

HIV AND AIDS IN AFRICAN COMMUNITIES

A FRAMEWORK FOR BETTER PREVENTION AND CARE



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Foreword

HIV and AIDS have disproportionately affected African communities in England. After gay men they are the largest group affected by HIV and since 1999 new diagnoses in Africans have overtaken new diagnoses in other groups.

This framework has been developed with experts from African community-based organisations, mainstream HIV organisations, the NHS, local authority social services, researchers and other stakeholders. It has been informed by two literature reviews and two empirical studies on prevention and care. The framework sets out actions to improve the effectiveness of HIV prevention and health promotion, and treatment and care services for African communities affected by or at risk of HIV.

Some progress has already been made. For example, the change in policy from a selective to a universal offer of antenatal HIV testing has reduced considerably the number of babies born to HIV infected women. African voluntary and community-based groups can provide a wealth of expertise in planning and delivering health promotion and social care services. The availability of new drug treatments has greatly improved health outcomes for many people with HIV. However, Africans have not benefited to the same extent as other groups in that HIV is often diagnosed at a much later stage of disease progression, limiting the effectiveness of drug treatments. African children and families infected and affected by HIV have particular social care needs, which should be addressed. The dispersal of asylum seekers with HIV brings with it challenges for the NHS, social services, the immigration service and the voluntary sector.

This framework is part of the Government's programme to modernise and reform the NHS and social services around the needs of patients, carers and service users, to tackle inequalities and to promote the spread of good practice. It supports implementation of the White Paper, *Choosing Health, the National Sexual Health and HIV Strategy* and complements Department of Health guidance on commissioning sexual health and HIV services and health promotion. The Framework is intended for local commissioners and service providers, including African providers, working in partnership with local African communities and the voluntary sector, to respond to the prevention and social care needs of African communities affected by HIV.

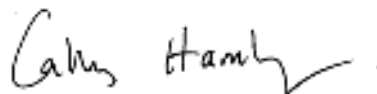
This Framework forms part of an evolving process, and we are committed to its revision and evaluation involving all stakeholders, and to the improvement of the content. We aim to produce a second edition of the Framework, taking account of further research and the input of African communities and providers by the end of 2006.



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Chapter 1

Context and relationship to other programmes and strategies

1.1 *The NHS Plan* was published in 2001 and sets out a vision for providing better quality services designed around the needs of patients, and delivered by a sustained programme of investment and reform.

1.2 Also in 2001, *The National Strategy for Sexual Health and HIV* was published, providing for the first time a national strategic approach to the maintenance of sexual health and the response to HIV in England. Of particular note, are the national goals set for HIV :-

- Reducing the transmission of HIV and sexually transmitted infections(STIs);
- Reducing the prevalence of undiagnosed HIV and STIs;
- Improving health and social care for people living with HIV;
- Reducing the stigma associated with HIV and STIs.

1.3 In 2002, *Shifting the Balance of Power* led to a radical restructuring of the NHS. Power and resources were decentralised and devolved to primary care trusts (PCTs) to ensure better delivery of health care to patients.

1.4 In 2004, *Choosing Health: Making Healthy Choices* was published, whose focus includes ensuring that the most marginalised and disadvantaged groups have the opportunity to see faster improvements in their health.

1.5 In January 2003, the *Commissioning Toolkit* was published, setting out detailed advice and guidance on the commissioning of sexual health services. This was set into a wider context in the *Health Promotion Toolkit*, published in June 2003.

1.6 In October 2003, the Medical Foundation for AIDS and Sexual Health (MEDFASH- formerly BMA Foundation for AIDS) published their *Recommended Standards for NHS HIV Services*, which should act as a best practice guide for planners, commissioners and people with HIV on quality and access to services.

1.7 The Framework for HIV services for African communities has been developed to fulfil the vision of the *NHS Plan* and meet the standards and goals set out in the *National Strategy*. It concentrates on what needs to be done to improve services for African communities, with examples of good practice, rather than setting detailed prescriptive requirements on how it should be done.

1.8 The Framework will seek to do this do this by:-

Keeping people healthy and reducing health inequalities – the Framework will help NHS staff to offer HIV prevention and sexual health promotion advice to African communities at risk of HIV and to those already living with HIV. Supported by national awareness campaigns this will in turn enable individuals and communities to respond effectively to the challenges they face.

Shaping services around the needs of patients, their families and carers – the Framework underlines the need for services to be responsive to those using them and specifically to involve African people affected by HIV in planning services for

African communities.

Working with others – improvements in services will require partnerships at all levels, involving health and social care agencies, central government, African Community Based Organisations (CBOs), HIV voluntary organisations (both those with a specific African focus and those with a broader remit), researchers and African people living with HIV.

Providing a comprehensive service – Some PCTs with established African communities will already provide services tailored to their needs. In others, particularly where such communities are recently established, there is an urgent need for new and effective partnerships to be established. These partnerships should include local CBOs..

Responding to the different needs of different populations – African communities are diverse and services should be appropriate to the needs of different groups.

Continuously improving services – the effectiveness of the measures set out in this Framework will be evaluated as part of the monitoring of the National Strategy for Sexual Health and HIV. In line with the strategy, the development of better services for HIV is supported by guidance on commissioning sexual health and HIV services, professional education and training, health promotion and research.

- 1.9 This Framework also links with the Department's guidance on providing health care for asylum seekers: *Caring for Asylum Seekers*, published in June 2003.
- 1.10 The NHS has recognised the need to engage with racism and promote racial equality and has set out its plans in its *Race Equality Scheme*. This Framework endorses these moves and seeks to give practical advice that will, at the same time help NHS staff to provide a better service and achieve, at least in part, the aims of the *Scheme*.
- 1.11 The descriptions of Government policy contained in the Framework do not necessarily imply any particular views of the National AIDS Trust, the African HIV Policy Network or other organisations, which contributed to the Framework.

Chapter 2

England's African Communities

Social Context

2.1 The 2001 Census established that there were just over 480,000 people in England who described themselves as 'black African'. This represents 0.97% of the population. There are, of course, wide variations in the distribution of these individuals. Over three-quarters live in Greater London, with the highest numbers in the Inner London boroughs where they account for 8.3% of the population. In Outer London, the percentage is 3.4%.

2.2 The Census also established that the population of 'black Africans' differed from the population as a whole on many dimensions.

2.2.1 **Age**

Those identifying as 'black African' in the 2001 Census were, as a group, younger than the population as a whole. Whereas some 46% of the population at large was between the ages of 16 and 49 (a convenient, though, inevitably somewhat inaccurate, proxy for the sexually active population), the proportion in the African Communities was 61%.

2.2.2 **Education and employment**

The Census reports that the African population is relatively well qualified compared to the population as a whole. Only 13% of the Africans were classed as having 'no educational qualifications', compared to 26% in the population as a whole and 27% of the Africans were judged to have 'higher level qualifications (degree and above)', compared to just 14% in the whole population.

Despite this, unemployment among Africans is more than double the rate in the whole population, at just under 6%, compared to 2.5%. In addition, they appear to be under-represented in some of the occupational categories (for example, those classed as 'managers and senior officials' - 3.5% compared to 7%), but the pattern is far from clear.

2.2.3 **Housing tenure**

Africans identified in the Census were far more likely to be living in rented accommodation (68%), than the population as a whole (27%). Conversely, only 26% of the African population owned or were buying their home, compared to an overall figure of 69%. Moreover, some 48% of Africans were living in accommodation classed as over-crowded, compared to a whole population figure of just under 9%.

There are proportionately more Africans below pensionable age living in single person households (27% of households) compared to the population as a whole (16%). Lone parent households account for 20% of African households compared to 9.5% in the population as a whole.

2.2.4 **Marriage and cohabitation**

About two-thirds of African men and women are married by their late 30s and are most likely to marry other African women or men. A quarter of African men and women marry or cohabit with non-Africans, of which white partners constitute the majority. A much smaller proportion of African men and women cohabit and may marry later. Of those divorced, a smaller proportion remarry compared to white

groups.

