

A Framework for better living with HIV in the UK

Public Consultation Draft

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Written feedback and comments are welcome from all interested parties.

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[**NOTE TO READERS** - The report of the 2007-08 *What do you need?* survey will be published in late November 2008. Since the release of this consultation draft of the framework pre-dates the publication of that report, we include here figures from the 2002 *What do you need?* survey. These figures are marked # **Replace next paragraph with data from WDYN 2007/8** #. All will be updated in this document before it is published].

1. Introduction and overview

1.1 THE GOAL, PURPOSE AND SCOPE OF THE FRAMEWORK

This is the first framework of its kind in the UK. It describes the shared aspirations of a group of agencies for the lives of people with diagnosed HIV in the UK. The overarching goal of the framework is:

All people with HIV are enabled to have the maximum level of health, well-being, quality of life and social integration.

This is no less than the majority of people expect for themselves. What we aspire to for people with diagnosed HIV is not substantially different to what any one else aspires to. However, numerous obstacles prevent people with diagnosed HIV achieving maximum levels of health, well-being, quality of life and social integration.

This overarching goal is the situation we want to bring about. We breakdown this goal into seventeen subsidiary goals (what we want to happen). Each of these has a number of related aims and target groups (what we want individuals and groups to do to bring about the goal). Therefore the framework starts with the individual and seeks to bring about the conditions most favourable to their self-determination and self-empowerment.

The purpose of the framework is to:

- Promote and protect the rights and well-being of all people with HIV in the UK.
- Maximise the capacity of individuals and groups of people with HIV to care for, advocate and represent themselves effectively.
- Improve and protect access to appropriate, effective and sufficient information, social support and social care services.
- Minimise social, economic, governmental and judicial change detrimental to the rights and well-being of people with HIV.
- Build consensus among those with a responsibility for promoting the well-being and rights of people with HIV.
- Provide benchmarks against which the activities of a range of key stakeholders can be assessed, critiqued and coordinated.

The framework does not describe all the activities of the organisations represented in the Framework Development Group (see section 1.4). Nor can these organisations undertake all the interventions necessary within the framework. Rather, the framework seeks to mobilise and coordinate the actions of a broad range of individuals and groups, from people with HIV themselves to government ministers.

The framework primarily seeks to benefit people with diagnosed HIV infection. It is concerned with the health and well-being of those diagnosed with HIV and not those with undiagnosed HIV or those who might become infected (HIV prevention). We believe diagnosing HIV is increasingly seen as a panacea for the epidemic. However, we are concerned with the lives of people with HIV after diagnosis. Therefore the framework is not focused on increasing HIV testing or HIV diagnosis nor does it attend to the needs of the broader population affected by HIV except where they relate to people with diagnosed HIV.

1.2 BACKGROUND TO THE FRAMEWORK

The UK HIV epidemic has undergone unprecedented change in the last decade. The size of the population of people with HIV has more than doubled and the range of anti-retroviral treatments for HIV has increased, so that treatments are now both more tolerable and more effective in the long-term management of HIV. Alongside the large increase in the number of people with diagnosed HIV and a reduction in HIV related morbidity and mortality, the way services are constituted and funded has also substantially changed and the volume of voluntary service providers has diminished. What we are seeing then is a divergence of need among people with HIV, with an increasing gulf between those with HIV who are well and living with a long-term manageable condition and those who are struggling to survive. There is no one way in which people are living with HIV in the UK. While the description of life with HIV contained in this framework may seem bleak, we also wish to acknowledge the many people with HIV already have our overall goal met. However, social care services for people with HIV are focused on those who need most, and have least, and these people are our primary concern.

1.2.1 Demographic changes

Of the total population of people currently living with HIV in the UK, over 85% are men infected through sex with other men or African people infected through (heterosexual) sex. Those infected through injecting drug use (IDU) make up about 4% of people with diagnosed HIV and less than 1% have been infected through blood products or vertically during childbirth. Therefore, the UK HIV epidemic disproportionately affects two different socio-demographic groups which are themselves diverse: gay and bisexual men and African migrants. The factors driving HIV incidence are different between the two groups as are the social, cultural and sexual contexts of the lives of individuals in them.

