks and discriminatory behaviour. Moreover, there was a consensus that the national British press fosters and maintains racial prejudice and stereotyping in its representations of Black people (and particularly Black African people) as an impoverished, uneducated and uncivilised group who present a threat to White British society. Such racism was perceived to be worse in rural and smaller metropolitan areas.

> **But if you are staying in places like [names town], we are not really that many Blacks here. You stand out in the crowd. And you find that it becomes a bit uncomfortable. You overhear racist discussions about tropical diseases, and asylum seeker numbers going down. And it is a pity, and uncomfortable. If you live in an area where you are a minority, then tension is a bit higher, and in cosmopolitan areas where there are so many nationalities, you wouldn't overhear things like that.**
> **African woman: African women's group, not London**

For most participants, racism forms a part of their experience of living in Britain and is managed by keeping away from potentially threatening situations.

> **If I can help it, I keep to myself.**
> **African woman: African women's group, not London**

2.1.2 Anti-asylum discourses

The majority of African respondents spoke of the long-term and pervasive personal insecurity they faced as asylum seekers whose applications remained either in process or had been refused (Refugee Council 2004a). Within the context of asylum policy changes over the last year, respondents caught up in the asylum process describe a life where they feel vulnerable to attack from the government, media and as a result, the public at large.

> **Another problem is, most of us are asylum seekers. So it is very difficult. You can't work, you can't get benefits. And again, in the eyes of British people, if you are an asylum seeker, there is a stigma.**
> **African woman: African women's group, not London**

The climate of rejection and intolerance directed toward asylum seekers leads ultimately to feelings of fundamental and debilitating personal insecurity.

> **We are uncertain. To be free, you shouldn't be in fear of an immigration officer at your door, you don't want to be called an alien, to be called names, as if you have come here in order to destroy.**
> **African woman: African women's group, London**

> **[Informal interpreter speaking for one woman who breaks down in the group]: She fears that she will be taken forcibly from her B&B because of her immigration status. The social worker is asking to see her Home Office papers. She can't focus or concentrate on anything. Waiting to be removed. If she thinks about it too much – bad things happen.**
> **African woman: mixed African group, London**

However, not all respondents were actively seeking asylum. Some had refugee status and others held student visas which allowed limited residency and employment rights. Yet the asylum seeking discourse which predominates in the UK tends to make sweeping generalisations which cast all Black African migrants as asylum seekers who are dependent upon the state. This popular discourse makes no distinction between migration (which can be undertaken for any number of reasons); the process of seeking political asylum; or the attainment of refugee status which grants an individual full rights of employment and movement.

> **I work full time and pay tax and it is so annoying. You sit on the bus and you hear these conversations... "Black people are bringing in these diseases... asylum seekers", and you think... Hang on a minute, there are many of us who are working and are paying taxes.**
> **African woman: African women's group, London**

Thus, stigma attached to asylum seeking is taken up and used as a means for Black African people to distinguish themselves from the 'others' most reviled in the public sphere: the asylum seekers. The response of the speaker above is not one of solidarity, but one of distinction.

2.1.3 Barriers to accessing services

The social and economic instability caused by migration among the respondents in our study often made them dependent on health and social services and support from UK agencies. For many, however, lack of a confirmed or legal immigration status limited or prohibited their access to health care and social services support. Yet, such limitations were rarely recognised. This student described how her health care provider and university support staff did not recognise that her status as a foreign student disallowed access to the benefits system.

> **I saw the difference when I was ill and ended up being hospitalised. I am an international student, and I need to pay my own fees. And they didn't seem to understand at the international student office how my illness was affecting my ability to work, and do my studies, and pay my tuition and accommodation fees. And they didn't really understand that I didn't have automatic entitlement to benefits [...] in fact one of the things the doctor said was, "Why don't you apply for benefits?". I said, "I am not entitled".**
> **African woman: African women's group, not London**

Although many described health and social work professionals as supportive and helpful (despite the limited resources at their disposal in terms of referral), racism and stereotyping in the statutory sector sometimes hampered access to the limited services to which respondents were legally entitled.

> **It's a communication barrier, they don't consider your background and language. They think they don't understand your basic English....**
> **African woman: African women's group, London**

In some cases the only direct interaction that respondents had with White Britons was through bureaucratic institutions such as the Home Office, social security offices or the NHS. In these institutional contexts, equal standards of care and respect were expected, but not always received.

> **I was in hospital with PCP. I'm not saying they were bad, when they asked me what I was studying and I told them I went to do my masters in [subject name], they were [thinking], "Oh..In Africa you are stupid". I showed the doctors I had some idea and they are shocked when they realise that you know things because they think you are nothing if you are African.**
> **African woman: African women's group, London**

One woman described how she had been trapped in the midst of an institutional disagreement about whether or not she should be allowed emergency treatment and care in a central London hospital because of her status as an asylum seeker.

> **For me there was one nasty experience. I was very sick and critical in a ward for five to seven days. I was getting better and then they changed me to a common ward. The doctors who came to see me [in the second ward], said, "She's HIV positive", and refused to treat me… This was because I was African, I was not entitled to treatment in the UK because of my immigration. Then a third group came, they are feeling bad and were sorry and said that if it was to save someone's life, then they would treat me.**
> **African woman: mixed African group, London**

This woman was later approached by an external party and was encouraged to make a complaint of discrimination against the hospital. She explained that she had no desire to seek compensation or to draw further attention to her situation, she only wanted access to the emergency care and treatment to which she had a right.

2.1.4 Income, benefits and unemployment

Levels of employment are generally low for people living with HIV in the UK. For those African people who are seeking asylum, whose asylum application has failed, or who are undocumented migrants, legal employment is ruled out entirely. Research findings demonstrate that despite generally high levels of educational qualification at a population level, 51% of African people with diagnosed HIV in the UK are unemployed (Weatherburn *et al.* 2003). Those in the process of claiming asylum are prohibited from seeking work, thereby depending on subsistence payments from the National Asylum Support Service. Those who remain after their asylum application has failed, or who are undocumented migrants, may find badly paid illegal work. Some spoke of being forced to sleep rough, or living in cramped conditions with insufficient income to eat properly. Many depend on the charity of their family, cultural networks, or voluntary organisations. Such dependency was experienced as being overwhelmingly detrimental to self-worth and personal dignity.

> **I need to earn money in order to feel worth, but I am not allowed.**
> **African woman: African women's group, not London**

Men also spoke of how such dependency and their lack of an ability to support the family damaged their personal identities. Without a role as an income provider, they felt particularly demeaned within a traditional African cultural framework which prizes men as a source of stability.

> **Men in African community are looked on as strong and will support the community. The community wants to find strength from you and not weakness.**
> **African man: African men's group, London**

2.1.5 Powerlessness

The ultimate result of the processes described above is that a core group of African respondents involved with the asylum process felt themselves to be politically powerless in the face of these deeply embedded social inequalities. While women spoke primarily about a dire need in relation to daily requirements such as food, shelter and security, men focussed on their resulting lack of a role in the broader community. Without any voice in mainstream British society, and with government policy making it clear that their access to basic human necessities were heavily restricted, it was no surprise that such individuals felt ignored and marginalised.

> **Everything depends on immigration – health and happiness, no medication, no employment – everything depends on it. Because the law is changing every minute, you never know where you stand.**
> **African man: African men's group, London**

This group of people described an existence consumed with the imperative to survive, while at the same time avoiding social contexts in which they felt prone to racial abuse, as well as formal institutional structures which could result in deportation.

> **Sleeping rough, even if they give you accommodation, you don't want to sleep there because you are not sure whether or not they will come and take you away in the night, so you sleep at friends' places.**
> **African man: African men's group, London**

For many, the capacity to stand up for basic dignity and human rights is eclipsed by the need for day-to-day survival (Refugee Council 2004a). Many report a quiet sense of defeat, which can be a rational strategy for those who see little capacity for personal or even collective action in the face of structural inequality. This does not mean that all African men and women living with HIV in the UK regard their position as one without hope. Those with confirmed residency rights, and professional and personal skills, are the most likely to figure among the leadership of African community organisations and anti-racist bodies advocating for political and social change in public attitudes and among British institutions. Yet the situation for the majority of participants can be described as one which requires the ongoing management of insecurity around basic issues of safety, deportation, shelter, income and food which is likely to minimise their capacity for participation in broader social advocacy or human rights discourses.

2.1.6 'Pan-African' communities: a necessary myth?

The concept of a 'Pan-African' community and identity is central to responses to the social and economic inequality we have described. Within a hostile world, the feeling that there are others with shared history, shared cultural norms and ultimately shared experience of discrimination in Britain provides a vital link to individual and collective identity as well as an informal network of material support. Belonging to a self-defined and personally constructed African network of support helped many to maintain a fundamental sense of cultural identity and security. Thus, familial, national and regional expatriate networks formed the basis upon which respondents were able to find work, accommodation, community and friendship.

The experience of being 'African' in Britain was often described by contrasting it to 'British' modes of existence. African social interaction was described as being bound by strict moral or religious norms and centred around the extended family. Thus, while African participants felt that it was a British norm to maintain a private sphere within the nuclear family, they characterised African networks of communication and support as broadly based and less boundaried. While the lack of boundaries can raise its own difficulties in specific circumstances (as will be discussed in section 2.2.2) participants appreciated the comfort and support that a 'collective' African way of life could offer.

> **Unlike African communities where we come from, where you have land, and you will plant the food you eat, here you pay money for everything from food, to the medical facilities we need as HIV positive people, pay for our houses and our bills ... In this country, without money you can't get anything. You can't go anywhere to get money. Back home it is very different. You can go to even just a friend, your friend will give you money if you just explain your problem. Anybody, I mean your neighbour will give you money. That's how easy it is, but here it is very difficult. Here just to get one pound it is hard here. There is no safety net in British community, money is needed for everything, you can't turn to a neighbour for help or support as you can back home.**
> **African woman: African women's group, not London**

Expressed in this way, 'African' is a loosely affiliative term. Participants frequently explained that migrant African people from different regions, countries, tribes and villages living in the UK were likely to socialise in smaller sub-networks (such as cultural organisations or embassy events). Often, however, there may be insufficient numbers of other migrants from the same country or tribe to establish formal organisations. In these situations, the loose notion of a broader 'African' community substitutes as a response to this need, and therefore takes on an essentialised nature. It is constructed as a mode of existence that is not Western, not White and specifically not individualised.

Overlaying this local (UK) affiliative sense of an 'African community' is a broader diasporic one based on ongoing communication with other African people across the globe. Such networks are made increasingly tenable by rapidly advancing telecommunication technology which allows information, messages of support and gossip to be passed, for example, from North America, to the UK, to Germany to home within a matter of hours (Bastian 1999, Collyer 2003).

> **Somebody called me from Nigeria, my best friend, and I told her that I am sick, because the medication makes me weak in the morning… and one hour later my Godmother called me and said, "What is wrong?"**
> **African woman: African women's group, London**

Both the local 'Pan-African' community and the links maintained with family and friends in other countries via telephone and internet combined to provide emotional support and a means of maintaining contact between those living in the UK, other countries and in the country of origin. At the same time, African people from different areas and different linguistic, cultural and political groups found that they were mutually dependent on one another for tangible physical contact and material or informational support in the British context. The maintenance of the protective mechanism of this 'community' is an important aspect in the conceptual lives of many African people living in the UK. As a practical tool, this notion of a 'Pan-African' identity allows for the formation of cultural centres and events where individuals from distinct regions, tribes, countries, villages and linguistic groups can connect, communicate and ultimately flourish in a way that is limited in broader British environments.

For those without access to others from their own background, the notion of 'Pan-Africanism' becomes a necessary fiction that allows for a cultural home in a foreign land. For example, such communities may form around African evangelical Christian churches. Local events and services aimed to provide support and socialisation for refugee communities can also provide a forum for diverse groups of African people to come together. As one participant describes, this is one reason why the policy of refugee dispersal is so damaging at an individual level.

> **I think it's sad. Most of us from Africa used to live in communities with people we know, and being related to someone in some way. So if you arrive in London and you find some people from your country, you feel a bit comfortable, and you feel you belong. But if the asylum system pushes you out somewhere else… it is terrible.**
> **African woman: African women's group, not London**

However, this sense of African unity, or 'Pan-Africanism', which is a necessary tool of reliance and resistance for post-colonial communities living in the UK also carries with it the fissures of historical and cultural division.

> **I am very sorry to say ... the most arrogant people are [names a specific African nationality]. They abuse people and it is sad, about [their] arrogance.**
> **African man: mixed African group, London**

> **Everyone belongs to their small set of people. You hardly meet all other African people. Sudan, Morocco. There is a great difference between different cultures, tribes and countries. Therefore, the notion of an African community is slightly false.**
> **African man: African men's group, London**

> **What happens in terms of politics in Africa, it also follows us here.**
> **African man: mixed African group, London**

Thus, the myth of a 'Pan-African' community exists for some as a required narrative for survival in Britain, while at the same time demonstrates itself to be a fragile and sometimes oppositional collective of diverse sub-groups.

2.2 BEING AFRICAN AND LIVING WITH DIAGNOSED HIV IN ENGLAND

The previous section describes first the ways in which existing inequality affects the experience of African people living with HIV and second, the way in which inequalities are managed through a 'Pan-African' sensibility and social organisation. In this section, we introduce the compounding problem of HIV infection in order to examine the ways in which the epidemic (and the stigma and discrimination associated with it) serves to reproduce these power structures and undermine the fragile systems of support so critical to African migrants.

First, we give respondents' descriptions of the HIV-related stigma and discrimination they have faced within British social and institutional settings. In a subsequent section, we examine the ways in which stigma and discrimination function to isolate HIV positive African people from the 'Pan-African' networks of support we have described. This latter issue has tended to get little attention in existing research and policy discourses, but given the critical role of such networks in the sustenance of many African migrants in the UK, isolation proves to be the primary concern of the vast majority of our respondents.

2.2.1 *Representations of African people with HIV in the British press*

A large proportion of respondents felt that the majority of the British population believed that all African people have HIV or AIDS. During discussions about the press, respondents commented on how media attention is exclusively focussed on the African epidemic. Although they acknowledged that often such coverage was aimed at increasing funding and political empowerment for those most in need, several people pointed out that the downside of such coverage is to isolate and blame African people for their own plight, and to support the notion that African people are responsible for 'importing' HIV to the UK.

> **It is important that it is not only African people and asylum seekers who have HIV. There are people in the UK who are born and bred! They get treated on the NHS! They [the press] just connect HIV and Africa.**
> **African woman: African women's group, not London**

> **Why not represent White African people with AIDS? [some laughter among participants] They are also human beings. They always show the interior of Africa, just to demonstrate that it comes from Africa. This phenomena was started by Western AIDS agencies. You would never see a Kosovan with HIV. Africa is a selling point for Western charities and for the media here, we are in the middle of a struggle ... We were slaves and it is the same imagery. It will take time before anything changes.**
> **African man: African men's group, London**

Many felt that such representations which associate all African people with HIV, exacerbated racism and anti-African feeling among the British. Living as an African with HIV who fulfills the stereotype, can sometimes make the burden of this stigma overpowering.

> **We went to a pub with a doctor friend and there were some nice looking friends who were White girls. There was another White woman. It was my round. So I bought for my friends. The White woman who was not part of our group asked me to buy her a drink. When I refused, she turned to the two girls with us saying, "You going out with these African men, they have got AIDS. All African people have AIDS". The two ladies said ,"Come on stop it". Now I knew I had AIDS. I had no intention of going out with any of these girls. The woman ended up being thrown out of the pub for misbehaving. So these are the conditions we are living in.**
> **African man: African men's group, London**

Thus, HIV-related stigma reinforces racist perceptions by situating Black African people as hyper-sexualised, irresponsible and infectious people who pose a threat to the public health and the stability of the health care system in the UK. Respondents felt that HIV had been mobilised as a means of maintaining a strict racial distinction between (predominantly White) British and Black African people and as a result reinforced existing structures of inequality.

Back home they think it is about prostitution. Here, the first people getting infected were Gay men. The way they look at it here is different than back home. So here it is not even prostitution as such, they just look at you as an African, and if you are African you must have HIV. Sometimes on the bus I feel that people must think I am positive. You see it in the paper. It is not about how we got it, it is just saying that African people have HIV. I don't think they look at it as a disease from prostitution.

African woman: mixed African group, not London

2.2.2 Immigration policy and legal responses towards African people with HIV

The majority of respondents were concerned about the way that government policy appears to echo such public perceptions. As a result, African people feel that they are being specifically targeted for deportation from the country.

Believe you me, they are sending people back home! Not even being on ARVs [anti-retroviral treatments] will stop deportation now!

African woman: African women's group, London

While recent policy shifts have caused substantial concern among African people with HIV, some respondents recognised the difficulties faced by the British government addressing the issue of African migrants with HIV. Some spoke of the rationale behind a degree of official silence around African people with AIDS in the UK as a measure of liberal protectionism. Cast in such a light, they could see how – at a governmental level – the interests of African people with HIV were served by not addressing their needs publicly and not drawing attention to the cost of providing treatment, support and effective prevention interventions, which in turn might exacerbate stigma.

On saying that the government must have a clear policy. The government cannot have a clear public policy because it will mean that they are spending a lot of money in NHS treatment for us people. So it will be like, it looks too expensive. So it is like they are accepting us when they should be sending us away.

African woman: mixed African group, London

This inhospitable policy environment was felt to have been exacerbated by the media coverage of a criminal case brought against an African male migrant. Mohammed Dica was charged with recklessly harming two people by transmitting HIV to them. This and subsequent similar cases were regarded by respondents as indicative of a particularly pernicious hatred and fear directed against African people by the British public.

I think the criminalisation, the stigma is going to increase as is the discrimination. A lot of people will go underground. For example, at [name of African HIV agency] a lot of men will not come out as positive and this will be worse and it will be a negative thing. Health promotion advisers are trying very hard to stop the spread of HIV whilst the media is undoing all their works. People have given radio interviews explaining the facts, and yet the media gives out the other message. What does the message, "You will die in six months", from the Dica case say to someone who has just been diagnosed?

African man: African men's group, London

About eight months ago I went to hospital and I introduced myself as coming from [names African HIV agency] and they said, "Ah, from [agency] you are a positive man". So I don't want to go back to that hospital. I even fear to go back there because of the Dica case.

Facilitator – The decision to be open about your status becomes a political decision?

Yes.

African man: African men's group, London

Many African men and women felt that the criminal justice system was being used to target and vilify African men with HIV. They argued that by allowing the complex matter of HIV transmission to be focussed upon by the courts in this way, with prosecutions aimed at African male asylum seekers, all African men with HIV would be regarded as guilty by association. The detrimental treatment, support and prevention implications of this highly stigmatising process were seen to be disregarded by a judiciary and Crown Prosecution Service that was intent on targeting a specific group of people.

2.2.3 Employment and HIV

Because of participants' insecurity regarding their legal immigration and residency status, it was difficult to get them to discuss in detail their experiences of employment. It was clear, however, that some participants were engaged in illegal work which they did not disclose on the demographic questionnaire.

African participants faced a range of obstacles to employment in the UK, mainly in relation to immigration restrictions. This bred resentment and anger within the focus groups. Not being allowed to work meant a low standard of living as well as a loss of self-worth and social value.

> **Giving us benefits is also not a solution. I want my worth as a person to be able to be employed and earn my own money. [Strong agreement from others].**
> **African woman: African women's group, not London**

Whether or not people were allowed to work, health emerged as a major concern influencing attitudes towards employment.

> **Speaker 1: At the moment I am wondering what to do with myself. I have health issues, I am tired, but there are times when I feel I need to be doing something.**
> *Facilitator: What are the issues about getting employment?*
> **Speaker 2: I am doing some courses now to help me towards employment.**
> *Facilitator: Are they going well?*
> **Speaker 2: Well yes, some things are holding me back, and my health issues, they are all in a tangle. And when your health is not stable, it is up and down.**
> **African women: African women's group, not London**

The issue of fluctuating health impacted on people's decisions about whether or not to disclose their HIV status to their employers. If they could not guarantee regular attendance, they felt they had to disclose. However, they felt that if they disclosed, they would either not get the job or else be discriminated against once employed. This had two effects. Either individuals did not apply for jobs, or they took jobs for which they were overqualified in order to avoid having to disclose. The following respondent was employed in menial casual work.

> **The other thing I would like to say is about employment. I have not looked for employment in this country in my own profession. But it is always in the back of your mind, if I get a job, should I tell my employer about my HIV status? There is a fear of how they will react to it. It may cost you your job, it may make you so uncomfortable it changes relationships. Yet you would want to be able to explain about why you are absent, and going to doctors.**
> **African woman: African women's group, not London**

Legislative changes relating to discrimination and disability in employment serve to confuse some people. The provision of equal opportunities monitoring mechanisms are meant to provide protective structures for individuals if discrimination arises. However, some suspiciously regard these systems as a means of imposing a duty to disclose HIV status hidden under a rubric of increased rights. In turn, many do not trust that they will not be discriminated against by employers if they disclose.