2.2.5 Migration

The size of the 'black African' population has more than doubled between the 1991 and 2001 censuses (from 212,000 to 480,000). This population is diverse, with many communities of varied ethnic identities, languages, and religions. Apart from London, African communities have also historically settled in Cardiff, Birmingham, Manchester, Leeds and Liverpool. The main trends in migration and settlement include:

- Post-war migration of West African families and students, primarily from Ghana and Nigeria.
- Migration since the late 1970s and increasingly from the mid-1980s, from non-Commonwealth countries such as Somalia, Ethiopia, Congo/Zaire and Angola.
- More recent arrivals include refugees from the Commonwealth countries of West Africa, East Africa and Zimbabwe and Zambia.

2.3 While many Africans living in England do so with permanent or limited residency permits, particular issues are raised by those who are affected by the Asylum legislation. These issues have caused confusion among Africans living in England and among some health and social care professionals alike and require clarification if they are not to act as a barrier to treatment access and health promotion programmes. These issues are:

- Rules on entry to the UK
- Application for asylum
- HIV testing on entry
- Article 3 of the European Convention on Human Rights
- Entitlement to free NHS treatment
- Dispersal of asylum seekers outside London

2.4 These issues are covered in some detail in *Caring for Dispersed Asylum Seekers: A Resource Pack* produced by the Department of Health and the Refugee Council, which is available on www.doh.gov.uk/asylumseekers. While this document is not specific to people with HIV, it does consider the issues of concern around asylum listed above, which may be more complex in this group. Some asylum seekers are wary of approaching the NHS, possibly because of its formalities and the fact that it is associated with Government.

2.4.1 Entry and Conditions of Entry to the UK

Conditions of entry to the UK are a matter for the Home Office. The fact that a person has HIV or AIDS is not of itself grounds for refusing entry to the UK if the person concerned otherwise qualifies under the Immigration Rules and refusal of entry purely on medical grounds is rare.

2.4.2 Application for Asylum

Decisions on asylum seekers' applications are determined on their individual merits with regard to the criteria for refugee status set out in the 1951 Refugee Convention.

2.4.3 Testing on Entry

Asylum seekers are currently offered a health check at induction centres, which may include an HIV test at the asylum seeker's request, or if after taking a medical history, the member of the medical team believes that a test should be offered. As with any person undergoing HIV testing, asylum seekers should be offered pre-test discussion and post-HIV test counselling. Such tests are entirely voluntary, and have no bearing on the decision about the application for asylum. Training in the issues affecting asylum seekers with HIV and their management should be given to staff undertaking this work.

2.4.4 Article 3 of the European Convention on Human Rights

Article 3 specifies the absolute right not to be subject to torture or inhuman or degrading treatment or punishment. Applications under Article 3 on medical grounds are considered on their own merits in accordance with the following guidelines:

- Is there a complete absence of medical treatment for the condition in the applicant's home country such that return would significantly reduce the applicant's life expectancy?
- Would the applicant as a result undergo severe mental or physical suffering on removal to his or her home country? And
- Has the UK assumed responsibility for the healthcare of the applicant? This does not mean simply that treatment has commenced in the UK. It means that withdrawal of a programme of treatment and support already under way in the UK would result in a particularly harsh outcome.

Provision of treatment for people with HIV is reviewed regularly, and this is taken into consideration when deciding Article 3 claims on medical grounds.

2.4.5 Entitlement to NHS Treatment

- The NHS is provided primarily for the benefit of those living lawfully in the UK. Neither nationality nor the past or present payment of income tax or National Insurance contributions are taken into account when establishing residence.
- People who have formally applied for asylum (or refugee status) in the UK, those granted Exceptional Leave to Remain, Discretionary Leave, Humanitarian Protection or Leave Outside the Rules, and refugees (those whose applications for asylum are successful) are exempt from charges for NHS treatment. This applies to both primary care (provided by a GP), and secondary care (including specialised HIV treatment). Chapter 1 of the Asylum Seekers Resource Pack covers this in detail.
- Other people who are in the UK on a temporary basis are required to establish either that they are ordinarily resident in the UK, or that they meet one of the other exemption criteria in order to receive free NHS treatment.
- On 30 December 2003, the Department of Health announced changes to the NHS (Charges to Overseas Visitors) Regulations 1989, to tighten up the rules on charging overseas visitors and modernise the charging system. The rule changes are aimed at ensuring that the NHS is first and foremost for the benefit of those living in the UK. A full summary of the outcome of the consultation was published on the DH consultations website, www.doh.gov.uk/consultations. The changes took effect on 1 April 2004.

- The Charging regulations list a number of infectious diseases for which treatment is free of charge to everyone on public health grounds, including a number of sexually transmitted infections. The changes announced at the end of 2003 have no effect on the arrangements for treatment of these specified diseases, which will remain free of charge, regardless of the patient's status.
- For HIV and AIDS, only the initial diagnostic testing and associated counselling is free of charge. Any subsequent treatment is chargeable unless the patient meets one of the categories of exemption from charges for hospital treatment. This position is unchanged.

2.4.6 Dispersal of Asylum Seekers outside London

- Once an asylum seeker has been assessed as eligible for support under the Home Office National Asylum Support Service (NASS), language and circumstances (including declared HIV status) are taken into consideration before allocating accommodation in a dispersal area. Dispersal means that some PCTs will acquire African communities, perhaps for the first time, and care needs to be taken that dispersal does not have an adverse impact or interrupt treatment regimens. . More detail on NASS support arrangements is to be found in Chapter 3 of the Asylum Seekers Resource Pack.
- The Home Office and Department of Health are working to improve the dispersal process in order to reduce disruption of health care provision.

2.5 The Cabinet Office is currently co-ordinating work between relevant Government Departments, including the Home Office and Department of Health, to review immigration and infectious diseases and access to NHS services. The review aims to establish the facts about health and impact on public expenditure and propose solutions should action be required. The review is ongoing and no decisions have been taken yet.

2.6 Sexual attitudes and lifestyles

Since many Africans have only recently migrated to the UK, many traditional practices and beliefs remain prevalent among local communities. Gender, ethnic origin (i.e. tribal groups), religion, acculturation and other factors influence these.

2.7 Most data on the sexual attitudes, beliefs and lifestyles of African communities have come from the United States and have limited relevance to this country. There are, however, a few studies in England on African communities that measure specific HIV-related risk attitudes and behaviours. Some themes emerging from research to date include:

- there is a predominance of traditional attitudes towards sexual relationships and behaviours;
- Religious faith plays a significant role in the lives of African Communities living in England;
- there is a relatively high incidence of detrimental outcomes of sexual behaviour such as HIV and unwanted pregnancies;
- in some communities, older respected females (“aunts”) have an

important role in imparting information on sexual matters and behaviours to young girls;

- there is uncertainty within communities and in sexual health services about the HIV related risk of some traditional sexual practices;
- travel to home countries was more likely to be reported by communities who had been resident for longer periods of time, with twice the number of men than women reporting having a new sexual partner in the visited country;
- the widespread intention to use condoms with new sexual partners was, as in other groups, not reflected in the numbers actually using them with new partners;
- a significant number of reports of sexually transmitted infections amongst Africans, despite low self-perceived risk and only a third reporting having ever knowingly had an HIV test.

2.8 There is a more visible population of African gay men in the UK who face a degree of discrimination from both African and gay communities. HIV prevention initiatives targeted at each population should be aware of this small but important sub-group.

2.9 Many Africans face discrimination and isolation on a daily basis, which can be compounded by HIV. Africans with HIV often experience additional stigma, not only from mainstream society, but also from within their own communities. This prompts many HIV positive Africans not to disclose their HIV status, which, in turn, can have a detrimental impact by masking needs for social and emotional support and delaying access to medical treatments.

2.10 Female Genital Mutilation (FGM) - sometimes misleadingly called female circumcision - involves the partial or total removal of the external genitalia and sometimes other injuries to the organs of girls, usually between the ages of four and ten. It is widely practised in certain parts of Africa.

All procedures involving the partial or total removal of the external female genitalia or other injury to the female genital organs, whether for cultural or other non-therapeutic reasons have been illegal in the UK since 1985. However, it has been possible to circumvent the law by having the procedure done out of jurisdiction. The prohibition is included in the new FGM Act, which received Royal Assent in October 2003 and took effect on 1 February 2004. The FGM Act amends and strengthens the 1985 legislation. It explicitly makes it illegal to take girls abroad for FGM.