Although, many gay and bisexual men possess significant social and cultural capital, gay identity and homosexual activity remain stigmatised. In addition, HIV disproportionately affects men with greater pre-existing social need and greater social exclusion such as men from lower socio-economic groups, migrants and ethnic minority gay and bisexual men [1]. Many parts of the African migrant population are also marked by a lack of social capital and social exclusion. Their situation is exacerbated by a substantial racism and xenophobia among the UK population and government immigration policy whose primary foci are preventing illegal entry and overstaying, maximising the benefit of immigration to the UK economy and the rigorous enforcement of immigration rules [2].

The social care needs of these two populations vary enormously. The survey of people with HIV conducted to inform this framework (see section 1.4) has found that among gay and bisexual men, psycho-social problems predominate (for example quality of life, mental, emotional and sexual health). However, while psycho-social difficulties are similarly common among African

migrants, they are eclipsed by overwhelming practical difficulties (or survival needs): getting enough money to live on; managing to eat well; lack of adequate housing; and needs around immigration and legal status. Finally, the two groups have different experiences in terms of access to services. The majority of gay and bisexual men with HIV are eligible to receive free NHS treatments and care, statutory social care services and welfare benefits. This is not the case with all African migrants where a precarious legal status often means that free entitlement is in question.

1.2.2 Service delivery

A recent review of voluntary and statutory health and social care services in the UK indicates little or no strategic interagency service planning or coordination [3]. The situation is exacerbated because HIV prevention, social care and treatment funding are often seen to be in competition and that an increase in funding for one might imply a reduction for others. In addition, providers often conflate prevention, treatment and care services and there is a lack of clearly articulated aims and objectives informing services. This situation is compounded by changes to the structure of the NHS. The end of ring-fencing and the devolvement to Primary Care Trusts (PCTs) has meant that we now have little idea of the scale of spending on HIV treatment, care and social support, how it is coordinated and indeed, which services are being prioritised. As a consequence of reduced investment from PCTs (and rising HIV treatment costs) the scale of the HIV voluntary sector has contracted sharply, and this contraction has been largely unplanned. Local Authorities, who have responsibility for the delivery and coordination of social care services to people with HIV, are increasingly 'main-streaming' designated HIV services or teams into generic adult social service. This has contributed to a loss of a vital synergy between clinical, statutory social and voluntary sector services, a loss of a social care presence within NHS settings and an even greater challenge to developing and sustaining coordinated care packages for people with diagnosed HIV.

1.2.3 Government responses

Government plays a central role in the management of HIV in that it drives laws and policies, regulates civil and professional associations and is constrained by its engagement with community organisations and political pressure groups. Government is able to determine the capacity of a country to minimise the harmful social and economic consequences of the epidemic.

The HIV epidemic in the UK has always disproportionately affected marginalised groups whose legal, social and moral status has been contested (gay and bisexual men, sex workers, migrants, injecting drug users *etc.*). Government forms the legal and policy 'environment' within which individuals and community organisations operate and can also influence how members of these groups are treated in society. This can be through passing legislation to increase the rights of marginalised groups, by drafting policy which supports communities and by ensuring all legislation supports public health aims.

The government has taken many steps forward since the *National Strategy for Sexual Health and HIV* [4], which specified aims including improvements in health and social care for people with HIV and reductions of the stigma associated with HIV. The Department of Health's *Action Plan on HIV Related Stigma and Discrimination* [5] and its subsequent web-based implementation action plan [6] articulates many ways in which HIV-related stigma in the UK might be countered.

However, it is limited in a number of ways: although it commits to cross-departmental initiatives to counter stigma, it does not suggest what these might be; it does not attend to the role of other bodies (such as the media, faith groups etc.) in perpetuating stigma; it does not articulate the relationship between HIV-related stigma and pre-existing inequalities; nor does it acknowledge the connection between social inequality and HIV vulnerability.

Although HIV is a government priority, it falls behind a range of other priorities which have a higher political and public profile, such as improving economic efficiency in the NHS. The lack of priority attached to the domestic HIV epidemic has ensured that longer-term strategies to combat HIV remain undeveloped.

At present, in the UK there is no overarching or coordinated approach to promoting the health and well-being of people with diagnosed HIV. Indeed, the current national response to the social needs of this group are undermined by the limited capacity of commissioners and providers of service to articulate and prioritise needs, approaches and methods [3]. These problems are exacerbated because responsibility for representing, advocating for and providing services to this group is divided between the statutory sector (Local Authorities) and the voluntary sector, each of whom have different approaches and different criteria to prioritising needs. Finally, UK government is not united in its response to HIV in that different departments produce policies which sometimes impact negatively on people with HIV and those vulnerable to it. Without the capacity to coordinate services, articulate aims and critique responses, this situation is likely to continue.