> **I am concerned about this disclosure issue, especially when you apply for a job. Sometimes they ask you on the equal opportunities form as to whether you have to disclose. I have had a bad experience. I disclosed that I am HIV positive and unfortunately the supervisor, the manager told the supervisor, and I didn't think that was good, and I decided to stop because I was feeling that I was going to be victimised.**
> **African woman: mixed African and Gay men's group, not London**

Legislation does not account for the fear of discrimination or the stigma attached to the (erroneous) perception that one may 'be required' to declare oneself as HIV positive or disabled. The following was exchanged between a Gay man and an African woman within a focus group.

> **Speaker 1 (Gay man): they will change it, forcing us to admit to being disabled under this act, whether we like it or not, because from the date of diagnosis, anybody with HIV is going to be considered disabled. So they are kind of forcing this whole disclosure issue on us, and because it is not a CV and it is kind of a legal form, if we lie on that form, and say no we are not disabled, and then it comes out that they find out that we are HIV positive they can then, if we are sick, if we need to take long-term sickness, or anything like that. Or if we want to take some time for change in medication regimes, or we later disclose it, we are then liable to lose our jobs because we actually lied on a legal form.**
> **Speaker 2 (African woman): [Regretfully] So all I can say is, I am disabled.**
> **Gay man and African woman: mixed African and Gay men's group, not London**

Others feel demeaned at having to provide evidence of their disability.

> **I have gone through an experience with employers who have insisted that I bring in my HIV results. I really felt discriminated against. So, that contributed a lot about me feeling about who I am. Quite negative.**
> **African man: mixed African group, not London**

In short, therefore, being able to disclose HIV infection to an employer was not perceived as a guarantee of fair treatment or personal well-being.

> **Once you have HIV, they will tell you that your life is finished. You won't get a job. They will tell you a lot of things you won't be doing. You won't have happiness. [...] Like if you got a job, they say, OK, if you need a job we have to test you. After testing you and finding out you are HIV, you become the talk of the place and the area you are living in. Or any place you are living with.**
> **African man: mixed African group, not London**

2.2.4 Health care and HIV clinical access

Respondents reported discriminatory attitudes from doctors and healthcare staff in a range of settings. Some women reported distressing treatment and overwhelming ignorance regarding infection control procedures among some staff in ante-natal services. This made their experience of childbirth in the UK deeply unpleasant.

> **When I was having my baby, she came three weeks earlier, so like my doctor liked me, and he was planning to do the operation. But unfortunately the baby came, and the doctor was not here, I think he went on holiday. And another doctor got me and they took me to [another ward]. I was supposed to stay on [names ward], but as my doctor was not here, I was not here, I was on [different ward name]. And the nurses were not treating me fairly. They wouldn't even come and clean the room. I was crying, it was because I had HIV they had to do that. They left the toilet, they didn't even clean the toilet. So even just after the operation, the next day, I was in pain when I told the lady to hold me, to help me, to sit up. She refused. She gave me something, to hold on to. I was crying and saying, "Oh God, why me?"**
> **African woman: African women's group, not London**

Others reported extreme measures taken in dental practices.

> **I have a dental problem and I go to this clinic, and I go there, two maybe three times. So eventually I told them about my condition. They explained that I would have to be the last appointment of the day. I have been to that room, and sat on that chair, and the same doctor examined me as before, but after I told them I was HIV positive. So I went for the last appointment of the day last week, they covered the chair, the light, the doctors were wearing three pairs of gloves.**
> **African woman: African women's group, London**

Others described ignorance from their GP around treating conditions related to their HIV.

> **[Spoken by informal interpreter on behalf of another participant]: At the GP, she was not getting the proper attention because of problems with interpretation. She had bad pains, stomach ache. GP said that as she was terminal, there was no need for any other treatments than pain killers. She thought that the lack of response from GP was down to her poor English. Went back with an interpreter, but the response was still the same. Another time, she was in pain, but was asked to come back the next day. She refused to leave until she was given treatment.**
> **African woman: mixed African group, London**

Others reported being treated badly in Accident and Emergency departments.

> **I was suffering from a stomach problem and headache, I have just moved, so I phoned NHS Direct and asked where I should go and they sent me to [name of hospital]. The doctor was friendly and was asking all questions of what medicines I was on. I said I was on ARVs [anti-retrovirals]. She afterwards said that she didn't know what ARVs were and asked me to tell her. She was shocked, she left the room and returned with gloves and gown, and kept her distance, acted panicky. She went to get an HIV specialist who was very helpful and gave me the medicine I needed. [others can't believe it, or laughing with surprise]**
> **African man: mixed African and Gay men's group, not London**

Stigmatising attitudes were also displayed by some specialist HIV physicians and staff. Some reported feeling that staff suspected that they (the respondents) were somehow less deserving of treatment and care than a British person with HIV. Sometimes these attitudes were quite explicit.

> **I started on medication and got side effects and then I went to my doc to say I had this problem and he told me I should be grateful.**
> **African woman: African women's group, London**

Such stigmatising attitudes are seen to be exacerbated by Department of Health policy around restricting the availability of anti-retroviral treatment to asylum seekers.

> **They are now refusing to treat visitors. I have a friend who came and they are refusing to treat her with ARV. They are saying her CD4 is OK at 250. They will give her the treatment for the symptoms she has, but not ARV. They are less likely to start you with ARV if you are African.**
> **African woman: African women's group, London**

There is evidence to suggest that HIV clinicians stand alongside Africans living with HIV in their objections to these restrictive treatment policies based on their harmful effects on individuals and the community at large (Pollard and Savulescu 2004, Revill 2004).

2.3 HIV STIGMA WITHIN THE 'PAN-AFRICAN' COMMUNITY

While the 'Pan-African' community was seen to be broadly beneficial in terms of material, emotional and social support, it was also clear that group membership was not unconditional. An HIV diagnosis was particularly feared as a basis for excluding individuals or families from networks of support. Just as stigma operates to reinforce pre-existing power inequalities between different groups (Black African people and White British people), it can also function in the same way within

groups. Within the 'Pan-African' community, negative connotations attached to disease tended to strengthen the boundaries between 'normal selves' and 'others'. In the African cultural context (as in many others), HIV and AIDS carry an association with homosexuality, prostitution and promiscuity and, as such, are heavily laden with notions of immorality.

> **Because it is about sex, in my country they then automatically think you got it because you have been loose. "You are not anything better than a prostitute". They will not tell it to your face, but that is what they think. They don't believe you didn't get it any other way. They think you have been around with so many men to pick it up.**
> **African woman: African women's group, not London**

> **Then you a get a certain group now influencing the others in terms of the way they speak about you. You are an outcast now. On the other side. As if you had just been careless with your life.**
> **African man: African men's group, London**

The possibility of rejection and ostracism from African support networks (including those in the UK, across the globe, and 'back home') as a result an HIV diagnosis was regarded as personally devastating. Participants described being barred from all contact with family members (particularly young children), exiled from their homes and from other community structures and enduring what amounted to a 'social death'. While the British environment may be hostile or unwelcoming, in many ways it represented a depersonalised hostility. The 'Pan-African' community operated in the collective imagination as means of restoring identity and establishing stability (albeit fragile). And it was the removal of that safety net of personal support that posed the most significant threat for the vast majority of migrant African people with diagnosed HIV.

2.3.1 Family

Rejection by the family was most directly and intensely feared due to its primary position in traditional cultural norms of identity and self-concept.

> **My brother-in-law in Zambia said, "What you have done is bad...how can you tell everyone that you are HIV positive? You have disgraced our family". Then I didn't answer back and without waiting for me to tell my Mother, they told her.**
> **African man: African men's group, London**

Within families that have lost members to the HIV epidemic, denial was sometimes the only means of managing the burden of stigma in a way that allowed for undamaged identities. Members who had died were sometimes never again mentioned and discussions about causes of death were banned.

> **I am from Zimbabwe, what happens is, I have lost a brother in 1998. But we cannot talk about what killed him. We know, all of us know, but we cannot talk about it. If a person dies, you ask them, what is the problem. "Ah, so and so is bewitching him, so and so is bewitching him." That is the trend in the Southern Africa. Even if you know it, you can't say it, no one will. You can't say because of the stigma. If I say, "My brother died of HIV", it takes the courage to talk about it in that manner. As it is now, I have failed. I say, "Today I want to tell my sister and my brother", those that are in the UK, you know. Each time I leave a support group I say, "Today I want to tell them". But I have failed to tell them that I am positive. It is a stigma that I don't know how to deal with.**
> **African man: mixed African group, London**

Those with children spoke of particular difficulties with disclosure. Often anxiety revolved around the tension between being seen as truthful and a concern about losing all credibility as a good parent and provider.

> **My children normally remind me of my medication, but to talk about it with the kids, I am scared that they will break down. They know that I am on medication, but they don't know what for. My daughter is 23 and I know she suspects something, but to approach me, she**

is a bit shy, but I will approach her when I am ready. My son is 18 and away at college, but I am waiting for them to be with me in the same home where they will see everyday that I am getting better and better, then I will tell them. I will tell them to look at me now and how healthy I am. I am scared, especially my son because he is close to me. He calls every day to see that I am taking the treatment. I need some ladies who have told their children already to tell me how to do it because I don't know how to do it.

African woman: African women's group, London

For some, these concerns were made worse by the fact that their children were being cared for by family back in Africa where a very different experience of HIV infection influences attitudes.

If you tell them that you have this disease, back home, once they know you are positive they think you are going to die. I don't want to send this message to my children. Maybe if they are 16, if I am still around then I can sit them down and tell them what I am suffering from. When I was diagnosed, the counsellor wanted to help me to tell my children, but I said there was no need. There is nothing they can do [as they are very young and are still living back home], and I don't want to add to their problems.

African woman: mixed African group, not London

One strategy that emerged within the discussion groups was to tell children at as young an age as possible, leading to a normalisation of HIV within the home before stigma and negative connotations had an opportunity to take hold. Within this context, some respondents spoke of the great challenge they faced regarding disclosure to their older children who already had strong negative attitudes about infection.

Speaker 1: But when they are grown up it is difficult. I have sons, one is twenty four and the other is twenty three. How could I tell them that I am HIV positive when they start saying... they talk about HIV and say, "That one was a womaniser, that was this, that was this"? Now how will I tell them I have HIV? They will say, "Oh mom, I think that you used to go with a lot of men". They will say that!
Speaker 2: That is ignorance!
Speaker 1: I feel I deserve my dignity. I will tell them the reality of HIV, but I cannot tell them because I need my dignity.

African women: mixed African group, London

African women frequently spoke of the way in which disclosure of an HIV diagnosis would raise questions about their own moral and sexual probity, often threatening their role in the family as wife and mother. The issues raised by men, were often somewhat different. Some were concerned that an HIV diagnosis might make others believe that they had sex with men.

And there was a false stigma that you are Gay, you know? And do you want to be associated with that?

African man: mixed African group, London

In addition, an HIV diagnosis for an African man was described as a threat to his masculine role as family provider and protector.

We are men, we are strong, we can work, we can provide like any other person. When that is gone, you are disempowered. Being looked on as a man in control and able to provide. That goes away if you disclose.

African man: African men's group, London

One man described his own personal priority after the success of anti-retroviral treatments. Regaining health for his own benefit was secondary to his concern that he would be able to once again provide for his family.

The meds are working and you are feeling better and then you can think. What next? I can begin again to work for my family.

African man: African men's group, London

2.3.2 The diasporic family

Concerns over family responses to disclosure were never far removed from the broader worries about disclosure to other members of the 'Pan-African' community. As diasporic peoples, migrant African people maintained strong personal connections with those still living on the continent. Yet the efficiency of this communication network meant that if people in the local African population (for example, in Haringey, or Church, or a Zambian community organisation) found out that an individual had HIV, then it was possible that this information would be transmitted back home through such networks. Once the information was released, the individual would lose his/her capacity to control who found out. Respondents feared that such news would reach close family and friends back home who not only were unable to 'do' anything about the situation, but also had little means of understanding that the virus could be successfully managed with treatment in the UK.

> **[Through interpreter] Most of the family members have died. If I say it now, they will just assume I am the same – finished – never seen again. This is hard to explain to my extended family because I cannot tell them why it is that I have to stay in the UK [for treatments] and why it is that I cannot come home.**
> **African woman: mixed African group, London**

Because of the lack of widespread and affordable anti-retroviral medication in most African countries, there was frequently little understanding expressed by people 'back home' about the care and treatment that was available in the UK. For most Black African people living in Africa, an HIV positive diagnosis was understood to lead to certain and often swift death. Without access to treatment, some health care systems have begun to buckle under the growing case load. Relying on their personal knowledge of this situation, African people living in the UK with diagnosed HIV often felt it was impossible to explain to friends and family in Africa that they were medically managing the impact of the virus with the help of advanced and accessible treatment and care. The gulf between the two worlds was just too great when it came to experiences of anti-retroviral therapy, health care and illness trajectory.

> **At home it is a death sentence. You feel that you don't want to put stress on your family there...the moment I say to them I am positive, that would be the end. They would say to my mother and so on, so.., I want them to know but they wouldn't understand.**
> **African man: African men's group, London**

Because of the stigmatising and immediate connection made between HIV and AIDS and death in high prevalence regions, the individual who chooses to disclose an HIV positive diagnosis to family and friends living 'back home' runs a high risk of being subjected to a ritualised 'social death'. Respondents reported that relationships were profoundly altered, and sometimes, funeral arrangements were begun by family members within days of hearing the news because the assumption was that the person who had disclosed would return home in a coffin imminently. For those who depended on ongoing emotional support from distant loved ones in order to survive the pressures of life in Britain, the risk of having these ties severed was too high. They recognised that they would not be able to successfully convince friends and relations in Africa that the news was not so dire because, in the African context, the reality of death from AIDS continues.

Therefore the fluidity of communication, gossip and communal networking typified by respondents as 'the African way' collided with the sub-Saharan African experience of HIV as a fatal infection. The result was that most diagnosed African migrants felt that they were prevented from telling any but the most trusted confidantes (or from telling anyone at all) about their infection. What the individual stood to lose from disclosure far outweighed what he or she might have gained.

> **I haven't actually gathered the courage of declaring my status to the community. Especially having that fear of rejection from the community. I have hardly phoned my relatives or close friends, because I feel it would be a shock to them, which ...I won't get any support or encouragement at the end of it. I feel it will be a type of blow on my side as well. So for the**

time being I feel like keeping my status to myself.
African man: mixed African group, not London

Especially to we African people, when I tell you, you are my closest friend, but then you tell your closest friend and so on. And then it goes all around the community. That is why sometimes people keep it to themselves.
African woman: African men and African women's group, not London

2.3.3 HIV-related stigma as it affects social participation in the community

Lack of discussion and openness about the ways in which HIV can be transmitted and the real prevalence of HIV among African communities in the UK leads to entrenched misconceptions about the risk that infected members of that population may pose to others. The social construction of people living with diagnosed (or suspected) HIV infection as physical contaminants serves to further reinforce the stigma associated with the epidemic (Douglas 1966). By establishing and acting on a belief that simply being in the physical presence of someone with HIV presents a risk of transmission, the manifestations of ostracism were most apparent and most damaging.

[Spoken through informal interpreter] When I became homeless, I went to stay with relatives. Because I was sick, they began to suspect I had HIV and they threw me out. When I went to another friend, I could only be put up for two days.
African woman: mixed African group, London

Many participants described actual or feared withdrawal of all types of casual human touch. In particular, some discussed how they had been banned from contact with children due to misguided fears of contamination.

[After diagnosis with UK hospital admission, a brother-in-law] said, "I think you have to look for somewhere to stay, you can't stay with me". And I said, "Why?" And he said, "[Respondent's sister] told me that you have got this situation, I am also scared of my children…even the plates". He said many things which…now I can't believe I was treated like that. That was how they were treating me.
African woman: African women's group, not London

One woman described her daughter-in-law's reaction.

[She] said, "Oh, your parents, I think they are HIV, I don't want my children to go there". It is so difficult when you are an older person, and you have children, grandchildren. You can't hold them! You know, it is very difficult that way.
African woman: African women's group, not London

In this context, cups, plates and toilets were frequently regarded as sources of infection if shared with a person known to have HIV.

One of my cousins died two months ago. We had the family to our place. So we met during the funeral procession. They were saying at the funeral that they heard he had died of AIDS, and they were so worried as this cousin had visited in the past, and used their bathroom. So I don't know what I should say in that circumstance. And these are supposedly enlightened people.
African man: mixed African group, London

This type of social quarantining was described by African participants as being equally acute among groups 'back home' as well as among migrant African people living in the UK. Although there were numerous examples given to the contrary (as detailed in section 2.2.4), African participants generally characterised migrant African people in distinct contrast to White British individuals who were portrayed as sympathetic, knowledgeable about modes of HIV transmission, and unafraid of the physical presence of someone with HIV.

Participants were particularly disconcerted about the evidence of ignorance and irrational fear of HIV contamination displayed by African peers and family members who were trained in health care. They expected better from these individuals, but in many cases felt acutely let down by their withdrawal.

> **My glands were raised, and my aunt who is a doctor noticed that. I assured her that it was just glandular fever. When I saw her again with her baby and her husband, who is also a doctor, he came and snatched the baby away from me, and stood back to greet me. Now, that to me showed to me that ignorance is not something that you can say someone is uninformed or uneducated. I mean, these are educated people in the medical field. They should know. And that even further worsened it. It kind of isolated me more, because I felt that the only person I could talk to was maybe my doctor, the counsellors, or other people at the clinic.**
> **African man: mixed African group, London**

Finally, fears about community disclosure can mean that people never access services.

> **There was a lady who lived with me in the hotel. She was from Zimbabwe. She was a great friend of mine. I asked her, "Can't we go to [names African HIV support agency] or something together?". She said, "Aye, I can't go there. I go there, and people know me, and maybe some people from home will see me and they will they know I am HIV positive. I can't go". She never came.**
> **African woman: mixed African group, London**

> **If I go to [names African HIV agency] and there are other Nigerians there, and if I ask you where you are from, perhaps I will know someone in your family. And then they don't want you to know, because maybe you will tell and this thing will spread. A while ago I saw a woman from my church there, and if she sees me she will tell her mother, and she will say aloud, "I am not the only woman in this church with HIV".**
> **African woman: African women's group, London**

This small selection of narratives demonstrates that there are many reasons for African people living with HIV to be hesitant about being open with their social networks about their HIV status. In many instances, telling members of the extended family will mean risking social censure from the broader community as well, so as a result the decision is made to withhold disclosure.

2.3.4   The effects of stigma on the 'Pan-African' community

Stigma develops and strengthens within a social context that makes it increasingly difficult to talk openly about HIV diagnosis. Within these communication gaps, fear and ignorance about immorality, infectiousness and treatment options take a deeper hold on the community. Thus, if HIV is raised at all, it is de-personalised and discussed as though it is something that only affects 'others'. This process is evident at the informal and personal level.

> **No-one talks about things like that. If I come to [names and African HIV agency] and meet another positive woman and then we meet again at an embassy event and we stand in the corner and talk quietly – how are you doing? Not saying HIV or AIDS, but we know what we are talking about.**
> **African woman: African women's group, London**

This is also an aspect of interaction at the broader organisational and structural level within the 'Pan-African' community.

> **They [African cultural organisations] do organise things and they will discuss HIV, but individuals talk about it as if it is happening to someone else and not them. When we go to African groups, they talk about educating people about HIV and nothing else.**
> **African woman: African women's group, London**

This situation mimics the historical, political and social HIV-denial dynamics within Africa. Participants spoke of the way that African people both at home and in the UK perpetuated myths about other nations and regions of Africa (ie. never one's own) being overwhelmed by the epidemic. This strategy allowed people to address 'the problem' of HIV as one that was distant and impersonal and resulted in inter-regional stereotyping and further stigma. For example, one Nigerian woman had a friend who told her that she should not allow her children to play with the children of a Ugandan neighbour. This friend felt that Ugandans were dangerous because they were highly likely to have HIV. The Nigerian respondent spoke of the internal difficulties that arose upon hearing such stigmatising comments against 'other groups' who were regarded as being much more likely to have the virus, particularly as she considered her own infection and her failure to disclose to her friend. This process was recognised by other respondents as evidence of larger political and cultural divisions.