Apart from the violation of human rights that it represents, and the mental trauma it entails, FGM also causes considerable physical problems, particularly at menarche, first intercourse and at childbirth. All those dealing with women from cultures where FGM is practised need to be sensitive to the problems and conflicts it entails. There are also obvious issues of child protection that may have a significant impact on the planning of social care. Health professionals should familiarise themselves with the guidance and statements issued by their relevant professional bodies (i.e. the BMA and the RCM) so that they will be prepared if they encounter patients who have undergone this procedure.

Chapter 3

The HIV/AIDS Epidemic in African Communities

- 3.1 According to 2003 data from UNAIDS, of the estimated 40 million people infected worldwide with HIV and AIDS, 25-28 million reside in sub-Saharan African countries. Sub-Saharan Africa, particularly Eastern, Central and Southern Africa, remains by far the region worst affected by the HIV and AIDS epidemic. This is reflected in the pattern of the epidemic in the UK, which has strong historical links to countries in this region. Adult HIV infection rates of almost 40% have been reported in some countries of Southern Africa.
- 3.2 There were 1134 children with HIV between the ages of 0-14 seen for care in England in 2003, (650 of whom were living in London). The majority of these children are from African communities. Of course, many of the adults with HIV will also be living with families including children, who will inevitably be affected by HIV and the attendant issues around disclosure, loss and many other factors associated with chronic illness. These issues are sensitively and comprehensively discussed in *Talking with Children, Young People and Families about Chronic Illness and Living with HIV*, edited by Jenifa Miah and published by the National Children's Bureau in November 2004. This report is on the websites of NCB on www.ncb.org.uk/HIV, Body and Soul at www.bodyandsoulcharity.co.uk and BHIVA on www.bhiva.org/chiva.
- 3.3 Figures from the Communicable Disease Surveillance Centre (CDSC) show that, in 2003, there were 4431 men, 8126 women and 1 person for whom sex was not reported (a total of 12,558) described as 'black African' who were living with diagnosed HIV infection and attending HIV related treatment and care centres in England. Of these, 57% (7133) were resident in London. The total number of people with HIV seen for care in England in 2003 was 34,689; black Africans accounted for 36% of this total. (2003 data are the latest SOPHID figures available).
- 3.4 In 2003, in the UK, there were 2624 new diagnoses of HIV infection in heterosexuals probably infected in sub-Saharan Africa. This accounts for 69% of all heterosexual diagnoses in 2003. Also, women outnumber men among heterosexuals diagnosed with HIV in 2003, with 65% of new diagnoses being in women.
- 3.5 An estimated 24,500 adults infected through heterosexual sex were living in the UK in 2002. Of these, 9400 (38%) were unaware of their infection (more men than women). This is a higher proportion than for other transmission routes, e.g. 24% of homo/bisexual men are estimated to be undiagnosed and 18% of injecting drug users. Black African men and women accounted for 70% of the total diagnosed infections in heterosexuals and 51% of the undiagnosed infections.
- 3.6 HIV prevalence among African-born women giving birth in 2002 was 2.47%, up from 1.5% in 1997. By contrast, the prevalence in UK-born women was 0.03% in 2002 and was unchanged from 1997.
- 3.7 Between 1997 and 2003, there was a 351% increase in patients seen for care in England, Wales and Northern Ireland who had been infected heterosexually. Within this sub-group, the largest increase has been in Black African patients. Of the 15,726 heterosexual men and women seen for care in England, Wales and Northern Ireland in 2003 for whom ethnicity was reported, 70% (11068) were Black African, 19% (3009) were white and 4% (657) Black Caribbean. Africans feature in all the main

transmission routes for HIV, but most cases of HIV diagnosed in the UK were reported as heterosexually acquired.

- 3.8 Surveillance data suggest that the majority of Africans reported as infected through sex between men and women, and the majority of mother to baby transmissions, are in those who have recently arrived in the UK. While most HIV infections in African communities in England are likely to have been acquired abroad, evidence from service providers and surveillance indicates that new adult infections are occurring as a result of exposure in the UK.

3.9 **Characteristics**

HIV infected Africans tend to be diagnosed later than other population subgroups. There is also some evidence to suggest that Africans have a lower uptake of anti-retroviral treatments. These factors can have a major impact on subsequent health and on transmission. In addition, there is evidence for:

- a different clinical spectrum of HIV disease among African adults in the UK in comparison with non-Africans, with tuberculosis in particular being more common;
- a more advanced stage of disease progression and with lower CD4 counts at diagnosis;
- relatively low attendance for clinical monitoring, uptake of anti-retroviral treatments and adherence to drug regimes;
- the special clinical and social needs of children and adolescents, some of whom may be caring for adults with HIV;
- a relatively low incidence of most STIs, including gonorrhoea, but a high prevalence of genital herpes (a recognised risk in HIV transmission) among both men and women.

Prevention Needs

- 3.10 It is useful for the clarity of this Framework to distinguish between prevention needs and the needs for health and social care of those affected by HIV. While needs for prevention are, generally, community based, needs for health and social care are more focussed on individuals and families. Spanning both however, are the HIV prevention needs of HIV positive people at diagnosis and subsequently.
- 3.11 The first step in effective HIV prevention work is a clear understanding of the dimensions of need in local communities. NHS commissioners should set in place a programme of rolling social mapping and needs assessments to monitor changing patterns of need in the communities for which they have responsibility.
- 3.12 While needs will vary across and within communities, the literature identifies the following general needs:-

Knowledge and Information

- 3.13 A number of studies point to the widespread unmet need for basic information regarding HIV transmission, testing and treatment. In particular, cultural practices that place some Africans at particular risk of transmitting or acquiring HIV requires specific, culturally competent attention. Examples include: perceptions of condoms, polygamy, meanings attached to sexual behaviours, reproduction, breast-feeding and secrecy and taboos regarding sex and

relationships. However, it is as well to keep in mind that there may be as much variation *within* communities on these matters as there is *between*. It should also be borne in mind that information on entitlement to treatment may also represent an unmet need.

- 3.14 African communities need culturally appropriate information about the relationship between HIV and sexual practices, relationships, sexual negotiation, reproduction and sexuality, and particularly on the implications of sero-concordant/ discordant sex.
- 3.15 Men and women, including women considering pregnancy or who are pregnant, need culturally competent information about the transmission of HIV. Although numbers are comparatively small, African men who have sex with men may have information needs which are not currently met by mainstream campaigns targeted at gay men.
- 3.16 HIV prevention campaigns for African communities need to assess levels of literacy in the community and bear in mind that information on intimate sexual matters may not be accepted in print or from sources perceived as 'official', 'interfering' or 'non-African'. It is unrealistic to believe that information needs can always be met simply through the distribution of leaflets or posters adapted from work with other groups. Ways of accessing those communities whose first *Western* language is not English, for example those from Francophone Africa, will need considering.

Skills

- 3.17 Information alone cannot change behaviour and reduce risk. The negotiation of safer sex between partners is not always straightforward, as it challenges deeply- rooted ideas about identity, commitment, gender, sexuality and pleasure. It also brings to the forefront issues of *power* - personal, social and within relationships; and of *control* - over sexual decision making, over life choices, over reproduction. Acquiring the skills necessary to negotiate safer sex is as important as acquiring knowledge and the teaching of these skills needs to be culturally competent and sensitive to the needs of both partners.
- 3.18 In some cases, only one spouse lives in this country, with the other in Africa. In many more cases, members of African communities travel to Africa, where sexual contacts may take place. The management of this long distance prevention is a particular need for these communities.

Building a Safer Sex Culture

- 3.19 For significant shifts in behaviour to occur, there must be broad agreement within communities that HIV is real and undesirable and that safer sex is necessary and desirable. There are however, in all cultures, many barriers to such an acceptance of safer sex.

Gender Issues

- 3.20 African cultures mainly invest men with social, domestic and sexual authority. The empowerment of African women, not only to insist on safer sex but also to control reproduction is a priority. But it is naive to believe that this can be achieved without addressing also the needs of African men whose social and sexual status is often profoundly challenged by the experience of migration.