A more effective response requires not only a thorough understanding of individual need, but also the ability to influence the social, political and economic contexts within which people with HIV live their lives. In this way, we can address the broader barriers to improving health and well-being. This framework attempts to provide the basis for this response by building on pre-existing initiatives such as the Department of Health's *Action Plan on HIV Related Stigma and Discrimination* [5], its implementation plan [6] and the Department of Health published *African Framework for HIV Prevention and Care* [7].

1.3 THE VALUES, ETHICS AND EVIDENCE INFORMING THE FRAMEWORK

This framework recognises the connection between people's social conditions and their health. In developed countries, people who have less money, are less educated, are unemployed or who live in sub-standard housing have reduced life expectancy and a lower quality of life. The social determinants of health therefore include poverty, housing, education, working conditions, unemployment, social support and diet.

In the UK, the interaction between social determinants of health and HIV is complex. At one level, some HIV infection in the UK can be seen as the result of adverse social conditions. For example, gay and bisexual men are a traditionally disenfranchised groups. Within this group HIV infection is more common among men with less formal qualifications and among those in certain ethnic minority groups [1]. African migrants' living conditions in the UK are likely to be significantly worse than the general population's and having HIV is also likely to adversely affect their social conditions. For the majority of individuals, contracting HIV is likely to adversely affect their capacity to earn, their accommodation and the quality of their life.

The framework is therefore committed to changing social conditions in order to enable individuals and communities to maximise their own health and well-being. Health and well-being is promoted by increasing individual and community power and choice. The *Ottawa Charter* [8] defines the values and ethics underlying our health promotion approach:

“Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being.”

Health promotion action aims to facilitate political, economic, social, cultural, environmental, behavioural and biological conditions favourable to the promotion of health and well-being. It aims to enable people to take control of those things that determine their health by ensuring access to information, life skills and opportunities for making healthy choices. Health promotion requires coordinated action by communities, governments, health and other social and economic sectors, voluntary organisations, local authorities, industry and the media. People in all walks of life are involved as individuals, families and communities. Professional and social groups and health service personnel have a major responsibility to mediate between differing interests in society for the pursuit of health.

Health promotion specifies these five areas for interventions:

- **Building better public policy** - Putting health on the agenda of policy makers in all sectors and at all levels.
- **Creating supportive environments** - Generating living conditions that are safe, stimulating, satisfying and enjoyable.
- **Strengthening community actions** - Strengthening and empowering communities enabling them to set priorities, make decisions, plan and implement strategies to achieve better health.
- **Developing personal skills** - Supporting personal and social development through providing information, education for health, and enhancing life skills.
- **Reorienting health services** - Individuals, community groups, health professionals, health service institutions and governments to work together towards a health care system which contributes to the pursuit of health in addition to merely providing diagnosis and treatment of illness.

Health promotion therefore advocates interventions on all levels: individuals and families; communities (for example community leaders or community groups); social institutions (for example churches or schools); health institutions (for example local hospitals or primary care practices); local government (for example local councillors or service providers) and central

government (for example government departments, MPs and ministers).

Adhering to the principles and values of health promotion requires us to grapple with ethical dilemmas and differences of approach. For example, as many migrants with HIV have uncertain immigration status, the question is begged as to how 'ethical' current government policy is. On one hand, we might conclude that it is detrimental to the well-being of people with HIV. However, others argue that the presence of migrants with HIV drains public resources and that the responsibility of the state is limited to removing them. In embracing the former viewpoint, we are embracing an ethical principle of health promotion (to maximise the capacity of disempowered individuals and communities to promote their own health and well-being). However, in so doing, we are mindful of the fact that we are embracing an ethical position. So, this framework is a product of the ethics and values of those agencies and individuals involved in its development. We are aware that some will disagree with our position, that the framework is unable to represent and advocate for the whole range of positions taken within the field and that the approach we have taken may lead to a degree of tension, conflict and dissent.

The framework has adopted this broadly liberal ethical approach, defining rights in their broadest sense. That is, we include enshrined rights, case law rights (rights through remedy) as well as positive duties (with regard to organisations). However, in emphasising the right of the individual to make informed choice ('you decide') rather than proscribing or prescribing the 'right' course of action ('we decide') we cannot assume that choice is universally available. Questions of individual choice have less importance for those whose basic needs (food, shelter *etc.*) are unmet. Some people with HIV are surviving in the face of substantial difficulties. The first imperative of the framework is to include clear aims about the minimum living requirements of people with diagnosed HIV.