> **Look at the way we are. Those from different nations, Uganda, Rwanda, Zimbabwe – people think of East Africa, Southern Africa – Nigerians refuse to accept they also have it. That divides us as African communities living in Britain. Some people won't acknowledge.**
> **African man: mixed African group, London**

2.4 DISCUSSION

In the introduction to this report, we characterised stigma as having the social function of maintaining social inequalities between groups. In this chapter, we have seen that stigma is not something that is done by one group to another. Rather, it is a process that mobilises a range of different groups (including those in power and those who are powerless) in perpetuating a social status quo. By examining the specific processes and contexts that will influence the experience of being a Black African (with or without HIV) in the UK, we aimed to illustrate that HIV stigma does not exist in a vacuum. HIV stigma is meaningless without the over-arching context of racism and xenophobia, and in turn, racism and xenophobia are perpetuated through HIV stigma. In short, all African people are prone to suffer HIV stigma (as all are suspected to be HIV positive) and all African people with HIV suffer racism and xenophobia in a heightened form. This understanding is important because it shows us the role of a range of communities in the perpetuation of stigma and hence power inequalities.

As a group, Black African people in the UK are rendered significantly less powerful than other groups by a range of factors. Social and institutional racism are compounded by anti-asylum discourses and practices (these include media representations, legislation, political processes and policy) which collectively construct African people as a potential threat to the UK. Central to these discourses and practices is the notion that Black African people have the capacity to spread disease and to drain state resources. These notions find strength in the fact that an HIV epidemic exists in Africa and that a significant proportion of African people entering the UK are HIV positive. Although the latter statement is true, the interpretation that is made of this by politicians and in much of the media is racist and xenophobic.

Pre-existing HIV stigma is evident among African people in Africa (Nyblade *et al*. 2003). This stigma is related less to racism than it is to sexism and homophobia (and to some extent national differences). The racism and xenophobia experienced by African communities in the UK plays into this pre-existing HIV stigma and increases intolerance of people with HIV and AIDS. Therefore, African people with HIV find themselves stigmatised not only within broader British society (for being Black, African, an asylum seeker and having HIV), but also within African populations in the UK, not only because they are suspected of being promiscuous, or a bad parent, or Gay, but also because they are a 'Black African with HIV in Britain'. This is seen as living proof that the overarching racism and xenophobia are 'justified', and in the eyes of fellow Africans, those with HIV are portrayed as denigrating the reputation of the entire community. Respondents repeatedly reported to us that the most painful form of rejection came from their own family and friends. Stigma classically

works in this way, making a powerless community turn on itself rather than trying to gain power. This is why we say that many different groups are involved in the workings of stigma. Stigma is not something that any one person or group is culpable of, rather it is something that individuals and groups find themselves implicated within. Stigma is a deeply entrenched social tool that develops and maintains social inequality, categorisation and exclusion. This understanding allows us to move away from an over-simplified notion of stigma and discrimination as being comprised of 'unfortunate' or 'isolated' acts.

On a personal and practical level, HIV-related stigma is a disaster for African people who know they have HIV. Because of the hostile racist and xenophobic environment prevalent in the UK today, they must rely on their expatriate and diasporic communities for emotional and practical support. Without such support, many Black African people in the UK today would find daily life unbearable and impracticable. Black African people with HIV have great disincentives to be open about HIV in society at large, but even more so among their own African networks because such a disclosure will result in almost certain rejection from what is sometimes a sole source of support. Therefore, many feel that they must keep their HIV status a secret. The problem is that this causes severe personal stress and often means that they cannot access social (and sometimes clinical) services. Thus, such stigma has a direct, highly detrimental effect on the health of African people with HIV. Compounding this are experiences of overt discrimination and stigmatising practices in those small areas where they can be open. Whereas most social, clinical and community services are exemplary, participant accounts of highly stigmatising and discriminatory practices in NHS and social service settings were all too common. Such practices served as a further disincentive to access the services needed by Black African people living with HIV.

Finally, African people with HIV find the area of work highly problematic. Those who are not legally allowed to work are open to the exploitative practices of the illegal labour market. The presence of a chronic or acute illness such as HIV can only increase their vulnerability. Those who can work are deterred from doing so because they do not feel free to disclose their HIV status to employers. This is because first, they feel powerless to resist the possible discrimination that might result, and second because they feel that they have little control of that information once it is revealed. In closed migrant groups, control of such information is paramount. As a consequence many do not seek work, or else they seek illegal or menial work for which they are overqualified because it does not demand disclosure.

3 Responding to HIV stigma associated with racism and xenophobia: 'The African HIV community'

Having described the nature of HIV stigma and discrimination associated with racism and xenophobia in the previous chapter, we now move on to describe the range of responses as articulated by our group respondents. Here we describe the personal strategies and social networks which enabled individuals to deal with stigma. We also talk in detail about the uses and limitations of such strategies and networks. We start with the capacity of the individual to resist HIV stigma associated with racism and xenophobia. That is, the resources and strengths upon which the individual has to draw. This leads us into a discussion of notions of a 'community of African people living with HIV' and the nature of an HIV positive African identity.

3.1 FAMILY AND FRIENDS

For a substantial minority of African people, their capacity to respond to HIV-related stigma and discrimination was increased by the practical support and understanding received from friends and family (either living in the UK or back home). It is important to draw out the personal significance of this support here, while recognising that it stands in sharp contrast to negative experiences of disclosing to the family as described in Chapter 2. Among those whose disclosure resulted in empathetic responses, many spoke of the important benefit of being able to rely on practical support from friends and family during times of ill-health.

> **I also feel that for me, if I am not well, my family will care for my children. We talk about medication. My sister is a big support. Stops my children being taken into care when I am ill.**
> **African woman: African women's group, London**

> **[Friend] cares for me, asks me how I am. I don't have regrets about telling her. Even if she tells another person, the main point is, I told her, and she supports me. I feel free after telling her. I did not even think about it, I realised it was the time to let her know, for practical reasons, she needed to know. "Take care of me, I am fragile". So they know, and they don't push me.**
> **African woman: mixed African group, not London**

The practical protection, stability and security provided by loved ones impacts on the individual's capacity to counteract stigma. Those who told us of receiving such support emphasised that they felt more able to cope with negative attitudes from others. This support allowed them to be confident that at the very least, their basic needs (such as mobility, safety, and sustenance) would be met during times of crisis. Women especially reported the protective emotional and psychological boost that such support provided. This woman related how her family's support allowed her to reject others' judgmental and hurtful attitudes. In the focus group, she advised other participants to galvanise themselves against harm in a similar manner.

> **I had a blessing in terms of my family, no negative reactions from them, I got warm acceptance and sympathy from everyone. I am the oldest person here, don't worry about those others who talk, you are the one who knows your status, they don't know. So I don't mind about them, feel free!**
> **African woman: mixed African and Gay men's group, London**

Such support can be similarly felt when family do not live in the UK.

> **After, when I went back home, I told them [adult children] I was going to the UK to seek treatment. They won't let me return home because they want me to stay on medicine. They feel so bad, but they want me to stay here. They are very supportive.**
> **African woman: mixed African group, London**

For that proportion of African people with HIV who received such support from family and friends, the experience had a profound impact on their own ability to challenge or at least cope with stigmatising responses from other family members and social contacts as well as wider forms of social discrimination. The self-confidence that they gained from positive interactions was often the primary means through which they felt able (both in practical and emotional terms) to manage fluctuating health within a broader social atmosphere that was deemed to be hostile.

3.2 THE 'AFRICAN HIV COMMUNITY'

In contrast, a significant number of respondents had either not disclosed their HIV status to friends or family, or found themselves rejected and isolated by those they did tell. For many, support was developed within networks of other African people living with HIV. Organised support groups, drop-ins or clinic waiting rooms provided the backdrop for this support. Longer-term friendships were established and close bonds were forged. Such forms of association were based around common adversity, common needs and common interests and, as such, were characterised by our respondents as an 'African HIV positive community'.

> **We also have an HIV community now! You tend to associate with people who are also HIV positive, you can go to peer support groups.**
> **African woman: African women's group, London**

This community was characterised by a lack of discrimination or antagonism.

> **There is no discrimination within the HIV community, there is only discrimination outside the HIV community.**
> **African woman: African women's group, London**

Often, such ties replace the familial, diasporic and 'Pan-African' bonds that are either lost or threatened because of the presence of the virus. The 'African HIV community' thus fills the support gap for those who are involved.

> **There is a tendency to move away from national or tribal communities and into HIV positive African communities because it is easier to be there. [A lot of agreement from others]**
> **African man: African men's group, London**

> **The few [family members] that are here live far away. That is it. The only thing that is keeping us afloat are these HIV organisations [group agreement].**
> **African woman: African women's group, London**

Those who spoke of the notion of an African HIV community made explicit reference to the way in which their shared experience of HIV allowed African people from culturally and geographically diverse backgrounds to divest themselves of these differences, as HIV superceded them.

> **If you can talk to somebody from another country, they can be more friendly than someone from your own one. In this country to be honest, there are more people from Uganda than other African countries. They have their social groups, the Ugandans. We used to go to one or two, [names London African HIV agency] and another. You will find most of them are Ugandans, and as a Zimbabwean you can go and talk to them. Because to be honest you can get help from somebody who is more experienced. The guy from your own country, maybe the same town, won't want to know you if he finds out you have HIV.**
> **African woman: African women's group, London**

For some, becoming close to someone who was not from the same country or region was easier because then the risk of gossip and rumour spreading to loved ones in other countries or at home was reduced. Thus, it was made clear that the 'African HIV community' and the 'Pan-African' communities had the capacity to overlap, and where this occurred, the management of confidentiality was particularly problematic. When individuals were first contemplating accessing HIV services, a central concern revolved around the likelihood that they be would discovered by an African person whom they knew, including someone who was also accessing the service because of their own HIV infection. On several occasions, respondents related stories about their own or others' difficulty negotiating the sometimes shared boundary between cultural group ties and participation in a group of African people living with HIV.

3.2.1   Facilitation, support and self-help

As a result of concerns over confidentiality, introduction into the 'African HIV community' was often a slow and mediated process. It depended on the building up of trust and an assurance of interpersonal confidentiality. Some women talked about the ways in which friends could operate as facilitators who gradually introduced new female members to a broader circle of people living with HIV.

> **I know that there are many other Zambians in that situation and don't know or won't go to [HIV support agency], then I would like to think they can come to my door.**
> **African woman: African women's group, London**

It was clear that a substantial number of African people living with diagnosed HIV feared that they may have more to lose than gain from using HIV services, particularly if they entered an unknown environment where they might encounter other members of their cultural or national group and become a source of rumour and gossip. Because of this pervasive fear, some respondents took on an informal role as facilitators. This function was best observed during the co-ordination of booking the focus groups, where individuals frequently asked to 'bring along a friend'. In fact, these friends were just being inducted into the African HIV community, they tended to do more listening than talking within the focus groups, and they usually had not disclosed their status to many people. Judging from the non-verbal reactions and the spoken feedback from many of these individuals, the focus group was sometimes the first place that they had ever spoken openly about their fears and concerns regarding social responses to their HIV diagnosis.

Thus, with a strongly entrenched belief in the value of 'self-help', the informal facilitators play a key role by inducting other African people living with HIV into the fold. This can take a range of forms from simple befriending, and informal networks of people living with HIV, to encouraging them to take part in HIV support groups (and research projects). These facilitators regard participation in HIV networks as a crucial means of ensuring the maintenance of the broader HIV support framework.

> **In our society it would be unheard of, insane, for such an older woman to be positive. But these days in Uganda, it is more OK now. People are talking about it. In the older days when I was there, people were afraid to come forward for medication. So it is our role to advertise more. To tell these people to get free. I can imagine, I have been in your situation, I know why you find it difficult to tell people. So if we get together we can find a way.**
> **African woman: mixed African group, London**

> **To come, to put information, make sure we are taking part. If we don't take part, no one will know whether there are some people there with some problems. First of all let's take the responsibility to do something, whether us with HIV, whether those affected, all...everyone. It is everyone's responsibility. You can't really say it is so-and-so's responsibility, everyone is, whether you have HIV or not. The whole community, the government as well. Maybe sometimes we find it is very difficult for us, we just leave it for the organisations to do it for us. If we leave it for the organisations and the organisations to organise things for us but we don't really turn out and support the organisations, then they won't really do anything for us. It is up to us to come out to support them and say something and make sure we participate.**
> **African woman: mixed African group, London**

Thus, the idealised conception of an African HIV community is characterised by a commitment to collectivity, mutual support and networking. This approach was most appropriate to the limited individual resources and capital possessed by most of its members. Moreover, it was a community not geared towards political transgression, defiance or a demand for rights. The majority of African people in our groups preferred instead to strive for normality, inclusion and a collective welcome within African and British society, which would not include the adoption of an adamantly oppositional HIV positive identity.

3.2.2 Role models

As well as the importance of a supportive community based on a self-help ethos, there was a strong belief in the value of positive role models – individuals who publicly represented ways of living well as an African with HIV in the UK. Programmes designed to facilitate public speaking by people openly living with diagnosed HIV were an example of this, and held much popular support in the groups. Some participants (usually those who functioned as 'facilitators' outlined above in section 3.2.1) spoke of the personal and community development that resulted from being trained and sent out to speak about living with HIV at public gatherings and to school groups. This activity was presented principally in terms of healing divisions, relaying information and increasing acceptance and compassion. It is principally an individual-level intervention that addresses group need in terms of improving HIV education and reducing stigma in broader society. At the same time it is an activity developed within a supportive framework and those who have been positive speakers relay the personal confidence and esteem that they have gained by being involved.

> **Last Sunday, I thought I would never do this, because of [names African HIV agency] I was a positive speaker at World AIDS Day and I went on the radio. This was fantastic.**
> **African man: African men's group, London**
>
> **When we look inside we can educate those around us, and protect our families and those we love. We don't have to be pushed down by this ignorance. Don't worry about them too much if others are saying things. Some of us go to support groups, or take part as positive speakers, we empower each other to teach groups about HIV, we speak from the inside and they know we are speaking the truth.**
> **African man: mixed African and Gay men's group, London**

This approach was presented as an activity that ultimately benefits all of those living with HIV as well as those who are not diagnosed. As a result, the adoption of an identity as 'facilitator', a positive speaker, or as someone who features in an article in the positive press, was regarded by most African respondents as the favoured means of individual activism because it is firmly embedded in a community-based model of social development. When discussing the applicability of this response, one man said:

> **That depends on someone's character. You may be free to talk your mind, he may not be. Let whoever feels free and open say what he want to say, and be supported.**
> **African man: mixed African group, London**

3.2.3 Limitations of African HIV community capacity

The African HIV community was limited, however, in its capacity to bring about broader social change. This is for a range of reasons. The first concerns the lack of individual and collective resources. The community response to stigma as articulated by the respondents, was based almost entirely on notions of individual self-actualisation and group solidarity. Almost all respondents described their varying degrees of involvement in the African HIV community as an empowering experience, yet this did not come without its problems. Individuals often expressed heartfelt anxiety about their capacity to live day-to-day, let alone help others or effect broader social or institutional change through their own action. In the following instance, the only African man in a focus group comprised of Gay and Bisexual men, and African women and men said:

> **In my case I have never told anyone about my status. So no one knows. Family and friends they don't know about my status, including my wife, no one except my doctor. So from there, I don't know where to start, telling someone, especially my partner.**
>
> *Facilitator – you think it starts with her?*
>
> **Because at the moment I have no problem because no one knows. And sometimes I think it will start to give me more headache if people start to know about my status. Because like African people, they talk too much!**
>
> **African man: mixed African and Gay men's group, not London**

In many groups, when those with the least resources to attend to their daily concerns and worries got up the courage to talk about their experience, they were often confronted with the opinions of more empowered individuals within the group who suggested that they 'buckle down and get on with things'. In this way the personal anxieties and material needs expressed by those in the highest state of need were frequently nullified by peers whose particular outlook overshadowed the real difficulties in which some people found themselves. Thus, in this particular group, many of the female participants became acutely concerned about the man's failure to disclose to his partner. On this occasion, the advice that his female peers offered to him was abrupt and direct:

> **You can say, "Hey, guess what?" If you can't find the words, just say, "I have HIV." She'll come round! Don't worry.**
>
> **African woman: mixed African and Gay men's group, not London**

> **And at the end of the day you realise you have to tell some people who matter to you. And of course at the end of the day it will get out to more than those you would want to know. But at the end of the day when you realise, I mean this is a global issue. This is something which is with us. Those who love you accept you and understand, the rest don't matter, really.**
>
> **African woman: mixed African and Gay men's group, not London**

Others provided accounts of feeling limited in their capacity to organise themselves and help each other. Such limitations arose because individuals lacked the basic means such as travel expenses, childcare or meeting space.

> **We try, but when your hands are tied, what can you do? Some organisations can pay for your transport if you want to volunteer that way, or cover for ten hours. So you are giving out your personal number, and people are calling you, and someone is in need, what do you say, "My ten hours are gone? Don't phone me at this time because at this time I am sleeping?" You find you are trying to break the barriers, but you can't.**
>
> **African woman: mixed African group, not London**

> **Some organisations try to organise for us to support each other. But let's say I want to call my friend [names another positive woman]. Because I feel low, she will have to pay for her transport, and like me she is struggling. And then she has to check on me and go back. She really wants to help me, but she is really tight, really. But I try only to rely on my friends who have the ability to help me.**
>
> **African woman: mixed African group, not London**

Thus, the capacity of many to volunteer was limited by often not being paid basic expenses (or an honorarium) from community organisations for their volunteering. In short, such small amounts would make a significant difference to the capacity of many African people living with HIV to organise because of their extremely limited personal funds. However, agencies are either not recognising the central role of expenses or may have too rigid guidelines on what constitutes expenses and what constitutes payment (as African asylum seekers are permitted to access the former but not that latter). Thus, individuals who are sorely needed as volunteers cannot do so because they do not personally have the spare material or physical means to expend when it comes to volunteering.

The ways in which individuals responded to stigma and discrimination within clinical and social care services provided a clear demonstration of the variable outcomes that resulted from *ad hoc* provisions of support. In a small number of cases, African respondents who had been discriminated against in health care settings insisted upon appropriate provision of services. Some of these did so on their own behalf while others found support from community nurses or social workers who facilitated direct intervention as a response to discrimination from health services.

> **Doctors, especially receptionists they harassed me in a way that I couldn't understand. I am diabetic as well and they kept putting off blood testing, although it was urgent, said there was no time and I should go home and call back for an appointment by telephone. I told my community nurse and he introduced change into that practice and now they are my friends and they give me appointments when I need them. I had wanted to change doctors, but he convinced me that wasn't in my own interest – he took me back, I am not eligible for public funds, so I could not afford to travel to a different doctor. I was compelled to work with them by the nurse and it has worked out well. The nurse wrote a letter, and ultimately they had a meeting on this issue.**
> **African woman: mixed African and Gay men's group, London**

Those who were already actively involved with their local HIV support agencies or positive friendship networks sought advice on selection of surgeries and clinics in order to avoid unpredictable responses.

> **I knew a couple of doctors and they know a lot of people who have HIV. The doc said to me that she had another African woman and said that it might benefit her to talk to you, even though you are not from the same country. She brought us together, but she did not tell either of us about the other's HIV status. From that came the support group and then it had about 14-15 women in it.**
> **African woman: mixed African group, London**

One strategy was to utilise the HIV clinic for all health needs, including sore throats and headache.

> **My own GP nearly fell off the chair when I gave him a letter showing him my results. Since that day I only go to my HIV consultant for health care, I haven't changed surgery, I just don't ever go to the GP.**
> **African woman: mixed African and Gay men's group, London**

As a result of the common experience of barriers being erected to primary health care access, a large proportion of African respondents simply stopped seeking primary care services or accepted the ongoing discrimination.

> **You fill in the forms at the dentist, and once you put you are HIV – I faced all the same problems as these people with the dentists, they postpone my appointment until I had to see the doctor to care for my teeth – they took extra precautions because I had HIV.**
> **African man: mixed African and Gay men's group, London**

> **Another time I had a better dentist, he felt more comfortable, and I am good with him. They only give me the last appointment of the day, and they postpone until they get you an appointment that is the end of the day.**
> **African woman: mixed African and Gay men's group, London**

3.2.4 *Painting over the (social) cracks*

The notion of an African HIV community was criticised by many respondents as simply 'painting over the cracks', thus disregarding some of the enduring antagonisms between different groups and tribes.

> **The only reason I still attend and get involved is to help myself out because of my immigration issue. I think if I was sorted, would I be here? I don't think so! To be honest.**
> **African man: mixed African group, London**

Moreover, it was often seen as a 'talking shop' where people could remain miserable and abject.