Effective HIV prevention makes safer sex a priority for both sexual partners: it does not set husband against wife or men against women.

Age

- 3.21 HIV related needs of older and younger community members may differ considerably, especially when there are inter-generational differences in contact with and participating in, English culture. The aim of HIV prevention is to give people the means to make informed choices about their sexual behaviour, not to impose a moral order on them. The HIV prevention needs of young HIV positive Africans are poorly understood. As HIV positive children become adults and begin to have sex, significant need for information, support and negotiation skills exists.

Accessible and Appropriate Services

- 3.22 The literature identifies the need for more information about HIV testing, as well as, more generally, diagnostics and treatment. Access to the means to test for HIV and to discuss HIV and sex in the broader context of sexual health is a key component of a robust approach to HIV prevention. It is also important in minimising late diagnoses, which can limit treatment options and detrimentally affect quality of life. New models of service delivery - shifting sexual health service provision and counselling into African community settings or contexts merits exploration.
- 3.23 While there is clearly a need to ensure that African communities are aware of the NHS services available, there is an equal need for the NHS to show there is no place for discrimination, harassment and stereotyped or prejudiced treatment – whether on an institutional or individual basis – on grounds of race ethnicity or religion. It has to create an environment in which individuals feel valued and in which differences are recognised when delivering service goals for patients with or at risk of HIV.
- 3.24 Early identification and treatment of sexually transmitted infections in African communities is necessary, not only as a means to better sexual health generally, but also, given their role in its transmission, for HIV prevention too. The literature identifies access to condoms as a significant need. Making the *means* of safer sex available without stigma or embarrassment is vital.

Promoting Access to Testing

- 3.25 Taking the HIV test is a momentous decision for any individual, but is invaluable in reducing the amount of undiagnosed infection, ensuring prompt access to treatment programmes and helping to reduce the spread of the virus. Novel and culturally appropriate approaches are needed to increase awareness of the health benefits of testing and early diagnosis. Such services are likely to be most effective if delivered through outreach services led by community-based organisations.
- 3.26 To date there has been little focus on encouraging African men to come forward for testing, yet their role in maintaining, and in time, limiting the extent of the epidemic is clearly vital. Campaigns, which address the concerns of men around testing and promote access to services, delivered in a way that maximise their use are crucial.

- 3.27 All parties involved agree that informed consent must always be given for HIV testing. There is evidence to suggest that linguistic and cultural barriers may prevent some African service users fully understanding that they have given their informed consent. Extra care needs to be taken to ensure that African service users fully understand what their rights and obligations are. Conversely, service providers need to deliver their services in a way that is sensitive to the real fears of those users.

Antenatal Testing

- 3.28 The policy of offering and recommending an HIV test to all pregnant women as a routine part of their antenatal care has already led to significant reductions in new paediatric HIV cases. However, clinical and counselling staff need to be aware of the particular sensitivities relating to HIV in their African service users.

HIV Transmission through Breastfeeding

- 3.29 Breastfeeding is known to be a route of mother-to-child (vertical) HIV transmission. For infants born to HIV-infected women who are not infected during pregnancy and delivery, breastfeeding results in infection in 8-16% of infants at 18 months of age, increasing to 15-22% at 24 months.
- 3.30 The Department of Health has issued guidance on HIV and infant feeding * to support midwives and other professionals who advise HIV-infected pregnant women. The guidance recommends avoidance of breastfeeding because, in this country, the risks associated with breastfeeding are considered to outweigh those from bottle-feeding with infant formula. The guidance also recognises that women need to make an informed choice about breastfeeding based on knowledge of the relative risks and benefits in the context of their own circumstances. If the cost of formula milk is the only reason why an HIV-infected woman feels unable to avoid breastfeeding, provision of infant formula free of charge or at subsidised rates should be actively explored. For example, hospital doctors may be able to prescribe formula milk if clinically appropriate and clinics are permitted to sell formula at cost plus 10% to the general public for the purposes of promoting the health of nursing mothers and young children.

*Ref: HIV and Infant Feeding: Guidance from the Chief Medical Officers' Expert Advisory Group on AIDS (Department of Health, September 2001)
<http://www.advisorybodies.doh.gov.uk/eaga/publications.htm>

Reducing HIV Related Stigma and Discrimination

- 3.31 HIV-related discrimination is not only unacceptable in and of itself, but also acts as a significant barrier to sexual autonomy and satisfaction by inhibiting disclosure, thus possibly making treatment less effective, undermining self-esteem and creating fear and uncertainty. HIV is heavily stigmatised in African communities and members of those communities with HIV require particular and appropriate support in dealing with stigma and discrimination.
- 3.32 The discrimination that many people with HIV experience often exists in a context of financial insecurity and uncertain immigration status. Discrimination has also been documented as leading to domestic violence against women

- and family break-up.
- 3.33 African men who have sex with men often face HIV related discrimination, as well as heterosexism from their communities of origin and racism within the predominantly white gay community.
- 3.34 It should be noted that people living with HIV in the UK enjoy some protection from discrimination through the Disability Discrimination Act 1995 (DDA1995). The DDA 1995 prohibits discrimination against disabled people in relation to employment, education, property, transport and goods, facilities or services (e.g healthcare and housing services). However, at the moment, the DDA 1995 only defines those living with HIV as disabled at the symptomatic stage and when diagnosed with AIDS. However, the forthcoming Disability Discrimination Bill proposes an extension to the scope of the DDA 1995 to include HIV from the moment of diagnosis.

Needs for Health and Social Care

- 3.35 Many people in the African communities are uncertain about the health and social care services that are available to them. There is also confusion about eligibility, access and confidentiality.
- 3.36 There is evidence that people experience improved access to treatment, care and other services when they are provided in the context of community-based organisations. About half of African service users learned about services by word of mouth from friends and relatives. This underlines the need for partnerships between the statutory and the voluntary sectors.
- 3.37 There is evidence that many Africans affected by HIV are unaware of the choice of services available to them. Because of their fear of stigmatisation, they may choose to access services outside their area or in mainstream clinics and voluntary organisations in an attempt to protect their anonymity. The confidentiality of services needs to be stressed, but the real fears of service users also need to be taken seriously by service providers.
- 3.38 Some African people, especially recent arrivals or those whose first language is not English may be put off seeking help for their health problems from the NHS. In order to overcome this, action needs to be taken by service providers and African communities themselves, so that these vulnerable people receive access to the care they need.
- 3.39 Language is a major barrier to health when health and social service professionals cannot communicate effectively with their patients and service users. Although many Africans speak English, it may be their second or third language and they may not fully understand the complex issues connected to HIV and its treatment. Translators and community advocates can help ensure that users are not disadvantaged by their inability to speak English
- 3.40 Translators and advocates can also help achieve mutual understanding of other cultural barriers. These include:
- Sensitivity to the issues of extended families;
 - Sensitivity to the needs of children and adolescents;
 - Sensitivity around taboos and totems;
 - The centrality of spiritual issues;
 - Language;

- Nationality;
- An African approach to counselling.

- 3.41 Services for people affected by HIV were set up before the epidemic among the African population in England developed and it may be that their specific needs are not always met, even where other groups are well served. Significant changes in the delivery and organisation of services may be needed in some cases. These will be informed by the work done by the Medical Foundation for AIDS and Sexual Health (MEDFASH) on recommended standards for a range of HIV services, which complements the Department's Sexual Health and HIV Strategy and provides guidance on best practice. This document was published in October 2003. In addition, discussion on service reconfiguration to meet the needs of Africans with HIV should be based on local research and needs assessment.
- 3.42 The Children Act 1989 remains a key document in the provision of health and social care services to children. *The National Service Framework for Children, Young People and Maternity Services* prepared jointly by DH and DfES, published in September 2004, provides detailed guidance for health and social services on ensuring that services are developed with the needs of the child at the centre. The Core Standards document of the NSF highlights the need for authorities and providers to acknowledge the needs of children in special circumstances, including children of parents with specific health needs, children from some ethnic minorities and looked after children.
- 3.43 The DH and DfES published *Children in Need and Blood-Borne Viruses: HIV and Hepatitis* in November 2004. This document updates previous guidance for local authorities and offers advice on the transmission of HIV, hepatitis B and hepatitis C and the provision of advice information and support to children with blood-borne virus infections and their families. (dh.gov.uk/publications).

Needs at Diagnosis

- 3.44 It is vital that clear and up to date, culturally competent information about appropriate local statutory and community-based services, including support groups, are provided in conjunction with a positive test result. It is also crucial that issues about eligibility for treatment are addressed. Helplines should also be promoted at the point of testing.
- 3.45 Women and children in the African communities are disproportionately affected by HIV. There is strong evidence to suggest that the provision of services for children are often inadequate. This will most often be the case where communities are small, diverse or newly settled, and emphasises the need for co-operation across and between PCTs. Following the London review of paediatric HIV services *Developing Clinical Networks for Paediatric HIV Treatment and Care In London*, (www.bhiva.org/chiva), work is now underway to develop HIV service networks for the rest of England, through the *Children's HIV National Network (CHINN)*. This work is supported by the DH, specialised commissioning groups and The Children's HIV Association (CHIVA), and the report and recommendations from the national review will be available shortly for implementation during 2005.
- 3.46 The reactions of some husbands or male partners to a woman's positive diagnosis can be unhelpful and sometimes brutal, born out of negative stereotypes within communities. Such reactions can severely reduce the access to and efficacy of treatment and care and these issues need to be addressed

within prevention campaigns and elsewhere.

- 3.47 Some African men with a positive diagnosis may have specific problems associated with, or exacerbated by the stresses of migration, subsequent loss of status, unemployment and stigma within their communities.
- 3.48 Bearing these points in mind, sensitive and appropriate models supporting partner and family notification need development.

Needs for Treatment

- 3.49 Recent evidence from *Project NASAH* shows that Africans are still presenting later than other patients even though they typically need to commence treatment sooner after diagnosis than their European counterparts (31 days versus 721 days). They also tend to have lower CD4 counts at diagnosis than other groups (166 compared to 357). Treatment information specific to people from African communities should be provided.
- 3.50 Diagnosis among Africans is also more likely to happen during a hospital visit for treatment that is unconnected to HIV, for example, this could be during routine antenatal screening or following a hospital admission for TB.
- 3.51 There is also evidence to suggest that Africans are less likely to realise or acknowledge their risk of HIV infection compared to white gay men. A recent study found that only 28% of Africans suspected they were HIV positive before testing positive compared to 65% of other high-prevalence groups.
- 3.52 Once diagnosed, there is also a lower uptake of combination therapy treatments by women than in the wider group of those diagnosed. Social factors such as poor housing and fear of disclosure also interfere with the willingness to start medication and the ability to adhere to combination drug regimes. Also, there is still much distrust of the medical profession by some members of African communities.
- 3.53 Treatment regimes for HIV are notoriously strict and demanding of patients and can present additional difficulties in a family situation or where people live in shared accommodation. If physicians are more aware of the context in which people live and accept the constraints this imposes, they will be better able to agree with their patients a treatment that will maximise its effectiveness.
- 3.54 It is well known that departing from the strict timetable required by current anti-HIV drug therapies could increase drug resistance and severely decrease the long-term prospects of patients. Physicians and pharmacists should work with advocates from appropriate community groups to ensure that the regime and its side effects are properly understood. This will allow patients to make properly informed decisions about treatment and the ways that it can be integrated into their daily lives.
- 3.55 Once diagnosis is made, it is essential that patients are made aware of and referred to other agencies. These are likely to involve appropriate community groups, primary care, specialist care and social care.
- 3.56 The DH AIDS Support Grant continues to allocate a total of £16.5 million annually to local authorities in England, as a contribution towards the social care

needs of people living with HIV. Since 2003/04, the allocation formula has prioritised women and children with HIV as a group requiring additional support.

- 3.57 Breastfeeding increases the probability of vertical transmission, but there is evidence that a considerable number of HIV positive mothers continue to breastfeed their infants because they could not afford infant formula milk.
- 3.58 As survival rates improve for children living with HIV, there is a longer-term need for services that are appropriate to the needs of young people and adolescents in addition to those for children and adults.

Chapter 4

Goals, Principles and Values

Goals

4.1 The *National Strategy for Sexual Health and HIV* sets out a number of aims, including:

- reducing the transmission of HIV and sexually transmitted infections (STIs);
- reducing the prevalence of undiagnosed HIV and STIs;
- improving health and social care for people living with HIV;
- reducing the stigma associated with HIV and STIs.

This strategy sets out to indicate ways in which those aims may be achieved in England's African communities.

4.2 The overall goal of HIV prevention for African communities is to:

- reduce the acquisition and transmission of HIV infection in African people living in England.;
- The specific prevention aims are to:-
- reduce the sexual transmission of HIV infection among Africans and their partners;
- reduce the vertical transmission of HIV from a mother to her baby;
- reduce the prevalence of undiagnosed HIV in Africans living in England;
- reduce the stigma associated with HIV;

4.3 The overall goal in providing health and social care services to African communities is to:-

- improve the quality of life of those African people in England affected by HIV.

The specific aims in providing health and social care are to:-

- ensure Africans affected by HIV have equal access to the full range of the highest quality services;
- ensure those services are sensitive to the cultural, religious and linguistic diversity of African communities;
- ensure that service delivery is organised around accurate assessment of individual need;
- maximise access to testing;
- make particular provision for the needs of children and adolescents;
- Improve adherence to anti-HIV treatment regimes;
- improve access to education, employment and leisure opportunities;
- support carers and families;
- reduce the social exclusion of those Africans with HIV in England.

Principles and Values

- 4.4 This framework endorses the aims of the *Ottawa Charter on Health Promotion*, which defines health promotion as the process of enabling people to increase control over, and to improve their health. Both the national strategy and this Framework reflect the five action areas of the Ottawa Charter:-
- building healthy public policy that promotes sexual health at local and national levels and addresses inequalities;
 - creating environments that are supportive of sexual health;
 - developing personal and social skills regarding sex, sexuality and sexual health;
 - ensuring that all services which promote sexual health build upon the evidence base and develop professionals skills, knowledge and positive attitudes through education and training;
 - strengthening community action in setting priorities, making decisions;
 - planning strategies and implementing them to achieve better sexual health.
- 4.5 The following values underpin all the recommendations in this Framework:-
- 4.5.1 Individuals should be empowered to make their own decisions and choices about their sexual health, informed by knowledge, understanding and skills on how to prevent HIV plus awareness of services.
- 4.5.2 Effective HIV prevention, treatment and care require clear and accurate information based on up to date evidence, particularly on drug regimens.
- 4.5.3 HIV prevention programmes and services delivering treatment and care should be sensitive to people's cultures and differences. African communities embody a rich diversity of culture, traditions and experiences that have an impact on their sexual health. Interventions should be culturally appropriate and sensitive to difference, not only between but also within communities.
- 4.5.4 HIV affects African communities in England more than any other ethnic group, but each community is differently affected, resulting in different needs and different levels of need. It follows that some African communities may require a disproportionate use of resources to achieve the same ends.
- 4.5.5 Planning of HIV prevention, treatment and care should involve those intended to benefit from it. Partnerships between African communities, commissioners and service providers are vital at all levels.

Chapter 5

Planning Prevention and Social Care

Planning Prevention

Social and behavioural research evidence is generally agreed that:-

- for behaviour to change, individuals must recognise the problem, be motivated to act and have the knowledge and skills to perform and sustain the action ;
- to increase the likelihood of action, barriers in the social environment must be removed or overcome and support or reinforcement provided wherever possible.

Therefore, in order to meet the HIV prevention needs of African communities, HIV prevention must operate at two main levels: individual and structural.

5.2 Examples of *individual* factors that might be addressed by HIV prevention activity include:-

- knowledge and awareness (of HIV risk, of condoms, of services, etc.);
- attitudes, motivations and intentions (attitudes towards condoms, motivation to use condoms, attitudes to HIV status etc.);
- beliefs and perceptions (perceived social norms, perceived vulnerability to HIV infection, belief in own ability to effect change, cultural and religious beliefs about sexual practices);
- skills (communication skills, sexual negotiation skills, sexual assertiveness skills).