> **I would go to special HIV groups, and they would all suffer with me. But when I am in these groups all there is around me is pity and suffering. But when I go home from those groups I am all alone, and all I think of are those negative things. We are all going to die in the end. I don't want people to feel sorry for me, it will make me feel isolated. I don't want to live closed off from other people because of the shame and the fear of other people's reactions. I don't want them to feel sorry for me.**
> **African woman: mixed African group, not London**

A number of respondents felt that such a model received only limited support on an organisational level.

> **Most of these NGO organisations are not doing what they should. Some are trying, but others are just sitting on government money and eating it for themselves. They should be looking for employment for such people. For example, I am sick, but I can drive. For example, why not set up an agency just for HIV people. We will get them to do things, but we will not get them off their benefits. We are tired of support groups.**
> **African man: mixed African group, London**

3.3 THE CRIMINALISATION OF HIV TRANSMISSION

We move on now to the extent to which participants saw larger national HIV agencies as understanding African difficulties and representing African interests. The research fieldwork took place during the trial and appeal hearing of Mohammed Dica, an African migrant living in South London who was convicted of grievous bodily harm for 'recklessly' infecting female sexual partners with HIV. This issue was discussed at length in most groups attended by African participants and served as a focal point for views on how African people with HIV were perceived and treated by British society, the media and the criminal justice system.

Typically, participants expressed great anger over what they perceived to be an unfair criminal justice system. More than this, however, the case was seen as an example of state attempts to instil fear among people with HIV as they begin to view themselves as potential targets of criminal proceedings.

> **The first image that came in my mind when I saw Dica case was fear. This case will lead to partners pointing the finger. All of us got it from somewhere. This was a waste of resources and money and money should be put into prevention instead because all of us are responsible for ourselves.**
> **African man: African men's group, London**

However, respondents also saw the case as an indication of the overall ignorance regarding the lives of African people in the UK and an overt government sanction of a broader xenophobic perception of African asylum seekers as a threat and a problem to be managed and contained.

> **Yeah, he [Dica] is an asylum seeker. [lots of agreement from women and men]. I think the issue is 'asylum seeker, period'.**
> **African woman: mixed African group, not London**

One respondent mimicked the judge's speech in a comic manner as facilitator read out the news article on the Dica case. She went on to discuss the way that this case exemplified the lack of understanding that those in power had regarding the daily lives of Africans living in the UK.

> **This is just going to stop more people from coming forward for testing. Dica has been used as a scapegoat and it is affecting other people like me. The judge and the jury do not know about HIV or what it is to be an African. [A lot of agreement about this]. The woman would have known to be careful and this just shows how little is understood about being African and the inter-dynamics.**
> **African woman: mixed African group, London**

A number of respondents felt that the prosecution and national media coverage of the Dica case demonstrated an attempt to define African men with HIV as a threat. That is, some groups of people with HIV were constructed as more dangerous than others (such as Gay and Bisexual men).

> **At first I thought is was sensational. The claim is that African men are carriers. It's another case of being discriminatory because I am sure there must be some other people who have done that, but because they are not Black. If it were a White guy, it would not be in the paper. This has not happened to other groups such as homosexuals.**
> **African man: African men's group, London**

> **When I see this article I feel belittled, as an African. What I think is that we are being associated with all these bad things.**
> **African man: mixed African group, not London**

3.3.1 Perceptions of a lack of support from larger AIDS organisations

Some respondents regarded the Dica case as a clear example that national and regional HIV agencies had failed to organise adequate advocacy for African people with HIV in the UK. Respondents in a number of groups felt that agencies who were meant to protect the interests of people living with HIV had not demonstrated a clear early response to this case. Agencies were criticised particularly for appearing to fail to effectively challenge an overwhelming media presentation of all diagnosed African people as a threat to the public health, and thus as appropriate targets for criminalisation. At the very least, these respondents had expected HIV agencies to make a stronger attempt to explain the complex social barriers to disclosure of HIV status.

> **HIV organisations, I am sorry to say, but none of them wanted to talk. This case was on the telly, that is where I get my information. But no one poses this situation as being 'our opinion'. It is all about how this villain must be tried. Infecting these innocent ladies.**
> **African woman: African women's group, not London**

Many distrusted the simplified presentation of the case in the media and were outraged by untrue claims made about the virus and its effects. They were not aware of any attempt on the part of HIV agencies to clarify for the courts the veracity of the evidence or to provide expert information on aspects like the likelihood of transmission.

> **This is a national thing, more than African men. But we can't do much if we do not have the support of the large NGOs in the UK. [All agree]. Not even a statement challenging the inaccuracies touted during the trial. We have already spoke about this issue at [name of African HIV agency] and decided we need to be more vocal, but it is only us.**
> **African man: African men's group, London**

> **[We] don't know all the facts and they are not reporting all the facts. It's important to get the facts right. I was at a meeting [of AIDS organisations] yesterday and this was nowhere. This is not being dealt with by HIV organisations.**
> **African man: African men's group, London**

Many questioned HIV agencies' willingness both to intervene before this case reached the courts, and to defend an individual with HIV against criminal charges. They were also concerned about their perceived lack of a public challenge to the criminal justice system's intervention into what they saw as an important public health issue.

> **With what I have seen, especially in this touching story of Dica, like whoever like the county court in London and whatever. The police around him. We have organisations like we have mentioned, like [names agency], if you live in [city] we know about these organisations which runs with people with HIV. They shouldn't have taken this matter to the crown court or something else. They should have found an organisation. Like people, we have like care workers or whoever who stands for people with HIV, they would have stood for this man. Not the police, even us, we should have been helping him as well, if we knew. Even me I would have gone.**
> **African woman: mixed African group, not London**

One man summarised his view of the case as being symbolic of the fundamental lack of understanding that HIV agencies have when it comes to the functioning of HIV-related stigma among African people, while also failing to challenge their own internal racist assumptions.

> **There was no defence of Dica in large scale organisations. The HIV community feels that an African man is just like any other person because they have the knowledge about AIDS. So for Dica, there was support and sympathy. However, it wasn't enough. On the other hand the same HIV community thinks an African man is a difficult person to handle.**
> **African man: African men's group, London**

Most respondents regarded the Dica case not as an isolated incident of 'HIV stigma', but as part of a prevailing climate of racism and anti-asylum sentiment in the UK, which was also simultaneously entrenched in the HIV agencies themselves. Regardless of any actions that HIV organisations may have taken and did take in light of the Dica trial and others that followed, the overwhelming perception of African respondents was that no visible or coordinated response had been organised. What was clear from this critical viewpoint was that the Dica case consolidated African respondents' feelings of powerlessness in the face of both a government that sought to control them and HIV agencies that appeared to ignore their needs and concerns.

3.4 CALLS FOR MORE NATIONAL EDUCATION CAMPAIGNS

In most of the focus groups, participants called for a particular type of governmental and structural intervention. Almost unanimously, respondents asserted that the core solution to HIV-related stigma and discrimination in the UK was to provide repeated basic safer sex messages to the British population as a whole. People held the conviction that once the public was informed about the sexual routes of transmission, the need for condom use, and the realistic outcomes of testing and treatment, then those who are already diagnosed with the disease would become more socially acceptable, and behaviours which contribute to the risk of HIV transmission would diminish.

> **A lot of people who are negative need to have more education and knowledge about what HIV is all about. AIDS you die and HIV, you just die. People talk with no knowledge and don't know that medications give you a better chance of health and life. Negative people need to get information about HIV and what that is about.**
> **African man: African men's group, London**

The assumption underlying this conviction was that a public informed about HIV – its aetiology, transmission and treatments – would be less likely to make moral judgements and would have a more positive attitude towards those living with HIV. Thus, education was seen as the means to social acceptance and understanding.

> **HIV, everything goes in generations. Right now people are paralysed. At this stage we need to fight against it, and say it is not so bad to have HIV. We should try to educate in the high schools, people with HIV going into high schools to give talks. That is the next generation. As they grow with that awareness about what is HIV, you know the next generation, people will accept it.**
> **African man: mixed African group, London**

> **If they understand. If they know that there is a difference between HIV and AIDS. They understand how it is transmitted, and they don't gossip.**
> **African man: mixed African group, London**

Universally, it was the government, the media and national HIV organisations that were perceived to have a key role to play in such educational strategies. Campaigns should consist of continuous general population mass media interventions as well as core HIV and AIDS education programmes in schools.

> **I feel pity for those young boys and girls who act like there is no AIDS. They are going together with all different partners. It is only a matter of time, this infection will take over, because of the way that they are carrying on, acting like there is no HIV. All Whites and Blacks, they are free, they drink, they do what they want. The government has to teach people to be careful. Maybe many of them have it but they don't know, they are not conscious of it. Maybe their parents have not told them.**
> **African woman: mixed African group, London**

African people with HIV felt that such an initiative should have solidarity at its core. That is, it should attempt to alert everyone that they are vulnerable to infection and seek to mobilise the entire population in struggling against HIV. It would characterise HIV as a 'common enemy' which could only be countered by national solidarity.

> **Maybe by setting up these support groups we have already divided a community. Maybe we should bring everybody together, whether you are negative or positive, come together and access this service. If we are talking about HIV and AIDS, everybody whether negative or positive, let us access this service together!.**
> **African man: mixed African group, London**

Overwhelmingly, the articulation of such a vision was modelled directly from participants' experience and knowledge of high-level national responses to HIV pandemics in African countries such as Uganda (and more recently, Botswana and Malawi).

> **I would like to mention in terms of having everyone who is diagnosed positive to go and disclose. You know for as long as the issues of stigma are still outstanding currently, it will deter a lot of people to come out in the open. So ideally what will be most appropriate is, like my colleague mentioned, you know. Why it is working out in Uganda so positive is such that people are able to talk. It is how much you talk about it. Let it be there in adverts, in magazines, newspapers. And when people don't read them at least when it clicks every time you see something about AIDS, it will start clicking on their subconscious, and finally, one day they will find time to read something about it and be able to know how to protect themselves and treat other people that have it well.**
> **African man: mixed African group, London**

> **The government in Uganda is much better. They got involved, and the president talks about HIV like we are talking now. It has said in the papers that they have lowered their rates. But they talk about it, and it is down to 60%, in the rural areas it is still bad. In the UK it is not even 1%, so why? People are still associating HIV with Black communities. Little do they know that because of the type of society here, the younger population overuses drugs, has one night stands, they use no condoms. The situation is ready for it to get really bad here. In South Africa years ago, HIV was unheard of, now look at it.**
> **African man: mixed African group, London**

Thus, the model was based on a conception of Britain as being on the verge of a heterosexual epidemic on the scale of Uganda and the consequent need for central and high level government intervention. Therefore, meaningful interventions by those in positions of political and social power were seen as the start to countering stigma on a population level.

> **More public leaders, if their statements are positive that is a good thing for us. Like Tony Blair, if he was talking about HIV just being the same as any other disease.**
> **African man: mixed African and Gay men's group, not London**

And finally, this vision includes the co-operation of the media, which would be responsible for ensuring a balanced representation of HIV that emphasised the encouraging stories of treatment success while simultaneously ensuring that those who live with HIV have the capacity to contribute positively to society.

> **The way HIV is represented by the media is important. They portray it as though you will be dead the next day. What if they presented it like cancer? It kills just as many people, but you also know that treatment is possible, and you can live a long time. So AIDS could be put on that same level. It is an infection but you can live longer because of medical advances. If people realised that, then they would be more encouraged to come and test, there is a reason then for them to want to find out.**
> **African man: mixed African group, London**

To this end, respondents felt that current media representations reinforced and exacerbated ongoing stigma. They pointed out their concerns about xenophobic reporting in the tabloid press, highlighting the relationship between African asylum seekers and the spread of the epidemic.

> **This is here, it is not only African. I read in some magazine about African people spreading this thing in the UK. That is unfair. If the government faced this squarely, we would have gone far with this, like with other things.**
> **African woman: African women's group, London**

In addition, they were concerned that liberal news coverage drawing attention to the scope of the pandemic in sub-Saharan Africa had a similar tendency to isolate HIV as an African disease.

> **They see a lot of pictures now of people dying and they see you in the same way.**
> **African man: African men's group, London**

3.5 A CRITICAL SUMMARY OF THE AFRICAN RESPONSE

The response of African people to stigma associated with the epidemic in the UK is singular in that it emanates from a position of almost non-existent resources and limited personal and collective power. In view of this, it concentrates primarily, by necessity, on what it can reasonably expect to influence: the individuals who make it up. Thus, it is based on a model of self-help, peer support and individual empowerment. However, we have seen that even this aim was often beyond the resources of our respondents. Individuals showed remarkable resilience in the way that they struggled against the stigmatising attitudes and discriminatory practices we identified in chapter two.

What is immediately striking is that given their lack of political and social power and the overwhelming social adversity they face, African people and African self-help efforts receive insufficient practical advocacy by national HIV agencies. Lack of funding for the most basic self-help requirements (travel money, telephone lines, childcare) hampers the efforts of individuals. Lack of a recognisable and coherent challenge to the government's asylum policies and local practices also limits self-help activities. However these are short term (though significant) lacks. What is remarkable is that, given the inhospitable policy environment that African people inhabit, we remain without an integrated strategy that seeks to change damaging legislation and policy supported and acted upon by national agencies. While an African HIV Planning Framework was drafted some years ago by a partnership of statutory and voluntary bodies, it has been delayed by a protracted review process and is now pending. An integrated response which would support the collective efforts of African people 'on the ground' and increase their individual and collective capacity, remains elusive. Moreover, the lack of an integrated strategy and a perceived lack of support alludes to a major gulf between individual African people living with HIV and the agencies that provide services to them and advocate for them. At many levels (but particularly with regard to larger national agencies, including those with specific responsibilities for African populations), we found little sense of a feeling of involvement with agencies let alone a sense of collective ownership of them.

3.5.1 Racism, xenophobia and liberal protectionism: a disaster for African people with HIV

We conclude our discussion by identifying what we propose is simultaneously the most important and most insidious obstacle to the formulation of an appropriate response to the African epidemic: a deafening silence around the true nature of the HIV epidemic among migrant Africans in the UK.

African respondents cited national education campaigns as the preferred action against stigma. This is a model that asserts a direct and often conflated relationship between HIV prevention or awareness raising and the goal of reducing the impact of and eventually 'eliminating' HIV-related stigma (see also Elam 2004). However, it is necessary to problematise this construction of prevention and awareness campaigns as a total solution to stigma and discrimination which will be uniformly applicable in all contexts. While the importance of well-funded and nationally-supported prevention and awareness-raising campaigns is well documented in the UK context, this approach in isolation would (and perhaps already has) allowed for the ongoing and pervasive inequalities that account for and reinforce HIV-related stigma to continue unchecked. In order to explain this point more fully, we need to look critically (and perhaps rather harshly) at the intricate relationship between the reasons why this common view is held by many African people with HIV, and the liberal protectionism surrounding the UK African epidemic as it is practised by HIV organisations (including those with specific responsibilities in relation to African populations).

The view expressed by the majority of participants in our groups (that there is no difference between the current HIV epidemiology in Uganda, South Africa or Zimbabwe and the potential for a similar pervasive and heterosexual spread in the UK) speaks to a politicised ideology which asserts that AIDS is everyone's problem; that 'everyone can get it'. This ideology appeals for national unity in the face of a common threat. The rationale behind the ideology is that a population made aware of its own vulnerability to infection, will be more sympathetic and less likely to discriminate against those already infected.

The problem with this view and its rationale is that it is based on a picture of the epidemic in the UK context that is not true. The long anticipated heterosexual epidemic among British people has failed to materialise. In short, we are not all equally likely to get HIV. Some are more likely to get it than others because of deeply embedded social inequalities and marginalisation. This is a harsh fact to face. Harder still when it returns the spotlight back on African people and Gay and Bisexual men as the main groups likely to have (and by extension) transmit HIV.

However the rationale we have described becomes more tenacious because it is often shared by larger HIV organisations and their attendant health bodies. We have called this the 'liberal protectionist' stance. To a large extent, the scale and shape of the heterosexual African HIV epidemic within the UK has been obscured by pervasive statistical reporting practices and widespread silence on the part of the HIV field. This is characterised by a particular style of reporting recent epidemiological changes in national HIV statistics. The number of heterosexuals living with diagnosed HIV in the UK has indeed undergone recent sharp increases and anonymous surveillance data also demonstrates that rates of undiagnosed infection among heterosexuals are high (Health Protection Agency 2002: 52 (Coreslide 3), 54 (Coreslide 6)). However, the collusion occurs when these statistical changes are noted without drawing any attention to the fact that the bulk of these infections and diagnoses are among UK-residents of African origin. There is a significant migrant African HIV epidemic unfolding within the UK that accounts for the bulk of heterosexual infection and diagnosis. These are the facts.

While it may be based on the best of intentions, the 'liberal protectionist' stance disallows any declaration of these facts because of a concern that doing so may result in further public and media backlashes against the African population in the UK. While such a backlash is altogether possible, there is little recognition at strategic levels that the 'protection' afforded by this approach is at best,

illusory, and at worst, actively damaging African people and their representative agencies' capacities to adequately comprehend the full facts of the epidemic as it currently exists in the British context and to demand specific, targeted interventions.

Therefore, the 'liberal protectionist' stance is a victory for stigma. It allows fear of retribution to come between the naming and the formulation of an appropriate response to the problem of the unfolding African HIV epidemic in the UK and ensures that African people with HIV remain invisible and largely ignored. Well-meaning HIV and African organisations are therefore heavily implicated in the continuing parlous state of individual African people with HIV. At present, they are an unwitting obstacle to the formulation of an appropriate response.

The migrant African HIV epidemic currently taking place in the UK needs to be thoroughly explicated and openly discussed. If relevant statistics are presented confidently and assuredly by HIV organisations and monitoring bodies alongside demands for appropriate interventions, then there is a real opportunity to make inroads into addressing the social inequalities and ongoing racism that continue to shape the experiences of African people infected with HIV. In the absence of such an approach, the status quo is likely to continue and nothing will be done to challenge the basic inadequacies in provision.

The parallels between the current state of the African response and that of Gay and Bisexual men just over a decade ago is compelling. In the mid-1980s a climate of considerable government hostility and press hysteria regarding Gay and Bisexual men (an environment we can scarcely conceive of today) prevailed. To avoid the further stigmatising of Gay and Bisexual men with HIV, (mostly Gay) HIV agencies promulgated the same notion of an impending heterosexual epidemic. As a result, by the early 1990's the vast majority of prevention resources had been re-allocated to campaigns targeting British heterosexuals while new infections rose among Gay and Bisexual men unchecked and ignored. At this point, a coalition of Gay and Bisexual men and others within HIV agencies intervened on a range of levels. A presentation of the epidemiological data was accompanied by a compelling demand that government meet their needs. This could not have been achieved without the nurturing of a policy environment that protected Gay and Bisexual men from stigma and discrimination. This report demonstrates that while Gay and Bisexual men living with HIV are not free of stigma, the forms that it takes differ in degree quite substantially, and to this end many of those earlier battles have resulted in success while still leaving room for further improvement.

However, there is one major difference between Gay and Bisexual individuals and groups in 1992 and African groups in 2004. African people living in the UK are not beginning from the same position of relative power that those Gay and Bisexual men had during the establishment and entrenchment of the HIV infrastructure in the eighties and nineties. As a result, it is deeply problematic to assume that African people should be able to 'follow in the footsteps' of the Gay epidemic, or that there is a simple equivalence to be made between Gay and Bisexual men fighting for adequate provision and protection, and African people who now need the same. Instead, what is needed is recognition of the particular cultural, social and economic features that contribute to HIV-related stigma as it affects African people, and a high-level commitment from national and local HIV, health and social services (both statutory and non-statutory) to work towards a comprehensive strategy which will bring real, rather than superficial, change.

4 HIV stigma associated with homophobia: Gay and Bisexual men with HIV

The experiences of the African respondents show us that HIV-related stigma and discrimination and responses to them depend on the mobilisation of a range of other social and personal factors. HIV infection in itself is not the source of stigma. Rather, stigma works on what a positive diagnosis implies about the person. Stigma operates to maintain power inequalities and to 'keep people in their place'. In the case of Black African people, HIV stigma depends on underlying racism and xenophobia.