Examples of individual level interventions might, therefore, include:-

- voluntary counselling and testing;
- one to one counselling;
- face to face detached or outreach work;
- telephone help lines;
- internet based work;
- clinical services to prevent mother-to-child transmission;
- provision of sperm washing services.

5.3 Examples of *structural* factors that might be addressed by HIV prevention activity include:-

- Economic factors (funding, poverty);
- Policy factors (including laws and regulations);
- Societal factors (community/peer norms regarding safer sex, cultural and religious beliefs, broad social attitudes, e.g., HIV stigma and

- discrimination);
 - Organisational factors (the structures and functions of community organisations and their capacity to deliver effective HIV prevention, the accessibility and cultural competence of health services).
- 5.4 Such structural factors might be addressed by interventions that target *groups*, those that are organised on the *community* level and those that focus on wider *social and political* issues.
- 5.5 Group level interventions are delivered to small groups of individuals, usually from the same peer group. These groups are usually facilitated and can be one-off or part of a series of group sessions. These kinds of interventions mainly address personal modifying factors, but can also address structural factors, for example peer norms regarding condom use.
- 5.6 Community level interventions target defined ‘communities’, for example a specific at-risk group (e.g newly sexually active young people) or a community defined by nationality (e.g. Congolese community), a faith community (e.g. Muslim communities) or region (e.g. Africans with HIV living in Manchester). Interventions at this level can also target organisations and professionals working with specific populations (e.g. community based African organisations or religious leaders). Examples of community level interventions include:-
- small media (leaflets and booklets);
 - mass media (posters and advertisements in publications such as The Voice);
 - condom provision;
 - peer education;
 - community empowerment and development, including building community infrastructure;
 - influencing practice of organisations, including training and technical advice.
- 5.7 Socio-political interventions address the laws, policies and cultures in which HIV prevention occurs. These interventions are often described as providing the ‘backdrop’ for HIV prevention, or as interventions to create a supportive policy environment for HIV prevention. Examples of such interventions include:-
- Legislation, including anti-discrimination laws;
 - Equality work - activities to reduce discrimination and social exclusion by influencing national and local policies;
 - Facilitation interventions - research and evaluation, programme planning, developing HIV prevention partnerships;
 - Resource allocation;
 - Regulation (eg. labelling of condoms).

The ASTOR framework

- 5.8 African communities in England are diverse with distinct and different patterns of needs. One model of HIV prevention will not fit all needs and it would be inappropriate for this Framework to propose a single model. What is proposed is the adoption of the ASTOR framework, which is also recommended in the Department of Health’s guidance on commissioning sexual health and HIV prevention and care services.

- 5.9 The ASTOR is a standardised planning tool that can be used to describe each planned HIV prevention in terms of its **Aims** and intended outcomes, **Settings**, **Target group**, **Objectives** and methods and **Resources/Rationale**. The DH guidance on commissioning explains the benefits of ASTORs for both service commissioners and providers.

Aims

- 5.10 While the overall aim of HIV prevention is to reduce the onward transmission of HIV, individual interventions work best if they concentrate on one aspect of established need, for example, improving levels of knowledge, developing assertiveness skills in sexual negotiation and changing attitudes to those with HIV.

Settings

- 5.11 The settings in which African HIV prevention takes place are many and varied, but should be chosen to maximise contact with the target group, and also be appropriate to the nature of the intervention. For example, most people find it easier to discuss intimate matters one-to-one or in small groups, rather than in a large crowd. Settings that have been used for African HIV prevention work include formal and informal settings including:-

- community groups;
- community specific organisations, self help groups and (CBOs);
- religious groups or churches;
- night-clubs and bars, African restaurants;
- annual community events, including festivals;
- embassies;
- service points such as sexual health services, outpatient clinics and GP surgeries;
- people's homes;
- HIV testing sites;
- work settings such as cab driver premises, garages and hair salons;
- schools, colleges and universities;
- local and community media;
- workshops and seminars at prevention agencies.

Target Group

- 5.11 While in some cases, the intervention might target the whole community, in others, particular sub-groups might be the intended audience. Clarity on this can affect the design, language and tone of an intervention. For example, a programme for young Somali males can and should use different language, images and approaches from one aimed at Nigerian church elders.

Objectives and Methods

- 5.13 Given the various HIV prevention needs of many individuals in different settings and environments, methods employed to achieve the desired prevention outcomes need to be appropriate to the task. Guidance on these is included in the forthcoming publication of *Doing It Well: a Good Practice Handbook for Community-Based Interventions with African Communities*, based on an audit of

community based interventions by the National African HIV Prevention Programme (NAHIP). Some African community organisations are undertaking very innovative interventions in different community settings. These include:-

- **Information giving:** Training seminars and workshops; visual, printed and audio media (leaflets, posters, radio programmes, audio and video tapes); newsletters;
- **Media interventions:** The use of alternative and credible community media such as theatre, fiction, music, poetry, song, dance, film;
- **Community/peer education:** Enabling peers to become informed and skilled in HIV prevention, to then provide HIV prevention work in community settings.
- **Behavioural skills training:** Group discussions and seminars, supporting people to put information about safer sex into practice, through the acquisition of communication skills; skills in condom use and low risk sexual behaviours.
- **Condom distribution:** Provision of free condoms (and lubricant for gay men) in various community and commercial settings.
- **One-to-one interventions:** information and advice from health professionals, advice workers, counsellors and volunteers that focuses directly on individual needs;
- **Outreach:** Contacting individuals not currently in touch with existing services by: going to places where people meet to socialise; improving access to information; one-to-one work in private or informal settings.
- **Community events:** Promoting HIV prevention initiatives at community gatherings.
- **Advocacy:** Services that enhance individual personal power and self-esteem by addressing their medical, social, legal and economic circumstances.
- **HIV treatment, care and support:** Many medical and community care services, as well as providing medical, practical and emotional help for people with HIV or AIDS, also provide one-on-one HIV prevention services in the form of advice and support. In addition, some districts fund community health advisor posts specifically to provide treatment support to African people.

Resources/Rationale

- 5.14 When planning an intervention care needs to be taken at the planning stage to consider the full costs and how these will be met, for example, statutory funders, charitable trusts, from within communities and community-based organisations. The costs of evaluating an intervention should also be built in to the overall budget.

Research

- 5.15 Properly focussed, conducted and published research is invaluable in targeting HIV prevention accurately and effectively. Useful research is community based and community focussed. Social and epidemiological research is needed in a number of areas including: sexual behaviour, gender, accessing local services and changes in settlement patterns as more Africans settle outside London and other major cities. Annex 3 summarises current priorities identified in the literature reviewed.

Social Care

- 5.16 Good quality, culturally competent services can help save lives and reduce the transmission of HIV. In the past, these services have often evolved rather than being the result of careful strategic planning. As such there are both gaps and areas of duplication in service provision.
- 5.17 Services are provided by health and social services as well as the voluntary sector. Some of these services may be adequate and appropriate for African communities. But they are not uniform across health and local authorities. This chapter aims to identify best practice in offering and providing effective and appropriate health and social care services for Africans affected by HIV.
- 5.18 The National Strategy for Sexual Health and HIV sets out five principles for the provision of social care:
- helping service users adhere to drug regimes
 - helping service users access education, employment and leisure facilities
 - ensuring people have their needs assessed and met
 - supporting carers and families
 - making sure that people living with HIV can benefit from wider initiatives that promote social inclusion
- 5.19 In collaboration with the Department of Health, The Medical Foundation for AIDS and Sexual Health (MEDFASH) published *Recommended Standards for NHS HIV Services*, as a tool for commissioners, providers and people with HIV. This document contains a chapter on the need to integrate health and social care.
- 5.20 There is high demand for these services and they are under considerable pressure. The section of the *Implementation Action Plan* entitled 'Better Support of People Living with HIV' sought to address this and referred to a review of the AIDS Support Grant, which is used by local authorities to develop social care support for people with HIV. The revised allocation formula targeted women and children among the HIV positive caseload as the sub-population most in need of input from social care. The use of the HIV positive definition rather than that of AIDS, also recognised the shift in importance of the former, following the success in the use of combination therapies. From 2003/04 the formula was based on 70% HIV caseload and 30% HIV positive women and children. The formula was phased in over two years. The allocation for 2004/05 was £16.5 million for English authorities.
- 5.21 There is evidence that many Africans had little knowledge of the social care services to which they were entitled. Since the demand for services will increase as the epidemic grows, there is a need to make African communities aware of

those social care services that exist and to encourage the growth of local statutory and voluntary organisations to meet these increasingly diverse needs.