Therefore, when we turn to Gay and Bisexual men, it is important to preface our findings with some comments on the nature of stigma as it relates to male homosexuality. Traditionally, such stigma associates male homosexual behaviour and identity with promiscuity, moral degeneracy and criminality. It depends on a simultaneous questioning of a man's masculinity and therefore his male role within society, and is associated with mental health difficulties and genito-urinary morbidity. Thus, stigma associated with male homosexuality constructs homosexual men as promiscuous, weak, feminised, diseased and open to criminal or degenerate activity of all kinds. Fear of such stigma led in the past to the majority of men seeking to hide their homosexual desires. The effect of such stigma was to uphold the supremacy of heterosexuality and to suppress visible sexual dissent. Although there is much evidence to suggest that men have had homosexual identities (in addition to desires) as far back as the 18th century, such stigma was only tackled by the development of socially organised homosexual movements from the late 19th century onwards reaching its height of political power in the last decades of the 20th century. However, stigma attached to male homosexuality is likely to still play a part in the lives of the vast majority of Gay and Bisexual men. Stigma associated with homosexuality still makes it difficult for a man to disclose his sexual identity to family and friends, in institutional settings and to his employers. The same stigma contributes significantly to Gay and Bisexual men being denied basic rights accorded to their heterosexual counterparts. In short therefore, stigma attached to homosexuality still plays an important role in keeping homosexuals 'in their place'; that is, invisible.

The power of such stigma is counteracted to some extent by the Gay political and social movement, an organised resistance effort with a long history, and by the fact that a sizeable proportion of Gay and Bisexual men have economic and social power. The capacity, both individual and collective, of Gay and Bisexual men to resist stigma associated with homophobia is often greater than that of African people, individually and collectively, to resist stigma associated with racism and xenophobia. This is not to say that the effects of stigma are uniformly resisted by all Gay men. Indeed, it is likely that the capacity of men with less personal and economic capital to resist stigma will be greatly diminished and that social divisions among Gay and Bisexual men mean that some continue to be structurally stigmatised. Moreover, the history of African resistance and organisation within the UK is shorter than the UK Gay movement.

It is important to place an analysis of stigma associated with HIV for Gay and Bisexual men in this context. AIDS emerged at a time when Gay and Bisexual men had developed a politically conscious social movement. The response to AIDS for the first two decades of the epidemic was based very much within the models developed by the Gay (and civil) rights movements. That is, Gay and Bisexual men (and others) with AIDS vehemently resisted attempts to stigmatise them and were 'on

the defensive' relatively quickly. Gay community organisations tended to be acutely aware of, and resistant to, attempts to associate HIV with homophobia in order to rob them of any of their basic rights. A range of strategies (such as direct and militant activism, quiet political manoeuvring and more visible direct lobbying) were used simultaneously to resist the tendency to capitalise on AIDS in order to discriminate against Gay and Bisexual men.

Both the Gay political movements and the AIDS rights movements they spawned have met with much success. However, the effects of HIV stigma as it relates to homophobia were still felt strongly by the men in our focus groups.

4.1 HIV STIGMA AND HOMOPHOBIA

In this section, we examine how stigma related to sexuality and HIV influences a man's relationship with his family. We then move on to Gay and Bisexual men's experiences of work and productivity. Finally, we discuss stigma associated with infection, sexual risk and responsibility.

4.1.1 Family

Men reported great difficulties around disclosure of their HIV diagnosis to their biological family.

> **It is going into a year now and I still haven't told my family. I have done support groups, I have told a few friends now because I couldn't handle all the secrecy..running to some little cubicle to pop my pills. It is still something I feel is a delicate situation. I can't decide when is the best time to share with my family.**
> **Gay man: Gay men's group, London**

Often disclosure to family was necessitated by physical proximity.

> **I have told my immediate family. Difficult not to tell them as I was living there when I was diagnosed. Just not practical to keep that a secret, with the medicine and other things. They took it the best they could. It was a long time ago.**
> **Gay man: Gay men's group, London**

Men's perception that their family would have a negative response to a disclosure of homosexuality extended to a disclosure of a positive HIV diagnosis.

> **I haven't told my family for over 20 years, but there are reasons for that. They come from a village in the middle of nowhere, and Gay life and HIV life has never encroached on their lives.**
> **Gay man: Gay men's group, London**

Thus, stigma associated with homosexuality impacts directly on a man's capacity to seek the support of his family around his HIV infection.

> **It is soul destroying to put them through that pain. Sometimes I so want to tell my mother or my sister, so that they understand me a lot better, but realistically I don't think they could tell me the things I need. So instead of feeling less isolated, it would probably isolate me more. I would have to handle that on top of everything else.**
> **Gay man: Gay men's group, London**

Moreover, men will sometimes go to extraordinary lengths to hide their condition from their family.

> **[I haven't told my family] at all. They think I am in [names country] at the moment. I went there to get a job, and you have to have a full medical there, that is when I was diagnosed. So I had to phone up here to get my job back. That is how everyone at work here knows. Everyone here is fine at work, and friends. But the whole Gay thing originally with family, took three years for my dad anyhow. They think I am back in March, so that is when I am 'back'. London is big enough to hide in.**
> **Gay man: Gay men's group, London**

Thus, an inability to disclose HIV status to family was based on a perception that they would express or already had expressed little sympathy or knowledge regarding their son's sexuality. Therefore men often decided whether to discuss HIV based on their family's attitudes towards disclosure of their sexuality.

> **I got very ill once. And I didn't [tell them] I was ill due to side effects of the medication. Anaemia, skin rash, the whole thing together. But once I recovered, I was OK. So now I don't really want to tell [mother]. It is not her business, it is my life. They never ask me about my boyfriends, they never ask me about my life. They didn't care. They didn't want to know, they actually kicked my ass out of the house when they found out I was Gay. I was only 19 and I needed them. They don't deserve it. I love them, but they piss me off.**
> **Gay migrant: Gay men's group, London**

Such fears were often based in a confirmed belief that telling the family about an HIV diagnosis would mean that some relationships would be irrevocably damaged.

> **Both my sisters and their children, they will refuse to see me. They will think I am infectious. Half of the family will refuse to see me, and the other half will be very supportive. I wish I could split them [the two parts of the family] in two.**
> **Gay migrant: Gay men's group, London**

More specific cultural stigmas often came into play. Some Gay or Bisexual men experienced similar effects of stigma attached to HIV as those described by African people, in that HIV carried with it a stigma associated with illness, weakness and rapid death.

> **People are afraid of HIV because they are afraid of death or infirmness, it scares them. People still associate it with death. This is one reason I haven't told my family, because in the Caribbean they do die immediately, so in my case they think I will instantly have AIDS.**
> **Gay man: Gay men's group, London**

The migrant Gay and Bisexual men found themselves in a similar position to the African people regarding their families in their country of origin and their expatriate groups in the UK.

> **Here in this society you have good general acceptance of people who are HIV. However, in the community of other Spanish people living here, they bring with them the same prejudice and attitudes from back home towards the people living with HIV. So in general, [people with HIV] live in the ghetto, so it is very difficult for them to be able to disclose their status to friends and family that come here. It is very difficult for them.**
> **Gay migrant: Gay migrant's group, London**

For migrant Gay and Bisexual men, 'the family' extended to the expatriate group.

> *Facilitator: ...You could be a Brazilian man, but also a Gay man, and also an HIV positive man. And when you come to London, what community do you belong to? Is it possible for you to belong to a Brazilian community in London? A Gay community in London? A positive community in London?*
> **All of them. Because since we arrive here we keep connections with some relatives who also speak the same language as you [...] Not speaking the [English] language properly means you are forced to belong to the Brazilian community. Finding those who speak the same language is always going to be what you tend towards when you are in a new place, because it is easier. You can learn the language, but still those who speak your mother tongue will always understand you the best.**
> **Gay migrant: migrant Gay men's group, London**

Like African people, Latino migrants tended to find strength in HIV positive groups of Latino Gay and Bisexual men run by service providers. These groups enabled them to live within their expatriate social networks while getting peer support around their HIV through service providers. Despite this, difficulties regarding disclosure to family persisted. That is, the association of HIV both with sexual deviance and with disease or imminent death was too great.

> What is the point of my family knowing? Many of my friends know, but not my family, what is the point? I am from Spain. In a Latin family it is like, AIDS = DEAD. And like being Gay, you are a poofter and that is all. For many people it is like that. My parents know I am Gay, but I haven't told them because I don't want them to worry. And I am fine, so what is the point? If I were to get ill it would be different. The distance helps. When I visit I take my pills with me, they don't even notice that I am taking them, they are looking somewhere else. I exercise, I eat well. I don't think I look like an AIDS victim, so what is the point?
>
> **Gay migrant: Gay men's group, London**

Thus, many Gay and Bisexual men did not disclose to their families because they feared their reaction. Such reactions towards Gay and Bisexual sons and brothers were based around their families' attitudes towards homosexuality and disease.

4.1.2 Productivity and work

Outside of the family, the world of productivity and work was a major source of anxiety for men with HIV. For some migrants, their position regarding employment was more extreme. To be unemployed brought with it the possibility of homelessness. This was either because they could not access benefits, or because of fear that flatmates/landlords might discriminate against them if they were found to be HIV positive.

> *Facilitator: Would you ever fear becoming homeless because of HIV?*
> **Speaker 1 (Spanish): Yes, I nearly did once.**
> **Speaker 2 (Brazilian): It is the worst possible thing, HIV or not.**
> *Facilitator: Do you think it is possible?*
> **Speaker 2 (Brazilian): Oh yes.**
> **Speaker 1 (Spanish): No, the local authority gave me a council flat, so I can sort it out with them if I can't pay the rent. My flatmate at the time I was diagnosed, made it impossible for me because I had HIV. So I had to get out. That is why I balance the risk when I disclose now.**
> *Facilitator: There is a difference between always having rights, and the fear of homelessness, and having no money.*
> **Speaker 3 (Brazilian): You do play through different scenarios. I do think I eventually will tell my family, I see people moving away and their lives change. They will move on. I am living with a friend now who has a flat through work. But he will move on, through moving jobs, what have you. So there is always a nagging doubt. What next, *etc*. Will I be able to work? Because if you are in private rented accommodation, you do have to have an income.**
> **Speaker 2 (Brazilian): For me as well. Without a home I couldn't claim my benefit. This is a circle, and that circle can happen to anyone. It spirals out of control.**
> **Gay migrants: Gay men's group, London**

Moreover, many migrants experienced employment difficulties. For the Gay and Bisexual migrants, the issue was not actually getting work, but managing to keep their job. They could easily be replaced if their employer found out that they had HIV and therefore could not risk disclosure.

> *Facilitator: Do people find that work is an issue? Finding work, maintaining work, or getting the right work?*
> **Speaker 1 (Brazilian): It is difficult not to be exploited in employment here, because they know you don't have the right papers to work. So it is finding the right work. You are submitted to lower kinds of work, and you can always find that, but to get valuable work which pays well is very difficult.**
> **Speaker 2 (Brazilian): with no papers you can't find the right employment. It can be impossible to get access to a good paying job, or to work for a good company.**
> *Facilitator: What we have been talking about, the lack of residency status, leading to low employment, leading to lack of money. This is the situation for many immigrants. How does HIV then affect that? Does it make it better or worse?*
> **Speaker 1 (Brazilian): It is impossible to reveal your HIV status under these work conditions, because your position is so tenuous in the first place, and you can be quickly replaced. The**

> **bigger concern is also whether your workmates discover that you are positive. They will also create problems for you if this becomes public.**
> **Gay migrants: migrant Gay men's group, London**

For non-migrant Gay and Bisexual men, anxiety surrounding work was more diffuse. Often, such anxiety concerned the management of disclosure to employers. Some feared that their employer might dismiss them if he found out about their HIV status and therefore, they did not disclose (despite the difficulties this entailed). Others experienced quiet discrimination from employers regarding certain jobs.

> **Working abroad is a big issue. I have been turned down quietly and gently for expeditions because they are concerned about what would happen with my health if we were out in the desert or something. I spoke with someone at my institute, and I was stuck here for three years. I had to take out special insurance for myself and then they felt a bit easier about that.**
> **Gay man: Gay men's group, London**

Thus, certain men found themselves having to take special measures to prove that they were employable and to allay their employers' fears regarding their illness.

Disclosure to potential employers and to colleagues at work posed a particular problem. Many had strategies of disclosure and concealment (often being deliberately vague about the exact nature of their condition). However, they feared being seen as dishonest or duplicitous by employers and colleagues when and if the true nature of their condition was revealed.

> **Speaker 1: Being upfront [about your HIV] is probably better, because if something happens you are protected. You can take time off, they are prepared to understand it.**
> **Speaker 2: [agrees] If you make too many excuses and later come out, then there is a feeling that you haven't been trustworthy before it.**
> **Speaker 3: But if they ask me if I have a disability on an application, what do I say? Technically it is defined as one, but will it affect my job as though I have a disability?**
> **Speaker 4: Or they ask how many sick days you have had. Maybe you were ill before diagnosis but that has changed now, will that count unfairly against you?**
> **Gay men: Gay men's group, London**

Therefore, although many favoured being 'upfront' about HIV from the start of employment, they were aware that they were likely to be overtly or subtly discriminated against if they disclosed.

Not only did men not want to be discriminated against, they also had to take measures to compensate against being seen as weak, a special case, duplicitous or dishonest. The source of stigma was about HIV, but it played on their identity and their fears around being honest, productive and enterprising individuals. In other words, HIV damaged their identity as productive citizens.

While some did not seek employment because they feared the negative attitudes of potential employers, others did not do so because they knew that they were simply not well enough to hold down a full-time job. Unemployment led to further experiences of stigma. Men often reported feelings both of personal inadequacy and suspicions that others (such as friends and family) thought of them as lazy or malingerers.

> **I haven't been working for a while due to my health and my therapies. That is causing problems with friends who thought I should have been fighting to get a job, even if I wasn't in a position to. That created problems, and also with family. They are all very much interconnected because they cause problems. They don't understand my position sometimes, because they don't have the HIV problem. They don't understand what it means to not be able to give a commitment. My doctor cannot give me the guarantee that I will be well, so I cannot take a decision.**
> **Gay man: Gay men's group, London**

Linked to this were men's fears that not having a job was socially embarrassing in front of friends *etc*.

> **People don't realise the psychological impact of losing your job, your life, your status...what it means to you to just go out and be with your friends, but you don't have money to. If they criticise you for not getting a job, they don't see that it's not that easy, particularly with all the psychological stuff.**
> **Gay man: Gay men's group, London**

Moreover, the expectation that a single Gay man would be successful and solvent limited men's capacity to seek relationships.

> **If you can't work, you don't have a job, guys don't even consider you. They think you'll always be taking from them or getting ill.**
> **Gay man: Gay men's group, not London**

In short, there was a significant stigma associated with being unemployed, disabled and on welfare benefits. In view of the normative culture of success and solvency among Gay and Bisexual men, this stigma was likely to be felt keenly. Therefore, illness and incapacity brought with it a particularly pernicious stigma for Gay and Bisexual men which was socially very limiting.

In several groups, men talked about how quickly they developed a sense of themselves as unemployable, dependent and stuck on benefits.

> **I think a lot of social services takes up a large part of our identity. So you feel unemployable, and friends who do have good jobs offer you their cigarette. You feel a bit embarrassed really. I had some conversations with friends saying, "Why don't you get a job?".**
> **Gay man: Gay men's group, London**

However, the extent to which employment or productivity was experienced as a source of stigma was influenced profoundly by HIV treatments. Issues such as length of time since diagnosis, medical prognosis at that point, and responsiveness to treatments were key in the way that men's self-concept developed (see also Weatherburn *et al*. 2002).

Men who were diagnosed after the introduction of treatments and who responded well to them tended to see the impact of a diagnosis as a major but not permanent setback in terms of work. For some, it was perceived as a 'wake-up call' and provided opportunities for training and career development (often the first time that the individual had taken advantage of such schemes).

> **I did an interview at [names HIV retraining intervention], doing retraining in computer skills. I got an unpaid office job. Then I just finished an accountancy course paid for by them. So now I will start to look for paid employment. I wouldn't have had that experience if I hadn't been positive. I would have kept going from shit job to shit job that I hated. I got diagnosed and a couple of months later was made homeless. Split up with partner, got ill. From there everything has got better because of accessing HIV services.**
> **Gay man: Gay men's group, London**

This experience stands in stark contrast to men who were either diagnosed before the availability of effective treatments or who were not responding well to treatments. In many ways, the stigma of unemployability was worsened by the notion that people with HIV were increasingly expected to be employed and productive.

> **I was diagnosed 15 years ago. Then you were treated as someone who had no future and I was 17 years old at the time. The constant stress of being told you will die all the time. People without this experience don't know how it feels. I feel like a bit of an alien, with an entirely different perspective at times. Like at work, how do you express to people all the things you have been through? I got through it, but I worked until I could and then had to stop, because I was only hurting myself.**
> **Gay man: Gay men's group, London**

There was an overwhelming consensus that to be in paid and productive employment was preferable to being on benefits. However, there was also a sense that this consensus in itself generated stigma in as much as it led to the notion of social hierarchy around benefits dependency.

> **Speaker 1: I think we have always had a caste society in the Gay community. Those who diagnosed a long time ago tend to be on benefits, and those diagnosed more recently seem to use things like [names HIV retraining intervention] more.**
> **Speaker 2: There are different generations of people with HIV. Anyone diagnosed in the last few years has a completely different experience. A lot are just sitting on benefits, but they had to put up with a hell of a lot that the people of this generation won't.**
> **Gay men: Gay men's group, London**

At the top of the hierarchy were those who had either maintained their job or had retrained/ educated themselves, while further down the scale were those who took part in active volunteering, and lower still were the disabled and those who were unable to work. Men in this category tended to feel isolated.

> **I have not met anyone else like me, where the treatment doesn't work. If I could take the medicine, then I could work. However the benefits are drying up, and for me also the medicine doesn't work so I have nothing. Ill health and not enough benefits to live. There is no recognition of people like me when it comes to the benefits.**
> **Gay man: Gay men's group, London**

The strength of such stigma came out in discussion around a particular HIV advertisement showing a man at a launderette washing his soiled sheets. Such an image was seen to play into the stigmatising stereotype of a debilitated, unproductive and quite literally 'washed-up' positive Gay or Bisexual man. Men felt that this said nothing about why positive men who were unwell experienced difficulties.

> **They don't point out that the incontinence follows on from the medications!**
> **Gay man: Gay men's group, London**

And why they can't hold down a job.

> **Speaker 1: They have deliberately gone for the most humiliating advert.**
> **Speaker 2: To me it is upsetting that they are using the poverty and the humiliation and all that to get money. Is that how low they have to get to get money?**
> *Facilitator: Do we really need to know about Mark's dirty sheets? Do we have to see them?*
> **Speaker 1: What about pointing out that he is usually well, but he spends about 150 days in hospital, so therefore he can't be in work. That is the reality.**
> **Speaker 3: He is just a washed-up queen.**
> **Speaker 2: What it says to me is that [sponsoring agency name] is waiting for him to get to rock bottom. He looks like he is wasting away..**
> **Speaker 1: With boredom!**
> **Gay men: Gay men's group, London**

Moreover, men felt that this representation of people living with HIV would strengthen employers' prejudices against employing a positive person.

> **It reinforces employers' thinking that people with HIV and AIDS are not employable, because they will be ill. It is a complete blank as soon as you mention HIV. They never get back in touch with you.**
> **Gay man: Gay men's group, London**

However, men in the groups also relied somewhat on this hierarchical system in order to protect themselves from stigma. That is, they contrasted themselves to men at the bottom of the pile, the so called 'benefit queens'. This refers to an individual who exploits the welfare system in order not to work. Such individuals were supposed to live well on benefits and have a house and a car *etc*.

There was a clear generational aspect to this construction. 'Benefit queens' were constructed as having been diagnosed early on in the epidemic, to have fared well in terms of health and to have continued to hold on to the range of benefits available to them (which were not made available to men diagnosed today).

> **Speaker 1: Quite a few of my positive friends from that generation are positive [ie. older and diagnosed a while ago], and the funds have dried up completely. [As a result of this, for those who are diagnosed now] unless you have a certain form filled out, the DLA won't push you onto benefits. They make it difficult for you to live on it, so your choice is to work or live on this tiny amount.**
> **Speaker 2: Those diagnosed a long time ago are sitting on benefits with a flat and a car. Those diagnosed more recently are back at work or are retraining. There is no such thing as a benefits culture for Gay men with HIV anymore.**
> **Gay men: Gay men's group, not London**

Men clearly disapproved of those whom they described as lazy or unproductive and on benefits. Some men talked of those whom they perceived as contracting HIV in order to access benefits.

> **A lot of people are quite healthy, but some people fiddle the system and then the people who really need benefits suffer a lot more. Benefits taken off them when they shouldn't.**
> **Gay man: Gay men's group, not London**

> **Speaker 1 (Gay man): [those who are out to get HIV] think it is a gold card to get benefits.**
> **Speaker 2 (migrant Gay man): Is that why?**
> **Speaker 1 (Gay man): It is the old school way of thinking, if you get it you will get benefits [shock, gasp from African participants]**
> **Gay men: mixed African and Gay men's group, London**

Others talked of such men as 'domestic benefit tourists' adopting a language reserved for African people and other asylum seekers. In this way, stigmatising archetypes and language reserved for one group can be adopted by another in order to define an object of stigma (the 'benefit queen', the 'domestic benefit tourist').