Helping Service Users Adhere to Drug Regimes

5.22 Peer support helps people to manage the challenges in their lives, including the management of their treatment. The Pan-London HIV Providers Consortium has recommended that peer support should be available at particular flashpoints of greatest need, for example:-

- when a person is newly diagnosed;
- when starting or changing treatment;
- when health status changes;
- during times of emotional distress, crisis or depression.

5.23 What evidence there is strongly suggests, however, that such services are rarely available. The role of CBOs in the development of these is clearly crucial.

5.24 Peer-led motivational and self-management programmes have been demonstrated to be effective in helping service users manage their drug regimes effectively.

Helping Service Users Access Education and Employment Facilities

5.25 *The Positive Futures Partnership* provides support, advice and training to people living with HIV wishing to go back to work, change job, retrain or take a higher education qualification for the first time (see www.positive-futures.org). (The Partnership currently includes the Globe Centre, the National AIDS Trust, Oasis North London, Positively Women, Terrence Higgins Trust and Lighthouse and the UK Coalition of People Living with HIV and AIDS.)

5.26 The efficacy of current therapies has meant that many people with a positive diagnosis are able to consider the possibility of working or returning to education or training. This is clearly desirable in itself, but it also improves self-esteem, which in turn has a positive impact on health. Given the high rates of unemployment faced by the African population as a whole, this is a particularly acute problem for Africans who are HIV positive. The role of social care agencies in fostering these moves can include providing peer-led motivational courses and programmes which promote skills development and option appraisal.

Ensuring people have their needs assessed and met

5.27 The particular needs of African service users should be taken into account when planning discharge from a stay in hospital. Involvement at this stage of representatives from appropriate community groups and/or the involvement of advocates is crucial and should come to be considered routine.

5.28 Although many people living with HIV are well, there is still need for a range of social care services for people who are ill, whether this is periodic or long-term. These include:

- home care;
- shopping;

- personal care;
- food preparation;
- day care;
- terminal care;

These services need to be planned and delivered in a way that is sensitive not only to service users' health, but also their family and community circumstances.

- 5.29. Poor housing can contribute to poor health generally and impede the ability to manage drug regimes. There is clearly a need for specialised housing for some people with HIV. There are, however, unresolved problems in the tenancy rights of dependents, should a person in specialised accommodation die.

Supporting Carers and Families

- 5.30 Many African families affected by HIV are headed by single parents, and in some cases the responsibility to raise a child may have been passed to a grandparent, (although this is more likely to be the case in Africa than the UK). There is a need for family support services that are specifically tailored to the needs of African families affected by HIV. These might include:-

- child-care to enable the mother to access treatment and care;
- children and young people's support groups (for positive and negative children);
- short respite care;
- longer respite breaks;
- family therapy and counselling for children with behavioural problems;
- services for young carers.

- 5.31 Specific youth programmes are needed to support HIV positive teenagers and other young people who care for HIV positive family members, by promoting their well-being and advocating their needs. Achieving high participation rates in such programmes requires not only cultural appropriateness but also active engagement in contemporary youth culture and as such are more likely to be successful if managed by community based organisations.

- 5.32 Teenage carers from the age of 16 are eligible for direct payments to meet their developmental needs under the *Carers and Disabled Children Act, 2000*, yet many are unable to benefit from this because they have not been allocated a social worker. Such administrative barriers emphasise the need for effective communication between agencies.

- 5.33 A number of barriers have been identified preventing African families from accessing care services. Greater understanding is needed among the providers of social care of differing concepts of family among African communities. Clarification is also needed over the use of African names, which can create difficulties in identifying the next of kin.

- 5.34 Counselling is an inexpensive and effective intervention at times of stress, but there is evidence of a need for greater provision of effective, culturally sensitive counselling. Yet there are many within the communities who have the skills to develop such a role, given sufficient support.

Making Sure that People Living with HIV can Benefit from Wider Initiatives to

Promote Social Inclusion

- 5.35 African people with HIV are at risk of being excluded from civil society both on the grounds of their ethnicity and their HIV status. Services are needed that address this particular combination of disadvantage in a culturally appropriate manner. These include specialist advice on benefits and welfare rights, housing and legal status and immigration.

Chapter 6

Partnerships

Partnerships for prevention and social care

6.1 African community based organisations, mainstream HIV and sexual health to HIV for African communities. Developments and initiatives have included:-

- the setting up of African HIV Policy Network (AHPN) to represent African communities in the UK in the areas of HIV and sexual health, and the establishment of the National African HIV Prevention programme (NAHIP) to undertake specific health promotion work with African communities in England;
- development of the African HIV Research Forum to promote interest and collaboration in HIV research for, by and with African communities;
- African regional forums, linked to the AHPN, providing a regional voice for African communities for HIV and sexual health;
- an African community based prevention sector;
- NHS funded prevention and support activity;
- national HIV health promotion projects including, information resources, a media campaign, capacity building, a *Health Africa* radio project and a African AIDS Helpline.

6.2.1 Many African community organisations are undertaking innovative and excellent interventions within their various communities, but much of this work has gone undocumented and unevaluated. It is not, for example, sufficient to record the numbers attending events or workshops: quality or behavioural indicators need also to be measured.

6.2.2 Partnership working, which brings together researchers, local commissioners and community organisations, can do much to make sure that lessons from such pieces of work are learned and disseminated.

6.2.3 Although some evaluations of these interventions have taken place, much remains unknown about the impact of some of these. Rigorous and independent evaluation is essential in establishing good practice and should form an integral part of new initiatives, both national and local.

Local commissioning

6.3 The Sexual Health and HIV Strategy recommends the setting up of local agency commissioning groups for sexual health and HIV, under a lead commissioner arrangement.

6.4 Commissioners may also need to consider supporting organisational or

capacity-building work with their funded African organisations so they can participate in the strategic planning and delivery of services and the building of effective partnerships.

- 6.5 African communities represent not only unmet needs for HIV prevention, treatment and care, but also largely untapped resources for the work. The involvement of communities is crucial if interventions are to be culturally appropriate and effective.
- 6.6 HIV prevention overlaps with other local initiatives including the *Teenage Pregnancy Strategy and Sure Start Plus*. These provide examples of successful local programmes, opportunities for joint learning and the possibility of shared initiatives and interventions.

Building Effective Partnerships

- 6.9 Effective partnerships are based on commitment to consultation and joint decision- making. The partnership role of the community is not a passive one involving consultation after decisions have been made. Rather, it emphasises and champions the involvement of the community in every level of decision-making and policy formulation.

Annex 1: Current Health and Social Care Provision

- A1.1 Given the reported high levels of ignorance as to what social care services are available among a significant proportion of Africans, it is important to highlight those currently available. This section highlights specific legislation that is relevant to the domains of health and social care and lists what is currently available in each domain.
- A1.2 In general, Africans' understanding of access to health services is quite good, although clarification is needed around the eligibility for services for asylum seekers and other migrants. The recently published *Caring for Dispersed Asylum Seekers* sets out the Department's policy on this.
- A1.3 Table 1.1 summarises the range of health care services currently provided. It forms part of the framework for the types of services that should be available to Africans. It could be used as the basis for guidance on the development of clear information for Africans who may not be familiar with the NHS.
- A1.4 There is a growing body of evidence that suggests that there is a great geographical disparity in the provision of quality services appropriate for Africans. Many statutory services outside of London have not had the expertise that is derived from having a critical mass of Africans to develop the expertise of working with clients or patients from Africa; nor have they had the experience of working in partnership with black and African voluntary sector organisations who assist them in providing culturally and linguistically appropriate services. This is especially the case with programmes to increase treatment compliance.