> **One thing that strikes me is, as people with HIV, is our situation is not that different than asylum seekers. Benefit tourism? Well, a lot of non-HIV people see beni[fit] queens as doing something similar. Benefits tourism except you are at home. You know what I mean?**
> **Gay man: Gay men's group, London**

In this way, such characterisations of others were used to redefine the self as productive, industrious and hence, not worthy of opprobrium.

Stigma around productivity and employment impacted upon men's attitudes towards 'back to work' or similar occupational or training schemes. Although men often saw these interventions as, on the whole, positive and useful, they were simultaneously perceived to be couched in a language and approach that was patronising. To access such a scheme, one had to admit that one had developed a 'benefits mentality'.

> **Speaker 1: [Organisation name] has workshops for people to get back into employment. I would use them rather than have to go through it on my own back.**
> **Speaker 2: Yeah, that is only if you need skills you don't have. But what if you already have those skills? I lost my job the same time that I was diagnosed. Not good timing and it took a long time for me to get back to work.**
> **Speaker 3: I think there are a lot of workshops, but what is available out there is patronising. It starts from the point of view that you are lacking something.**
> **Gay man: Gay men's group, London**

Men had to relinquish any vestigial sense of themselves as productive or employable in order to be 'rehabilitated' into the world of work. In order to access retraining opportunities, they felt an imperative to construct and present themselves as helpless or useless.

4.1.3 Sexual propriety

The question of sexual propriety, responsibility and infection was an important theme around which stigma was generated by and for Gay and Bisexual men with HIV.

In the majority of groups, the question of the criminalisation of HIV transmission either emerged or was prompted. Responses to prompting on the Mohammed Dica case were interesting in the way that the men clearly delineated themselves as Gay or Bisexual men with HIV as being distinct and different from heterosexual African men and women with HIV.

First, most groups felt that the likelihood of a similar case emerging against a Gay or Bisexual male sexual partner was unlikely because it would be simply too difficult to prove the source of infection. This was because most perceived Gay and Bisexual men to be promiscuous. Moreover, Gay and Bisexual men were presumed to be responsible for their own actions – they should 'know better' if they allowed themselves to become infected.

Second, the circumstances of the Mohammed Dica case were perceived to be in clear contrast to the sexual behaviours of most Gay and Bisexual men. That is, the fact that HIV exposure in the Dica case took place within the context of supposedly committed monogamous relationships somehow increased both the culpability of Mohammed Dica, and the innocence of the two women. This scenario was consistently contrasted with evocations of foolish, risky or inebriated Gay men engaging in anonymous unprotected anal intercourse in sex venues.

> **There is a difference between these cases. These women are saying that their partners were supposed to be for life, to build a relationship. That is very different than fucking around in backrooms.**
> **Gay man: Gay men's group, London**

The image of HIV exposure evoked above constructs both positive Gay and Bisexual men and those who presume themselves to be negative as foolhardy, pathological or malicious. Often, other positive Gay or Bisexual men were described as maliciously infecting others. Referring to reports of the Dica case in the mainstream press, this man says:

> **The terminology they used, was like, sexual terrorist. It was scary that they were promoting the idea that this man was deliberately going out of his way to kill. I know people who do that on the Gay scene, shagging around to infect as many people as possible to make it easier for themselves.**
> **Gay man: Gay men's group, London**

> **Do you ever see anything telling diagnosed people why they should be careful and why they should be practising safer sex? Once you are diagnosed, they don't bother with prevention anymore. I hear about lots of people going on a bender after being first diagnosed. My thinking was...some bastard has given this to me, and you go through a phase of, "Why should I care?" None of the safer sex stuff is aimed at positive people. But as soon as you mention it, people say back to you that positive people have a right to unsafe sex...and stop spoiling the party! We want to keep on barebacking and whatever. But you get accused of spoiling the fun. In the 80s, if you were positive, you weren't bothered about sex. Now that we are on treatments, we are around longer, having sex, and it will snowball.**
> **Gay man: Gay men's group, London**

The image of the malicious positive man is matched by that of the foolhardy or pathological undiagnosed Gay or Bisexual man.

> **Condoms just aren't fashionable. Barebacking is everywhere in magazines, and everywhere you turn that is the topic of the moment. Almost by ignoring it and liberating yourself in some kind of weird and twisted way, you think you are freeing yourself from the disease. The man I got it from, I knew he was really promiscuous and didn't like using condoms. The relationship was bad and ended and I got tested and diagnosed. Six months later he said I should be tested and I was so glad I went earlier and did it on my own. He even had 'immune' tattooed over his arse. How could he think he was immune to it? You seem to think that once you have it, you don't have to live in fear any more. But once you are diagnosed you realise you aren't free from anything, you have to be obsessed with condoms and things even more now. But you don't realise that until you have got it. That seems to be the psychological loophole.**
> **Gay man: Gay men's group, London**

Gay and Bisexual men were not seen to be 'innocent' of their own or others' HIV infections. The implication then, is that to be a Gay or Bisexual man with HIV is to be 'culpable'. The men in our groups tended to engage in a great deal of virulent denigration of both positive and undiagnosed Gay and Bisexual men in this respect. In contrast to this, men tended to construct themselves as conscientious regarding risk and transmission.

> **I have beaten-up people I know who are positive and who have gone into the toilet and have had casual sex with my friend. It is like, "What the fuck are you doing?" In the Gay scene it seems acceptable not to say anything, because we are not here to like each other, it seems we are here to abuse each other in a lot of senses.**
> **Gay man: Gay men's group, London**

The grim irony contained in the above statement escaped the notice of the other men in the group. Men tended to construct themselves as long-suffering disclosers who put up with the constant rejection and vagaries of negative or untested men. Yet accompanying this, there is often much discussion about the need to clarify the positive person's duty of care to his sexual partners.

> **The person who gave HIV to me 15 years ago knew he was positive. I don't think that was fair. I think you have to say it. Just reflecting on the fact that there is confusion about responsibility now. How far you can go and what are your responsibilities?**
> **Gay man: Gay men's group, London**

If they did report engaging in unprotected anal intercourse, the majority of respondents were careful to point out that this was solely with other individuals diagnosed with HIV, with full knowledge and consent.

As focus groups are good for eliciting group norms, we must expect that those within them are unlikely to disclose activities which are seen as stigmatising, which risk the opprobrium of others or which cast them in a bad light. Therefore, we must be aware that discourses around sexuality, HIV and transmission in the group context are likely to be highly moral and not reflect actual practices (whatever they may be). However, in one group, the question of personal and collective guilt/shame was discussed. In reference to a Positive Nation editorial condemning the actions of Dica, one man said:

> **Isn't that part of the prejudice of HIV and part the guilt that is attached to it, is that you already feel responsible? Or feel that you lack responsibility for allowing yourself to be infected in the first place?**
> **Gay man: Gay men's group, London**

Gay and Bisexual men living with HIV made efforts to represent themselves as conscientious and risk-averse individuals. However, it was also clear that their discussions about responsibility were infused with the notion that as a group, Gay and Bisexual men were more culpable for their own infections because of the types of behaviours from which transmission had resulted. The matter of responsibility and sexual propriety is therefore one that continues to be contentious for many men living with HIV.

4.2 DISCUSSION

In this chapter we have identified several important ways in which HIV stigma and discrimination associated with homophobia affects Gay men and Bisexual men. It is clear that the experience of most Gay or Bisexual men diagnosed with HIV has been profoundly influenced by the historical relationship between Gay activism and attendant organising around HIV. This is evidenced by men's shared sense of a chronology of response to HIV and AIDS in the UK (contrasting 'the old days' to 'now'). In addition to this broader sense of collective history, participants believed health promotion interventions ensured that all Gay and Bisexual men now living in urban centres could be expected to have a working knowledge of HIV transmission as well as broader aspects of HIV disease.

This is not to say that HIV diagnosis does not attract disdain and judgement from other Gay and Bisexual men. In fact as we shall see in the next chapter, since the introduction of anti-retroviral treatments and the ensuing normalisation of HIV, this type of response is increasing. However, Gay and Bisexual men's testimony shows that HIV and AIDS are deeply and openly integral to urban Gay life. White British Gay and Bisexual men's residency and citizenship rights, alongside their social participation as members of the ethnic majority mean that they are not affected by the same legislative, social, racist, xenophobic and economic pressures that govern the experience of so many African people living with diagnosed HIV. Yet this sharp contrast in the degrees of exclusion between the different groups participating in this study does not make the discriminatory and stigmatising experiences that are a part of daily life for Gay and Bisexual men with HIV any less problematic, nor does it mean that all Gay and Bisexual men come from the same positions of power or equality. There is certainly evidence to demonstrate that factors such as class, educational achievement, ethnicity and migration status differentiate the extent to which diverse Gay and Bisexual men have the capacity to exercise power and resist marginalisation at both a personal and a social level (see Cant 2004, Keogh *et al*. 2004a, Keogh *et al*. 2004b, Keogh *et al*. 2004c).

First, we looked at the ways in which men discussed their difficulty disclosing HIV diagnosis to family members. A large proportion of men described their biological family as a place where their individual homosexual identity came into direct conflict with normative heterosexual values. In many instances, HIV infection was regarded as a final and damning evidence of a son or brother's immorality and irresponsibility. In this way, HIV infection justifies, and reinforces homophobia.

Second, the complex ways in which Gay and Bisexual men described the relationship between HIV diagnosis, work and notions of productivity provide further evidence of the pervasiveness of homophobia and HIV stigma. HIV infection (even while it is asymptomatic) threatens men's view of themselves as productive wage-earners, either because of the intrusion of illness, treatment side-effects and clinical appointments, or because of discrimination from employers and colleagues. Within the context of a Gay and Bisexual population that is hugely influenced by perceptions of status, wealth and independence any threat to a successful self-identity is very important. We have seen the ways in which Gay and Bisexual men with HIV can perpetuate this situation, with their discourses about 'benefit queens' (see section 4.1.2). While most men might feel secure about their access to fundamentals such as health care and HIV treatment, they feel acutely threatened by the prospect that HIV will restrict their ability to earn an adequate income because it is through this means that they have the greatest prospect of maintaining self-respect and continued involvement in Gay social life.

Finally, Gay and Bisexual men had a great deal to say about the way in which HIV diagnosis elicits connotations of sexual promiscuity and debauchery. To a large extent men were deeply implicated in these moral discourses around HIV, while at the same time being highly critical of them. In some ways, men described systems of social norms that applied to heterosexuals, from which Gay and Bisexual men were excluded. This type of boundaried practice in relation to norms affords men an illusory type of 'protection', evidenced by their belief, for example, that Gay and Bisexual men will probably not be criminally prosecuted for transmitting HIV because they have sex with too many

partners. Yet at the same time this holds men captive within their own referential sphere, in which there is an explicit sense that Gay and Bisexual men infected with HIV probably 'get what is coming to them' as a result of their assumed behaviour. Thus, at the same time that individuals struggle with the personal and social impact of HIV stigma and discrimination, they find themselves deeply implicated within the structure which perpetuates it. As we have asserted throughout, this means that we can no longer simplify stigma as an isolated act which is done by one person to another. It is a part of a much broader framework of inequality within which we all operate on a daily basis – it is most frequently a means of distinguishing the 'good' self from the 'bad' other.

The next chapter will explore the ways in which the model of a Gay and Bisexual community has shaped the development of a notional Gay and Bisexual HIV positive community as a response to HIV-related stigma and discrimination. Men's perceptions of the extent to which such a community might be said to exist and the ways in which it has changed over time will also be explored.

5 Responding to HIV stigma associated with homophobia: A Gay and Bisexual community united?

Having described the nature of HIV stigma and discrimination associated with homophobia in the previous chapter, we turn to describe a range of responses discussed at our groups, including the personal strategies and social networks which allow individual Gay and Bisexual men to cope with stigma. Similar to our treatment of the African response in chapter three, we talk critically about the limitations of such strategies, networks and contexts.

We have already seen in chapter four that HIV emerged at a time when the notion of a Gay and Bisexual community was strongly emphasised as a counter to stigma and discrimination. Intrinsic to this was a development of a Gay or Bisexual identity based on the notion of self-actualisation and personal liberation. The response to HIV developed along the same lines. In the earliest days of the epidemic, collective Gay solidarity and support was seen as the most effective counter to HIV-related stigma and discrimination against Gay and Bisexual men (with or without HIV). Moreover, there was a strong and politicised emphasis on self-help and 'community mobilisation'. In short, the individual took his place within and gained strength from a supportive and combative collective. In this chapter, we move on to examine how the men in our groups responded to HIV and assess how these strategies have fared. We start by looking at how the men in our groups constituted themselves in relation to the notion of a Gay and HIV community and go on to look at some of the current limitations of that concept of community.

5.1 INDIVIDUAL RESPONSES

The experiences of the Gay and Bisexual men in this report demonstrate (with the exception of many migrant Gay and Bisexual men) that the resources available to the individual to deal with stigma related to HIV are comparatively greater than those available to the majority of African people. However, this attests more to the powerlessness of African people with HIV as a group than the collective powerfulness of Gay and Bisexual men with HIV. We have seen in previous chapters that the majority of Gay and Bisexual men with HIV had access to benefits, medications and housing. This basic state provision allowed them a limited defence against the damaging attitudes of employers, families *etc*. Moreover, many men had personal resources (such as educational attainments, personal wealth or insurance) which allowed them to further delimit the consequences of HIV-related stigma.

By far the most common and important personal response lay, however, in living among a large concentration of Gay and Bisexual men. The groups of Gay and Bisexual men were conducted in the Gay urban centres of London, Manchester and Brighton. The idea of Gay and Bisexual community, Gay socialisation or at least urban concentration of Gay men was central to the development of their identity as positive Gay and Bisexual men and often formed the basis of their social lives. Gay social life reduced the effects of stigma in two ways. First, by living and socialising in areas with high concentrations of Gay and Bisexual men, men felt more secure and safe about living openly as Gay and Bisexual men. Second, men were more able to establish supportive social networks in urban areas.

Urban concentrations of Gay and Bisexual men alongside a Gay scene were seen to create an atmosphere where men felt less stigmatised about their HIV status. Men often compared their situation in, for example, London or Brighton to where they came from (either as migrants from other countries or from across the UK).

> *Facilitator: Why did you move to Brighton?*
> Sodom! [Laughter from other members]. To recover from illness and to have sex and meet other Gay people. London wore me out.
> *Facilitator: Brighton has a big Gay population. What's it like being positive on the Gay scene?*
> Everybody I know knows all about it and there is no attitude. No rejection. I tell everyone. When I lived in [names town], I didn't tell anyone.
> Gay man: Gay men's group, not London

In addition, internet chatrooms were seen as places where positive men could 'be themselves', offer each other help and support and find sexual or longer-term partners. Specifically, entering a positive chatroom or including HIV status in online descriptions obviated the need for disclosure. Therefore, the internet was seen as a vital 'positive' place.

> One guy who is emailing me on [Gay commercial website] was positive and he was able to go to an HIV+ chatroom and talk to people. I said if you need to talk, talk to me. There are various different internet places you can go.
> Gay man: Gay men's group, not London

Men discussed in detail how HIV affected their social life and the potential for disclosure to friends and acquaintances. Specifically, they talked about their social relationships with other Gay and Bisexual men (both positive and negative) and the extent to which such relationships offered them the potential for support. On a one-to-one level, men tended to differentiate 'friends' from acquaintances by their reactions to a disclosure. People who accepted them as positive were seen as 'real' friends. This attested to a desire to avoid negative or difficult attitudes regarding HIV from others. Being surrounded by people who were either positive or entirely accepting of HIV was emblematic of a need not to have to engage in acts of self-determination or resistance around HIV status, to integrate it as a part of the self.

> I don't think of people in those categories. The deciding factor of discussing my status is if I feel they are open to talking about it. Very recently I may have the strength to challenge negative attitudes, but up until recently, I wouldn't go there and I just wouldn't discuss it with people who expressed negative things about HIV. That was my method of dealing with it. If someone was open, regardless who they were, then I could feel open to discuss it.
> Gay man: Gay men's group, London

The determination that men's social circles should be made up of supportive or open individuals speaks to a particular construction of HIV positive identity among Gay and Bisexual men. That is, an HIV diagnosis often informs and fundamentally changes their perceptions and functions in the social world. The notion of having an 'HIV positive identity' was central to many Gay and Bisexual men's response to HIV-related stigma.

> A while ago, after I was ill, I had lots of insecurities, and I was feeling I wanted to nurture bonds, and there were people that I told, as I was getting to know them. It came out in a gush of a lot of other tragedies that happened, and I loaded all this on them at once. In more than one occasion, I was asked to leave, and at the time it upset me and put me on a low for weeks. But now I have got to the point where I feel strong enough within myself that I tell people outright and make sure that that's all in the open. And I do it in such a way that it doesn't seem such a problem to me, and that reflects that it isn't something that they should have to worry about, beyond their own issues.
> Gay man: mixed African and Gay men's group, not London

The importance of a proximal Gay and Bisexual population comes into focus when men talk about organised social or drop-in services for people with HIV. The following exchange is between a group of Gay and Bisexual men, all of whom take part in the Gay scene in Brighton.

> **Speaker 1: If I go to see my mum in [names county], the closest thing is [names local HIV agency] and that is 23 miles away from my mum's. So how do I get there? They say they can pick me up, but does he want to spend three hours in the car coming to get me? The availability down here is extremely good, I guess we take it for granted.**
>
> *Facilitator [to speaker 2]: What is there in [names the town participant is from]?*
>
> **Speaker 2: There really isn't anything, I know THT have started a group, but I am not a group person. I am quite solitary and I don't like groups very much. So consequently there is nothing really for me. I clam up. On a one to one I am quite chatty, but in group situations I tend to clam up. The clinic is like a factory, they pump you in and out as fast as they can. They are just quite clinical and cold and that's it [...] I am not shy, I suppose I lack confidence to a degree. And I guess it is sort of imposing to go into a room of people I don't know, I don't know, what to start talking about. ...**
>
> **Speaker 1: When you are just diagnosed, it can really be like making a statement to go to these groups, and when you do go all you hear are these people who have had it like for years.**
>
> **Gay man: mixed African and Gay men's group, not London**

Support groups were contrasted with 'normal' social interaction among Gay and Bisexual men (which can only be found where there are sufficient concentrations and a sufficient commercial infrastructure). However, it was important to find the right kind of Gay and Bisexual scene. The following man in the same group contrasted Brighton to London (where he was diagnosed) and his home town (where he went to stay with his family).

> **When I was in London, first diagnosed I went to quite a few organisations. But they seemed to have so many people coming and going all the time that it was... I didn't manage to register with any of them, I was very confused, I had enough other stuff on my mind I couldn't get any real support network at that time, and I was getting ill. As I was getting ill, I ended up back in [names town] where I come from. I mean chances are there is something there, but I didn't know anything about it, and no one told me or my mother who looked after me. And I was getting very ill and I wasn't even seeing any HIV specialist doctors down there. I ended up with tuberculosis, and my mother's GP just diagnosed it as a chest infection. I wasn't checked into hospital or anything until I had a fever and was on the verge of death. And the doctors said, "You should have been checked in a week ago". So yeah, the best support network I have had is since I moved to Brighton.**
>
> **Gay man: mixed African and Gay men's group, not London**

Thus, for some men, being in the right place, having access to both clinical and social services, and also having the capacity to build a social network among other positive Gay and Bisexual men was significantly health-enhancing.

5.2 THE EFFECTS OF 'HIV NORMALISATION'

The model of the strong individual within the supportive, cohesive, broader collective was challenged both by differences among individuals and also by treatment advances and the passage of time. The normalisation of HIV among Gay and Bisexual men elicited particular problems for a number of the men in our groups.

What it means to live with diagnosed HIV continues to change as treatments and consequently health improve. This has inevitable consequences on the perceived strength of a positive Gay or Bisexual identity. For example, a minority of men who tended to be younger and more recently diagnosed did not feel as strong a sense of shared adversity around their HIV status, possibly because they had never been ill and had been diagnosed at a time when treatments were available so their prognosis at diagnosis was comparatively good. For this minority of more recently

diagnosed men, their HIV status was a condition which they needed to control – a part of them and not something that defined them in any way. As they did not see HIV as a life-changing, life-threatening or identity-forming phenomenon, they tended not to disclose their status to social contacts.