Table 1.1: Current healthcare provision

Service Name	Brief Description
Primary & Community Health services	GPs, district nurses, health visitors, home visits etc.
GUM services	HIV testing, support if HIV positive, health advisors, advocacy
Hospital in-patient services	Infectious diseases and other wards
Paediatric services	children and medication, HIV positive adolescents and medication
Family HIV clinics	partnership between GUM/ paediatric services
HIV clinics	Adherence support (to understand medication)
Antenatal clinics	Testing women. If HIV positive: counselling, advocacy, support, breast-feeding advice.
Palliative care	Hospice care
Mental health services	Psychiatry, psychological care

- A1.5 In contrast to health services, service users are often confused about social care services, entitlement and how and why they might qualify.

Furthermore, they often believe that there is a statutory obligation to provide specific service to specific categories of service users (such as people living with HIV, gay men or Africans). Such beliefs cause misunderstandings.

- A1.6 These and other differences need to be clarified to Africans as confusion in service users' minds can cause dissatisfaction with social care services generally.
- A1.7 There has been little investment in high quality research in social care for Africans, compared to research in health care. The three key issues, which need to be addressed, are:
- *information* – different groups of people require different methods to raise awareness of available services. The statutory sector often makes use of leaflets, but these are often not accessed by many who need services. This is a generic problem.
 - *access* – how to access services is also often unclear to service users. Social Service departments need to make this more explicit. Again, this is a generic problem.
 - *care management*- understanding of the assessment process for service entitlement is poor. Social Services need to work on improving this understanding and involving service users in the development of the care package.
- A1.8 Table 1.2 summarises the range of health and social care services currently provided. It forms part of the framework for the types of services that should be available to Africans. It could be used as the basis for guidance on the development of clear information to service planners and for Africans who may not be familiar with Social Services.

Table 1.2: Current social care service provision

Service name	Brief description
Specialist advice services	Benefits advice, welfare rights etc
Legal services	For Africans, mainly linked with immigration advice and housing.
Hardship funds	Helpful contribution to daily living on benefits, and in accessing respite care.
Counselling/emotional support	Emotional support in times of crisis.
Services for children	Child social worker, childcare, support groups for children, summer clubs
Domiciliary care	Home help, food preparation, meals on wheels, personal care, shopping
Other social support	HIV support groups, HIV peer support, including for children
Housing services	Especially important for families with sick children
Travel pass and transport	Free travel passes, orange badges scheme, taxi card etc.
Career planning	Currently mainly IT courses
Respite care	Short-term respite breaks (for example, to enable parents to keep out-patient appointments). Longer-term residential breaks
Support for carers	Support groups, provision of services focused on the carer's needs

Summary of Research Needs

- **Epidemiology and monitoring:** Much remains unknown about the epidemiological and demographic features of the African HIV epidemic in England, particularly as the dispersal system forces many new and vulnerable people out of London where much of the current HIV prevention activity is located.
- **Sexual behaviour:** There is a critical need for a better understanding of the sexual behaviours and attitudes of Africans with or at risk of HIV, in the context of cultural practices and beliefs, relationships, gender disparity, and economic status. Properly designed studies should do more than merely collect epidemiological data: they should also directly assess HIV prevention and care need. This is a model successfully developed in gay men's work by Sigma Research;
- **Gender specific research:** More information is needed on: attitudes, beliefs and practices surrounding breast-feeding; the impact of the ante-natal testing policy on decisions about pregnancy, termination and sexual behaviour; the attitudes, feelings, experiences and behaviour of African men; male approaches to condom use; sexual negotiation and masculinity;
- **Specific sub-populations:** More information is needed on the HIV prevention needs of: Africans who inject drugs; asylum seekers and visitors, African men who have sex with men, African sex-workers;
- **Health services and prevention interventions:** Sophisticated work is needed on the barriers to use of sexual health services; evaluation of HIV promotion initiatives, and the development of research tools to reflect African community experience.

Glossary

CD4 count. The CD4 is a molecule on the surface of some cells onto which HIV can bind. The CD4 cell count roughly reflects the state of the immune system.

Evidence based There is an evolving commitment in the NHS to ensure that all its services are designed in the light of evidence from reliable research. In the last few years there has been increasing effort spent on identifying the best research, drawing the implications for practice and disseminating this evidence to practitioners.

HIV prevention A general term to encompass all interventions, programmes and services that aim to reduce the onward transmission of HIV. These may range from national media campaigns to individual counselling.

Infected/ Affected People with HIV in their bodies are said to be infected with HIV. They, their families of origin and choice, children, friends and communities are said to be affected by HIV.

Men who have sex with men This is a technical term and describes those men who, in a given time period have sex (however defined) with other men. It is, therefore, a behavioural category and will include men who identify as gay, bisexual and heterosexual.

Gay men Many men who have sex with men, as well as some others, choose to identify themselves as gay. This is therefore a personal and political category.

Vertical transmission Transmission of HIV from a mother to her child, either pre-natally or in the immediate post-natal period.

Sexual health The English *National Strategy for Sexual Health and HIV* states: 'sexual health is an important part of physical and mental health. Essential elements of good sexual health are equitable relationships and sexual fulfilment with access to information and services to avoid the risk of unintended pregnancy, illness or disease.'(p 5)

Incidence The incidence of HIV in a population is the number of new cases that occur in that population over a given time period (usually a year), expressed as a proportion of the population. Thus, the incidence of HIV among 'black Africans' (the CDSC term) in the UK was (roughly) 1.2% *per annum* in 2000. That is to say, in that year there were 1.2 reported cases of HIV infection for every hundred 'black Africans'.

Prevalence The prevalence of HIV in a population is the percentage of people in that population who have HIV at any one time. Prevalence is, thus, the total number of infections since the start of the epidemic, less the total number of deaths. (In practice, of course, populations do not remain static and in- and out-migration will also affect the numbers).

Anti-retroviral therapies In the late 1990s, a range of therapies became available that have proved successful in improving the quality of life and the life expectancy of very many people with HIV. Often known as combination therapies, they use a combination of drugs that attack HIV (which is, in technical terms, a retrovirus) at different stages of its life cycle.

Sexually transmitted infections (STIs) Conditions and diseases that are most commonly passed through and during sex. These include fungal, parasitic and bacterial agents as well as some viruses. Although HIV is passed during sex, it is not, technically an STI, but a blood borne virus.

Sero-discordant A sero-discordant couple is one where one partner is HIV positive and the other HIV negative.

Epidemiology The scientific (in practice, usually medical) study of disease at a population level. Epidemiology is primarily interested in the patterns of spread of disease that may, in the case of new infections, give clues to the origin, mode of spread and agent of infection. In the case of existing diseases or conditions, epidemiology is concerned to monitor the impact on groups within the population or the population as a whole.

Safer sex A term used to describe that range of sexual practices that carried lower risk of passing HIV than the 'high risk' practices of unprotected anal and vaginal intercourse with ejaculation. Often used to refer to the use of condoms during sex.

Advocacy In this context, the practice of one person or group helping another to understand and navigate state organisations and procedures and, commonly, representing them in formal hearings, meetings, assessments etc.

Peers (As in peer education, peer-led interventions, peer support) It is commonly thought that some HIV prevention messages are better understood and more trusted when the source of information or advice is identifiable as a member of the community, rather than an outsider, however expert.

Appendix: Acknowledgements

Supporting documents

This Framework is informed by four research reports, two pieces of commissioned research and two literature reviews. They are:

- Chinouya, M & Reynolds, R *HIV Prevention and African communities living in England: A review of the literature*, October 2001
- Chinouya, M *HIV Prevention and African communities living in England: a study of challenges in service provision* October 2001
- Hamujuni-Smith, B., *Provision and Access: Health and Social Care Services for Africans Affected by HIV: A Review of the Literature*, August 2001
- Hamujuni-Smith, B, *HIV Health and Social Care Services for African Communities in England: A Study of Provision and Access*, August 2001

The research evidence that informs this Framework is referenced in the Literature Review, rather than here in the Framework. It is recommended that this Framework be read in conjunction with these supporting documents.

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