> **I haven't disclosed to a lot of my friends, not because I don't think they'd understand, because I have got good friends and I think they would understand. But I haven't disclosed because I want a lot of my relationships to stay the same. People become a lot more concerned about you. And a lot of my relationships I want [them] to stay the way that they have always been. So I haven't disclosed on that basis.**
> **Gay man: Gay men's group, London**

The same man went on to report that part of his decision not to disclose his status revolves around his concern that if he were to tell people about his diagnosis, they would place him in the stigmatising position of the 'sick role'.

> **I see myself telling them at some stage. My reasoning is, once I have told my family and a few friends, all you get is, "How are you?" I just want to be able to carry on and keep things the same as they are now. You don't want to talk about it all the time. You don't want to talk about it most of the time!**
> **Gay man: Gay men's group, London**

We see, therefore, how identity-formation and the means of resisting stigma can change depending on the perceived severity of the condition. Increasingly, as HIV becomes normalised as a chronic and treatable condition for Gay and Bisexual men, an HIV positive identity is likely to change enormously. This clearly affected who men were likely to socialise with, as the idea of a supportive HIV positive community had become less central in many of their lives. Thus, some men talked about their reticence to engage in the formal support mechanisms existing among positive Gay and Bisexual men.

> **Speaker 1: And in my area they are all older Gay men, and aging queens, I don't really have much in common with them. [laughter all round]**
> **Speaker 2: "Oh, yeah, I had PCP and TB at the same time"…, they are all competing!**
> **Gay men: mixed African and Gay men's group, not London**

Many men, however, were unhappy with such attitudes, especially those who had experienced major illness or for whom treatments were not working. The question of normalisation of HIV among Gay and Bisexual men affected their capacity to cope with both their illness and the social stigma attached to it. An almost universal theme within Gay groups was a sense of disappointment or outrage at what they perceived to be increasing complacency around HIV among Gay and Bisexual men generally. Often they were critical of other men's attitudes towards HIV and the representation/ discussion of HIV within Gay scene venues and Gay media, specifically, the complaint that HIV was not taken seriously enough was often repeated.

> **I don't think some Gay men think about positive men among them. Not something that is discussed or asked about. People 10 years ago carried condoms and wore red ribbons. I don't think I have been with anyone in the last five years who has said, "Lets use a condom". I am always the one who has to bring it up.**
> **Gay man: Gay men's group, London**

It was common for men to report a sense of fragmentation: of a previously solid collective response to HIV falling apart. Generally, it was felt that Gay and Bisexual men were less obviously concerned about HIV. Specifically, Gay and Bisexual men with HIV were seen to be no longer visible within Gay social and cultural life.

> **It is a reflection of things on a wider scale. People are not respecting themselves, and each other and the whole environment. It is so fragmented.**
> **Gay man: Gay men's group, London**

The notion of the disappearance of HIV and of positive men on the Gay scene was seen to be partly a function of the fact that there were simply far fewer visibly HIV infected men about.

> **I have had to go to some clubs where I wouldn't usually go. Before, you may have looked at people and seen their illness. Now, there is no way you can see it. And at the same time, there is no discussion about safe sex. And I saw guys having unsafe sex and I thought, "What the hell is happening?". There was no even stopping for a second, and the condoms and lube are right there.**
> **Gay man: Gay men's group, London**

As a result, men reported feeling that they should be more quiet about their infection and 'just get on with it'. A further symptom of this normalisation of the epidemic was the perceived tendency for Gay and Bisexual men to engage in more sexually risky behaviours, to dispense with condoms more and to be less worried about possible infection. Men tended to hark back to an ideal time when all men were seen to be more afraid of the virus. The disappearance of support for HIV positive men and the perceived lack of care around HIV was experienced by some men as silencing and isolating. They felt that they had to deal with HIV-related symptoms, illnesses and stresses on their own. Such feelings of isolation did not only exist between positive men and other men generally, but also between positive men. That is, there was a sense in which solidarity among positive Gay and Bisexual men was also breaking down.

> *Facilitator: You said you identify with him because what you have in common is that you have HIV?*
> **I can't say I have nothing to identify with him because he has HIV. But that blasé mentality means that sometimes I have a hard time taking it seriously, and getting the people around me to take it seriously. They just think you take your tablets and it is out of the way. I want others around me to take it more seriously. When you are diagnosed, you may put on a brave face, which results in you not dealing with a lot of emotional shit. Like colleagues at work, you are very apprehensive about talking to them about it at all. I still am apprehensive about telling family, a few friends know but it is not something I make public knowledge.**
> **Gay man: Gay men's group, London**

Overall therefore, the normalisation of the epidemic and fragmenting of collective responses to it among Gay and Bisexual men was experienced by some as silencing and in a way, stigmatising.

5.3 A CRITICAL SUMMARY OF THE GAY RESPONSE

In this chapter, we have characterised the Gay response to HIV stigma associated with homophobia as dependent on and integrated into an older and more broad-based response to homophobia generally as a part of the Gay rights movement. Compared to African people with HIV living in the UK, Gay and Bisexual men have successfully weathered a period of intensely stigmatising and discriminatory actions on behalf of government and the press over the past two decades. As a consequence, if the African response is one of accommodation, the Gay one was one of active resistance. However, such resistance came from a position of increased power both on an individual and a collective level.

The men in our groups described the importance of a sense of collective belonging and support which existed outside structured HIV support venues. This notion of a 'Gay community': with meeting places, friendship networks, bars and clubs was identified as providing the backdrop against which Gay and Bisexual men with HIV derived the social support to withstand stigma. In this sense, the Gay response to HIV stigma is characterised, similar to the African response, as based on the notion of self-help and self-empowerment within a supportive collective. Unlike the notion of a small and protective African HIV community however, for Gay and Bisexual men, this community is the broader Gay population. Thus, Gay and Bisexual men with HIV are expected to be somewhat less sequestered – to be more open within Gay social settings. The problems posed by HIV are supposedly widely understood and accepted by the generality of Gay and Bisexual men (positive or negative).

Yet increasingly, with the normalisation of HIV, a presumption of supportive and knowledgeable Gay population is becoming more uncertain. Gay and Bisexual men in our groups talked of an erosion of their benefits and their rights as people with HIV allied with a sense that they were losing the support and understanding of the broader Gay population.

Improvements in treatments and the withdrawal of many benefits was creating a 'two tier' population of Gay and Bisexual men divided between those who could maintain their health and as a consequence work, and those who could not and therefore had to live on benefits. Moreover, Gay and Bisexual men with HIV said that they experienced substantial social pressure to be healthy and to work (to 'get on with it') and substantial social opprobrium if they did not. This was from the Gay press and from other Gay men. This development marks the breakdown of solidarity among Gay and Bisexual men with HIV and support from the Gay population generally. Some might argue that this is an inevitable consequence of the normalisation of HIV among Gay and Bisexual men. However, it is a form of stigma that functions by denigrating illness and poverty among Gay and Bisexual men rather than insisting that those who are ill are supported properly and with which individuals and groups can either collude or actively resist.

6 'Sticking together'?: the possibility of a collective response to stigma among those living with HIV

We have seen in chapters three and five that the notion of the self-actualising individual finding support within a cohesive peer group was central to responses against stigma and discrimination. This response tends to de-emphasise difference and dissent within groups of people living with HIV in order to emphasise the common good. We also saw in both chapters the uses and strengths of such a response, and its limitations. We move on to briefly analyse the feasibility of a supportive and cohesive collective response among those living with HIV (which would include African people, Gay and Bisexual men and others). Much is made among AIDS service and activist organisations about the need for solidarity, common purpose and common identity around HIV. We first discuss the extent to which individuals recognise and share this ideal. We then look at the differences and antagonisms that emerged among the groups. We open with the following quote which was commonly expressed at some stage in mixed African and Gay men's groups.

> **I feel proud when we are in such a group when we are all HIV. I feel comfortable.**
> **African woman: mixed African and Gay men's group, London**

The respondent's pride (echoed by the rest of the group) is warranted because the individuals in the focus group have had to overcome or suspend a range of attitudes and judgements about each other in order to attend and identify collectively as a group of people with HIV. We cannot underestimate this achievement. Rather, in this chapter, we seek to emphasise its magnitude by talking through these differences. In doing so, we hope both to emphasise the social function of difference among people living with HIV and the importance of the collectivist response, but also its significant limitations. We deal first with Gay and Bisexual men and then move on to African people.

6.1 GAY AND BISEXUAL MEN WITH HIV

In all Gay groups, men were prompted to talk about their sense of having a common experience with other people living with HIV and to comment on what they felt they had in common with other non-Gay people living with HIV, particularly African people. The men in these groups displayed a range of attitudes towards Black African people. In some cases, men failed to distinguish between Black African people and Black Caribbean people, talking about well-documented tensions between the Gay population and the Black Caribbean population in some urban areas. For some (White) Gay or Bisexual men, experiences of homophobic violence from Black Caribbean people tended to influence their perception of all Black people in the UK.

> *Facilitator: In clinics and in say, [names community organisation], how might Gay and Bisexual men and African people get on, or share experiences. Is there any commonality?*
> **Speaker 1: I moved from Italy when I was 19. I lived in [names area of London with high Black Caribbean population] since that time. I was amazed how much heterosexism there was in the Black community here. The only time I was attacked physically was by two Black guys, they thought I was looking at them, maybe I was, and basically they kicked me. I haven't reached for them much, because I was very shocked by those differences, I wasn't expecting it in a way.**

Speaker 2: If you use some of these services, I think they [African people] integrate quite well. I don't see a problem.

Speaker 3: I think it depends on the context. At [names AIDS organisation] I met some really nice young Ethiopian women who I never would have met otherwise. And the HIV is our commonality. However, in the broader community, and like what you hear coming out of peoples' mouths say around [names same area]. Particularly among the Jamaican community, the whole batty boy thing. If that came out of White people's mouths...I think we know that Black people with HIV are equally pushed out. But I don't know what that space is, where we find the commonality.

Migrant and non-migrant Gay men: Gay men's group, London

This exchange illustrates how broader tensions around race and homophobia mediate the potential for relationships between Gay and Bisexual men and African people with diagnosed HIV. For others, these feelings were stronger. They believed that homophobia from African people with HIV precluded any possibility of a common cause developing between them.

Not everybody, but many African people have prejudice against Gay men. So the fact that we are at risk is not important. So I find it very very difficult to relate. I mean I know they are positive, I know I think somehow, your problems are not exactly my problems. The things I am facing are not your problems.

Migrant Gay man: Gay men's group, London

On the other end of the scale, some Gay or Bisexual men felt that they could not relate to African people because of a recognition that the scale of adversity experienced by most African people with HIV was out of proportion to their own experiences.

I did volunteer at [names HIV organisation] ... mostly refugees who couldn't speak English. They were so relieved to have someone to interact with. They had been so isolated. You are aware of it, but so used to normalising it in yourself. Seeing their situation it was destroying. I had to leave because I couldn't cope with it. We had no support, no counselling for us – and I couldn't disclose my status to them, because I thought that might blur the boundaries. They knew I understood, but I couldn't be totally open. It doesn't unify you.

Facilitator: If you were upset, did it mean you felt connected in some way?

But only on a very individual level. They had been raped, and through refugee camps. To me that is very different than IV [drug] users and people who made their own mistakes. How you contracted it makes a big difference.

Gay man: Gay men's group, London

In the groups, there was much discussion about asylum seekers. Here also, men saw a necessary disconnection between themselves as British Gay or Bisexual men and asylum seekers with HIV. They objected to the way in which HIV was being used to vilify asylum seekers, but also to the fact that they, as people with HIV, were being associated with asylum seekers.

If they are using HIV as an issue to attack people for, or to misrepresent, I find it offensive. But I don't personally associate myself with positive asylum seekers because the two issues are quite different. But to use HIV in that way, I find quite upsetting really. And I do think it reflects on people with HIV generally, on the way that they are perceived.

Gay man: Gay men's group, London

We are not saying that HIV positive Gay and Bisexual men cannot or do not empathise with other groups of people living with HIV. Rather, that there is a limit to their capacity to identify with people in these other groups and to feel a sense of shared identity. In short, the differences in culture and experience of people in the two groups are too great. To seek to ignore these differences would demean both groups.

In East London [...] you have small communities with different issues. Even in the same city, their needs are very different. Their problems are very different. And they form very different groups. It is very different to see both and be part of that. To see what the priorities and the needs are.

Gay man: Gay men's group, London

Moreover, on a personal level, men feel that there is a limit to their capacity to identify with other people living with HIV and a limit to the quality of 'community' that might emerge from disparate groups of people living with HIV.

Facilitator: Would you have something in common with an Eastern European or Ugandan grandmother with HIV?

Speaker 1: Not politically, but maybe spiritually or more humane... doing things on a personal level.

Speaker 2: I have not ever had this sense of community, despite going to every sort of support group. In those groups there were lots of different kinds of people. Through that I have made individual friends, but I wouldn't say I walk into those places and feel totally at home, that this is my community. That isn't the way it is.

Gay men: Gay men's group, London

In most groups, men commented on their impression that historical and social change as well as state intervention had lessened the potential of a collective response among people with HIV. That is, the population of people living with HIV had become polarised into those for whom medications worked and those for whom they did not; those who had access to benefits and those who did not and those who had basic rights and those who did not.

Facilitator: If we were all sitting here before the treatments, would we be saying the same thing, because we are healthier?

I think the fear would have brought people together. If we are going to die, let's all die together. There would have been solidarity then, because people were losing friends. Knowing people who die bring you into common with others in your group. That isn't the same now.

Gay man: Gay men's group, London

Facilitator: Is there an HIV community?

There really isn't. No support networks, there may have been years ago but not now. The state is making it worse, taking things away, messing about with your medications, monitoring you.

Gay man: Gay men's group, London

For some, the notion of community was seen as itself a political tool used by the large AIDS service organisations in order to assert that they represented the entirety of the population of people living with HIV.

Facilitator: A lot of agencies depend on that notion of community solidarity.

Speaker 1: And where does that come from? From the textbook! There is a fallacy of community – just generally in society. Community doesn't exist anywhere now, everyone has their own agenda. In the '90s more support groups existed. They weren't perfect, but people were in the same boat, but they have closed now.

Speaker 2: The All Party Parliamentary Group on AIDS – I have read their transcripts. Organisations like [names AIDS service organisation] give the impression that there is community, it sounds great to ministers, but it doesn't really exist.

Gay man: Gay men's group, London

In short, people with HIV living in the UK were perceived not to be suffering the same levels of adversity as they had in the past and therefore the capacity for common cause and unity was diminishing.

6.2 AFRICAN PEOPLE WITH HIV

Turning to the African groups, discourses on difference among people living with HIV differed somewhat according to the gender of the respondent. Some heterosexual men expressed a discomfort with being associated with Gay men simply because they are also affected by HIV.

> **And I don't want to be seen, you know? So I attend such [family] gatherings, and I am always alone. Somebody is bound to ask questions, "Why, is he Gay? Or what?". It is because of my status.**
> **African man: mixed African group, London**

However, for the majority of African people, both male and female, differences centred on race. There was disagreement and confusion in groups as to the extent of the epidemic among 'White' British people.

> **Speaker 1 (African man): In all the groups I have gone to, I have only seen two White people. That is because they are not infected.**
> **[huge outroar from a few participants...]**
> **Speaker 2 (African woman): That is not true!**
> **Speaker 3 (African man): Don't even start. There are many, many, many. There is a fellowship somewhere on Friday, they are all White people infected with HIV.**
> **Speaker 1(African man): Where? Is there?**
> **Speaker 3 (African man): It is Black and White, it affects all people. I am involved with [names AIDS organisation] in that area, all the people asking for assistance are all Black in that area. But you get the idea that the White people in that area is that they don't want to come to us because they don't want to be associated with the Blacks. That is how [HIV anti-stigma] posters are working, it is connected to racism.**
> **Speaker 1 (African man): Sorry, but HIV is affecting a lot more Black people than White people. You don't see White European babies dying of HIV the way they are in Africa.**
> **African men and women: mixed African group, London**

The exchange above illustrates a number of misunderstandings and elisions about the 'White' epidemic that is explained perhaps by reference to countries of origin. It is possible that the perceived absence of a White epidemic refers to a heterosexual epidemic (such as exists in certain African countries). It is not that the individuals in this group do not know about the Gay epidemic (and that the Gay epidemic comprises overwhelmingly White Gay and Bisexual men), but rather, a White epidemic does not signify in any meaningful way because it is not a heterosexual White epidemic. In these circumstances therefore, the idea of overcoming racial differences with the aim of enhancing an 'HIV community' becomes more fraught because, in this construction, it is unclear how race is associated with sexuality.

In other groups, participants felt that services that served the population of people with diagnosed HIV were constituted in order to serve either White or Black clients with HIV. The following story was told in several groups.

> **Speaker 1 (African man): In many clinics, on certain days if you turn up it is mostly White people attending the clinic, and on other days in the same place it is mainly Blacks there. It is a policy of differentiating the dates.**
> **Speaker 2 (African woman): That is what the prejudice is about!**
> **African man and African woman: mixed African group, London**

These perceptions were backed up by beliefs that White people with HIV exercised more power and discretion about the services they used and how they used them. White people were presumed to have greater anonymity or use social support services less.

Facilitator: So there are divisions about who is using which services but I assure you that there are white people with HIV.

Speaker 1: They have their own organisations [...] What I know is the White people are holding it in confidence. They talk on the telephone, and get information privately. They don't have to be seen going in the front door. On our side, there is a lot of Whites, in the hospital you meet them, even in sexually transmitted clinics.

Speaker 2: But the thing is, it depends on the area where you live, a White or a Black area. It depends where the clinics and groups are located.

Speaker 1: A lot I meet in the hospital only go to their clinics, and never get in any groups.

African women: mixed African group, London

With the possible exclusion of service use, from the perspective of group participants, much of what they say is true. Globally, HIV affects far fewer White British than Black African people and certainly the White British heterosexual epidemic is minuscule compared, for example, to the Ugandan heterosexual epidemic. What these exchanges show, however, is a limited conception of the nature of the local epidemic in the UK and the place that Black African people with HIV hold within it. Moreover, the understandings we have outlined serve to explain perceived (and real) power inequalities between African people and British people. Finally, as difference is mobilised in terms of race as opposed to sexuality, the question of the relationship between Black African migrants with HIV and Gay and Bisexual men with HIV is avoided.

6.3 THE POSSIBILITIES OF AN HIV POSITIVE COMMUNITY

The straightforward conclusion to be drawn from the discussion presented above is that White Gay and Bisexual men with HIV are capable of racism and African people with HIV are capable of homophobia. Sharing a stigmatised infection does not change that. However, it would be insufficient to draw this conclusion alone. What is more important is that different histories and cultures give the epidemic a different meaning and mediate people's experience of living with the virus. There is a lot more difference and a lot less commonality than we might imagine between different groups of people living with HIV. This is what makes the emergence of any common response to HIV by such groups more remarkable.

Individuals will find reaching common ground a struggle. We should therefore be wary of assuming that responses to HIV-related stigma developed by one group will be appropriate to another. Perhaps most importantly, notions of an HIV positive identity (important to both the Gay and African HIV collective response to stigma) will not necessarily translate from one group to another. To have an identity as a Gay or Bisexual man with HIV is fundamentally different to having an identity as a Ugandan woman with HIV. The two different identities are borne of radically different political models, historical circumstances, levels of need and experiences of discrimination and therefore result in very different models of behaviour and political stances. Whereas individuals from different groups are certainly capable of remarkable empathy, we should be very wary of assuming that this means that they are necessarily capable of identifying with each other.

7 Conclusions and recommendations

This study had four aims. First, we aimed to problematise and extend the limited conceptions of stigma informing interventions and strategy in the UK. We have described stigma as a social process which maintains and increases power inequalities between individuals and groups in society. Moreover, stigma and discrimination related to HIV mutually reinforce and are dependent on other forms of discrimination: specifically racism, xenophobia, sexism and homophobia.

Stigma is a process that implicates a range of individuals and groups in certain ways. Thus, we have seen how African and Gay and Bisexual populations can stigmatise their own members living with diagnosed HIV. As a result, stigma is not something that one person or group can inflict or be guilty of, in an isolated sense. Stigma exists in the nature of our responses to a given situation or set of facts and is an undeniable aspect of the way that power inequality is established and maintained. Stigma is a process in which all members of society are implicated, whether it be through compliance or resistance. Once we know how stigma works, we can choose to act in a way that increases stigma or decreases it. Stigma can be resisted if people and groups choose to do so. However, they cannot choose to resist stigma without the knowledge of how stigma works and the individual and collective capacity to do so.

Our second aim was to describe the workings and effects of HIV stigma within two different groups of people with HIV in the UK: African people and Gay and Bisexual men. In order to do so, it was necessary to describe the social, political and historical context within which these two groups exist. In order to understand HIV stigma in relation to African people in the UK, it is important to understand the extent and nature of xenophobia and racism against African migrants, as well as the specific African political and historical frameworks that migrant groups function within. Because HIV stigma related to African people with HIV reinforces and is dependent on racism and xenophobia, we conclude that the first strategy in countering such stigma is to name it properly: HIV stigma associated with racism and xenophobia. By identifying HIV stigma according to what it serves to reinforce (homophobia with Gay and Bisexual men, sexism with women *etc*.), we signpost both its gravity and the means to resist it.

In describing and contrasting the experiences of African people with HIV and Gay and Bisexual men with HIV, we became acutely aware of differences in the magnitude of social need between the groups. These differences influenced individual and collective capacity to resist stigma within these two populations. We feel bound to emphasise that overwhelming need among African people with HIV should not be seen as justification to trivialise the needs of Gay and Bisexual men with HIV. For this reason, comparison might be seen as unhelpful, but in another way, it highlights the necessity to describe the epidemic, its effects, and its responses, separately for each group affected. Sometimes, talking collectively about 'people with HIV' serves to trivialise the experiences of the different groups and individuals that make up this population and can lead to unhelpful conflations and confusions in terms of the most effective responses to meeting need and countering stigma.

Our description of the experience and impact of stigma in both population groups leads us to conclude that stigma cannot be tackled without addressing the causes of stigma and increasing the individual and collective capacity of those affected to resist it. As stigma serves to perpetuate and increase inequality and injustice, it can only be countered by fighting inequality and injustice. In other words HIV-related stigma is merely a (rather ugly and distressing) symptom of an underlying power imbalance. Tackling stigma by trying to change attitudes at an individual level (with say, mass

media advertisements) without tackling the social structures upon which those attitudes depend is merely treating a symptom.

Our third aim was to describe the responses to stigma by and for the two groups under scrutiny. Again it was necessary to describe the social, political and historical context within which such responses emerged. As stigma is related to other types of discrimination, forms of resistance to stigma are framed by pre-existing forms of resistance to these other types of discrimination. Therefore, resistance by and for Gay groups to HIV stigma related to homophobia is modelled on pre-existing forms of resistance to homophobia and heterosexism. Likewise, African groups' resistance to HIV stigma associated with racism and xenophobia is informed by considerations such as African national self-determination, 'Pan-Africanism', resistance to colonialism and to sexism, as well as by pre-existing models of resistance to HIV stigma developed by Gay groups in the UK.

We conclude from our analysis that the past and current forms of resistance taken by the two groups are very different. The Gay response has been influenced by a comparatively long history of Gay and AIDS activism in the UK which strongly and directly resisted attempts to deprive Gay and Bisexual men with HIV of their rights by conflating HIV with homophobia. Thus, with the exception of some migrants, most of the Gay and Bisexual men in our sample had three strengths: pre-existing basic rights accorded to all citizens and permanent residents of the UK; greater personal and hence collective social capital; and finally, a history of activism which countered the negative effects of stigma. These were coupled with a reasonably supportive Gay response that reached back twenty years. However, we have also seen that as HIV is normalised among Gay and Bisexual men and as treatments improve, there is a danger of an already existing subset of less-well educated (and hence generally, poorer) Gay and Bisexual men suffering from a loss of solidarity with other positive Gay and Bisexual men and the support of the Gay and Bisexual population generally. Hence, the collective Gay response to stigma associated with homophobia currently appears to be at risk of breaking down.

In the case of African people with HIV, the conditions which give rise to HIV stigma associated with racism and xenophobia are entrenched, structural and virulent. African migrants with HIV face a government actively engaged in minimising their basic rights and capacities; a national press which seems intent on representing them in a way that maximises racism and xenophobia; and are increasingly being targeted by a hostile judicial system. Moreover, the current response originates from a much lower power-base than that possessed by Gay and Bisexual men. What is noteworthy is the extent to which the African response comes almost entirely from African people with HIV themselves and is based within a self-help, individual-empowerment model. While we acknowledge and support the conviction that responses to stigma must emanate from the groups most affected, we have pointed out the severe limitations of this response. In short, the response is not commensurate with the challenge. We conclude, therefore, that in order to make the response commensurate to the problem, an integrated multi-level anti-stigma strategy is needed.

As we have noted in chapter three, one strategy to resist stigma lies in a full and open appreciation of the difficulties faced. We have shown that there has been a damaging liberal protectionism at work around the African HIV epidemic in the UK. African people themselves are careful to ensure that responses to HIV among Africans emanate from African social support networks and organisations and there has been a more general consensus not to bring direct attention to the African migrant epidemic in the belief that this may protect them from any further discrimination. However, we have argued that this approach has the effect of containing the problem within African populations and therefore containing the response there also. This is insufficient in terms of protecting individual African people with HIV from the hostile environment in the UK, or building individual and collective power among African people. We recommend that a full account of the African epidemic in the UK be made known both within the African population, the HIV service sector and more widely. However, the way to minimise further backlash is to ensure that such clarity is accompanied by an integrated anti-stigma strategy.

This leads us to the fourth aim of this study: to frame an integrated response to HIV stigma

associated with racism, xenophobia, sexism and homophobia. The remaining sections of this chapter suggest what such a strategy might look like. If we are to take seriously the conception of stigma as a means of maintaining social inequality that was outlined in the introduction, we must consider the response to stigma and discrimination as it relates to HIV in its totality. We therefore suggest that the recommendations should be considered across a range of levels. That is, we recommend interventions which seek to impact on structural and organisational practices, social relationships, and individual well-being. All the interventions are interdependent and support each other. In order for such a strategy to have the optimal effect, interventions on all levels should be enacted simultaneously.

7.1 LEVELS OF IMPLEMENTATION AND LEVELS OF IMPACT

A successful strategy to combat stigma and discrimination associated with HIV must seek to challenge the *status quo* that such stigma perpetuates.

At present, most responses to stigma are enacted through a model of self-help and individual empowerment. Although this model must be at the **centre** of an integrated response to stigma, there are a range of other supporting responses which are currently lacking. Without broader social support and the social conditions for change, the efforts of individuals and groups to resist stigma will not be maximally effective. Our examination of the 'African HIV community' in chapter three demonstrates how a response based entirely on individual empowerment without reference to the broader social and political impediments to such empowerment has the effect of sequestering 'African' problems into subsets of the African population. This means that ongoing strategic support from larger and more powerful quarters is relatively rare. Without such strategic support, the very real lack of capacity among individuals and groups is not addressed. Thus a vicious circle of powerlessness is created where individuals are encouraged to speak out, disclose and provide support to one another, in the absence of appropriate economic, social and political conditions. The frustrations expressed by African individuals in relation to these issues demonstrated an acute awareness of this basic contradiction. Where successful support and networking has occurred, it has often been through the actions of insightful and resourceful individuals and smaller agencies – but such *ad hoc* provision is simply not sufficient. In the case of African people, dependance on models of individual and group empowerment in the absence of real advocacy and structural change is likely to fail over the long term. Moreover, it is unjust. It puts the onus on the beleaguered individual while absolving larger agencies and social structures of any responsibility to properly defend and extend the rights of disenfranchised people with HIV.

Therefore, although we support entirely the continuance of interventions which focus on enabling individuals to empower themselves within their peer group, in the recommendations that follow we concentrate mainly on improving the broader social environment within which they do so. However, in making these recommendations, we must draw attention to a damaging gap in communication between individuals living with HIV and the agencies seeking to provide services to them or advocate for them. Among our respondents, little was known about the activities or aims of the larger HIV agencies. Moreover, there is a sense that such agencies have little contact with African groups or agencies. While the majority of our recommendations involve the larger HIV organisations (either in their role as lobbyists or as service providers), unless individuals and groups are made aware of, consulted about and actively engaged in such efforts, they will continue to feel that little advocacy is taking place on their behalf and that HIV organisations are remote and out of touch with ground-level issues.

The recommendations which follow are aimed across a range of levels. Although some of the interventions we recommend may already be in existence, we have made such a comprehensive list because we envisage that these recommendations will inform and be strengthened by the forthcoming Department of Health Action Plan on Stigma and Discrimination.

7.2 RECOMMENDATIONS FOR GOVERNMENT, CIVIL SERVICE, AND PROFESSIONAL ASSOCIATIONS

The findings presented in this report reveal that government, civil service and professional associations have the largest role to play in tackling stigma and discrimination. A government committed to tackling HIV stigma must be committed to tackling homophobia, racism, xenophobia, sexism and other forms of inequality. It must do so in a way that explicitly recognises the connection between these forms of inequality and the quality of life and health of people living with diagnosed HIV. Thus, the government should re-affirm its commitment to tackling stigma and discrimination associated with racism, xenophobia, sexism and homophobia through its departments (for example, through the actions and policies of the Home office, the Department of Education and Skills and the Department of Health). Similar commitment is required at regional and local levels (for example, through the actions of local authorities, police authorities, local education authorities and strategic health authorities).

HIV is currently not a priority for the government or the NHS. Furthermore, where HIV is addressed, it is almost always in relation to HIV prevention or HIV treatments and rarely, if ever, in relation to the care and support of people with HIV. This research shows that people with HIV know this and that this lack of prioritisation affects their self-worth and their sense of belonging in society.

Recommendation 1

Those taking part in the research who had been asylum seekers described the way that the government's policy of dispersal meant that individuals were isolated from their only means of social support. In specific reference to HIV, respondents felt that dispersal substantially reduced access to adequate specialist HIV care and social support.

1.   We recommend that the **Home Office** policy of dispersing asylum seekers with HIV across the country (as supported by Section 97 of the Immigration and Asylum Act 1999) should be reconsidered.

Recommendations 2 & 3

Those taking part in this research who were seeking or had sought asylum, described the way in which being disallowed from legal employment had a pervasive effect on their capacity for self-determination and their personal security. In addition, many who took part in this research held practical and educational qualifications, and a breadth of work experience, but were not employed. A significant proportion of these wanted to work, but faced legal or practical barriers to attaining employment.

2.   The **Home Office** policy of disallowing asylum seekers from seeking legal employment (Section 8 of the Asylum and Immigration Act 1996) is harmful to individuals with HIV and the groups they live within. In the light of this, we recommend that this policy should be reconsidered.

3.   For all people living with HIV who are legally entitled to work, more needs to be done to enhance their ability to find and keep appropriate employment. We recommend that the **Department for Work and Pensions** and the **Trades Union movement** take action to make it easier for people living with HIV to work. Considerable effort is required to educate employers about HIV, alongside supporting existing approaches such as flexible working and job sharing for those whose health and childcare needs demand it. In addition, **HIV organisations** should collaborate with other organisations to further develop HIV education interventions for employers.

Recommendations 4, 5 & 6

This study has shown that people experienced stigma and discrimination associated with HIV in clinical contexts, both in respect of prescribing practices and medical procedures. Some respondents felt that their eligibility to treatment was open to question simply because they were Black (irrespective of their residency status or nationality). Others reported unusual medical procedures and unnecessary medical precautions that they found demeaning and stigmatising. Such incidents were clearly the result of a lack of training of medical staff. However, they were exacerbated by a growing atmosphere of mistrust and caution regarding who is, and is not, entitled to HIV treatments – engendered by NHS charging policies. Whereas charging policies may be necessary, more consideration needs to be given to how such policies might serve to reinforce pre-existing racist or xenophobic attitudes among some NHS staff. This research demonstrates that there is a clear and ongoing need for improved HIV training in medical, nursing, midwifery and dental courses. It also demonstrates that there is a need for procedural training with regard to HIV care for existing primary care practitioners, particularly dentists and General Practitioners.

4. Current **Department of Health** policy stipulates that asylum seekers whose application has failed, and those not ordinarily resident in the UK, are charged for 'non-urgent' hospital treatment and care. For those living with HIV, this contributes to HIV stigma and is at odds with the broader aims of public health. We recommend this policy should be reconsidered.

5. We recommend that training toolkits be developed by the **Department of Health** in collaboration with HIV organisations. Direct government funding should also prioritise the establishment of HIV educators within educational and medical contexts. Their role should be to provide expert training and consultation within further and higher education settings, as well as at Primary Care Trust level. Topic areas should include: how to make a surgery a safe place for disclosure of HIV status; what sterilisation or protective measures are required when treating a patient with HIV; the benefits of ongoing communication with a patient's HIV consultant; how to keep up to date with anti-HIV treatments information *etc*. The training should focus on the rights and dignity of people with HIV receiving care. In addition, efforts to increase inter-cultural awareness and multi-lingual service provision in GP settings should be increased.

6. We recommend that various **professional associations** allied to health care should review and update their codes of conduct in relation to HIV. These should cover issues about informed consent for HIV testing, freedom from discrimination in health care settings, and other human rights. These associations should also become actively involved in resisting policy changes which result in reduced health outcomes for people with HIV.

Recommendation 7

Criminalisation of reckless HIV transmission emerged as a matter of great concern for people participating in this research. Given the recent prosecutions under the Offences Against the Person Act (1861), people living with HIV are uncertain about the legality of their actions. This situation operates to profoundly reinforce stigma and discrimination related to HIV.

7. We recommend that the **Crown Prosecution Service** reconsider the rationale for applying the criminal law to HIV transmission.

7.3 RECOMMENDATIONS FOR HIV ORGANISATIONS: INTERVENTIONS ADDRESSING HIV STIGMA DIRECTLY

Recommendation 8

Across the UK, general population mass media campaigns constitute the bulk of interventions intended to address HIV stigma. However, most respondents indicated that HIV-related stigma and discrimination emanating from those in their own social networks had the greatest impact, as these were the places where emotional, material and practical support was usually sought. African and Gay communities are one of the mechanisms where stigma operates. They often stigmatise members of their own communities with HIV.

8. There is a need to address HIV stigma within African populations and Gay and Bisexual populations. It is crucial that **African cultural and faith leaders** who have a high degree of influence in their local communities provide or participate in HIV awareness and training events. **HIV organisations** need to find inventive ways of making living with HIV visible once again on the Gay scene and in social networks, since Gay and Bisexual men describe a cultural and social life where positive representations of men with HIV are increasingly rare.

Recommendations 9 & 10

Press coverage of HIV and AIDS was a matter of great concern for people taking part in this research. They felt that stigmatising and inaccurate media coverage relating to HIV was the norm in the UK, and this had an adverse impact on their individual well-being and quality of life.

9. **HIV organisations** need to continue to find innovative ways to get supportive and encouraging representations of people living with HIV into the mainstream and community press. The **mainstream media** should be effectively and constantly challenged about its coverage of HIV and AIDS, especially where racism, xenophobia and homophobia are involved. HIV organisations should collaborate to undertake effective press monitoring and response. Ongoing engagement with editors and use of the **Press Complaints Commission** may also bring change.

10. **HIV organisations** should lobby to ensure that the **National Union of Journalists** updates its publication *HIV and AIDS: a guide for journalists* (NUJ & HEA 1993). They should also lobby to add 'immigration status' to item 10 of the current NUJ *Code of Conduct* (NUJ 2004), which specifies that, "A journalist shall mention a person's age, sex, race, colour, creed, illegitimacy, disability, marital status, or sexual orientation only if this information is strictly relevant. A journalist shall neither originate nor process material which encourages discrimination, ridicule, prejudice or hatred on any of the above-mentioned grounds."

7.4 RECOMMENDATIONS FOR HIV ORGANISATIONS: POLICY AND STRATEGY

Recommendation 11

African participants voiced their concern that there was a lack of adequate funding and skilling-up of African HIV organisations and interventions within the broader HIV sector. In some instances this perception was based on their involvement in organisations, while others formed this opinion based on their experiences as service users. The ongoing culture of competition between HIV organisations was obvious to people with HIV and was considered counter-productive.

11. **African HIV organisations** (and HIV projects based within other African agencies) require practical and strategic support from **larger HIV organisations** in order to secure more funding; develop extensive and high quality services; and to lobby effectively for change at government levels. To this end, it is crucial that African (HIV) organisations are given comprehensive training and support on attracting funds and administering them. It is the responsibility of the national HIV organisations to insist on better funding streams for prevention, care and support services for African people with HIV.

Recommendation 12

Those taking part in the research discussed the ways in which perceived discriminatory attitudes within the HIV sector itself affected the provision and take-up of services for people living with HIV.

12.	It is vital that **all bodies providing services** to – or advocating for – people living with HIV be continually aware of the ways in which homophobia, heterosexism, racism, sexism and xenophobia may influence their policies and practices.

Recommendation 13

A number of respondents felt that existing interventions addressing HIV-related stigma and discrimination were either inadequate, confusing or inappropriate.

13.	**HIV organisations** of all sizes require ongoing research and evaluation that will allow them to determine the extent to which anti-stigma and discrimination interventions are successful, and what future areas of focus should be.

Recommendations 14 & 15

In many instances, respondents described a sense of connection and ownership with HIV organisations and networks. However, where they did not, it was clear that a feeling of disconnection exacerbated isolation and stigma. Some participants described the difficulty that they and their peers had when trying to access clear advice and information from HIV agencies. This issue arose across a range of themes, such as advice relating to the legal status of sexual behaviour in light of the criminalisation of HIV transmission, and the ways in which priorities are set for the development of policy and the provision of different types of services.

14.	**HIV organisations** must be increasingly vigilant about the needs of their service users. In many cases, service users are able to articulate their vision for improved services and innovative communication mechanisms. Meaningful needs assessment and consultation processes will elicit information useful for planning.

15.	**HIV organisations** should ensure that their service users are aware of their policy and lobbying efforts on their behalf. This will help combat the widespread notion among many people with HIV that 'nothing is being done'.

Recommendation 16

This report locates HIV-related stigma and discrimination within underlying structures of inequality. Hence, it is clear that responses from the HIV sector alone are insufficient.

16.	**Non-HIV** organisations such as the **Commission for Racial Equality**, and the **Men's Health Forum** have an important role to play in the ongoing development of effective and supportive responses to HIV. **HIV organisations'** existing relationships to such bodies need to be strengthened, and new ones should be continually fostered. Some examples might include the establishment and maintenance of links with **Patient Advice and Liaison Services** at a local level within the NHS, and in national terms, to consider the ways in which the **Social Exclusion Unit** could support the work of HIV agencies.

7.5 RECOMMENDATIONS FOR HIV ORGANISATIONS: MEETING THE NEEDS OF PEOPLE WITH HIV

Recommendation 17

People taking part in this research who have been a part of the asylum application process highlighted the severe material and psychological impact of ever-changing asylum policy in the UK. It is likely that the numbers of asylum-seekers and undocumented migrants with HIV living in the UK will increase, and the burden of service provision will continue to grow.

17. Given increasing demand for HIV services, funding for them needs to be derived from a wider variety of sources. **HIV organisations** should also pursue partnership working with organisations such as the **Refugee Council** and **Refugee Action**.

Recommendations 18, 19 & 20

Many of the people living with HIV involved in this research experienced HIV support services that had varied in terms of continuity and quality. This was especially common among those that lived outside London. People with HIV also articulated a need for improved communication from HIV agencies across a range of topics.

18. HIV organisations need to continue to prioritise the range of 'living well' services that they offer, and increase efforts to convince funders that such provision complements HIV prevention activity.

19. HIV organisations need to continue to provide clear, language-appropriate information about asylum, immigration, criminalisation, employment, health-care and welfare benefits rights. As these interventions are information-based, they need to be continually kept up to date.

20. HIV organisations need to ensure that national policy developments are explained clearly to people with HIV using a range of communication methods. A current priority would be the forthcoming amendment to the Disability Discrimination Act which will include HIV infection as a defined disability. Lack of clarity around this amendment has clearly generated much unwarranted anxiety around a presumed 'duty to disclose' (in much the same way that concerns are being raised in relation to criminal prosecution on the basis of HIV transmission). This situation can make people living with diagnosed HIV feel more at risk of exposure to discriminatory behaviours and practices.

Recommendations 21 & 22

This research demonstrates the connection between social capital and individual and group capacity to combat stigma.

21. **HIV organisations** should prioritise peer support and empowerment interventions which allow people with HIV to help themselves and each other. These should include, but not be limited to: facilitating peer support groups, paying expenses for visiting, calling and supporting others who are also diagnosed with HIV, and speaking as a positive person in the community. Further, the provision of adequate childcare support is essential to allow many African people with HIV to access and participate in support services.

22. **HIV organisations** need to prioritise skills-based interventions which aim to give the individual personal and professional skills (including employment and training opportunities) as primary tools in countering stigma. However, it is important to attend to how these interventions are perceived by different groups. African people, on the whole, supported them while some Gay and Bisexual men felt that they had the capacity to increase stigma against those who cannot work and have poorer health outcomes.

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