The framework is evidence-based. We consider as evidence any information used for decision making that is systematically and transparently gathered and reported. We have used research evidence in decisions about its strategic goals, the aims and the target groups along with other sources of information. As most of the questions raised by, and directions taken in the framework would benefit from further evidence, this document also outlines a research agenda.

We anticipate that, in time, this framework will be accompanied by another document dealing with interventions. This might include planning tools to enable key stakeholders to target and prioritise methods and approaches, and monitor interventions based within this framework.

1.4 THE PROCESS OF DRAFTING THE FRAMEWORK

There already exist planning frameworks to address HIV prevention among both African people in the UK [2] and gay men, bisexual men and other men that have sex with men [1]. There is also a framework concerned with the standard of HIV clinical care [9] that can be expected by all those with diagnosed HIV in the UK, and regularly updated evidence-based guidelines on anti-retroviral therapy have become the benchmark for clinical practice. However, HIV social care and support remains under-served in terms of strategy and policy. This framework aims to begin to fill this gap by describing an integrated response to HIV social care need.

The needs of people with HIV in the UK vary enormously, both in scale and nature. It is therefore important that this framework originates from a group which is sufficiently diverse and

experienced to represent the variety of needs and perspectives of people with HIV. Its authors come from a range of backgrounds including first and second tier voluntary sector, local government social care personnel and clinical care providers. This group was first convened in April 2007 and met regularly to plan the framework and to discuss emerging drafts over the following 12 months. Individual members gave advice and co-wrote sections particular to their own expertise. In all, the group met five times during the process.

The development of this framework was supported by a large-scale survey of people with HIV in the UK, called *What do you need?* This survey estimated the incidence and severity of need among the population of people with HIV in the UK and described differences in needs within this population. The design and content of the survey underwent a national consultation and was distributed by more than fifty agencies across the UK. More than 1800 people with HIV participated in the survey. The survey assessed need in the following areas:

- Migration / asylum
- Housing
- Eating / diet
- Sleep
- Self-care and housework
- Mobility
- Money and benefits
- Anxiety and depression
- Self-esteem
- Childcare
- Relationships with partners, families and friends.
- Sex and sexual health
- Drugs and alcohol
- Training and skills
- Work
- Discrimination
- Information needs

The full methods and results of the survey are presented elsewhere. However, throughout this framework, we use the survey findings to provide background information.

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2. Basic requirements for health and well-being

The absence of those resources essential to individual health and well-being can compromise an individual's capacity to live well and determine his or her future. These elements include having enough money to live on, enough nutritious food to eat and reasonable accommodation. Adverse socioeconomic conditions, precarious housing, financial difficulties, and food deprivation through lack of money all compromise an individual's capacity to maintain his or her health.

There are other basic requirements without which individuals and groups could be defined as being in poverty. These include access to information and education or the right and capacity to form intimate relationships. In thinking about poverty in this way, it is helpful to draw a distinction between absolute poverty and relative poverty. Absolute poverty is defined by the World Bank as "a condition of life so characterised by malnutrition, illiteracy, and disease as to be beneath any reasonable definition of human decency" [10]. Relative poverty is defined by the United Nations Development Programme as "the lack of ability to live a long, healthy and creative life; to be knowledgeable, and to enjoy a decent standard of living; to enjoy dignity, self-respect, and the respect of others" [11].

The definition of poverty used in this section includes financial poverty as an indicator but also includes other indicators of poverty such as respect and value, access to decent sanitation, basic health care and education, life expectancy, literacy levels, family life *etc.* We must also recognise that human poverty is part of a vicious cycle. It is caused by, and in turn exacerbates, lack of money, education, health *etc.* In terms of this broader definition, the question of poverty can be said to underpin all social need described in this framework.

In this section, we define the following poverty-related needs:

- the need for enough money to live on;
- the need for adequate housing;
- the need for sufficient and acceptable food;
- the need to grow up well and healthily;
- the need for education, training and employment;
- the need for information about living well with HIV; and
- the need for good sexual and reproductive health.

We describe the groups in which these needs are most likely to be unmet and the different impacts that these unmet needs have on life and health. We also define goals and aims around each of these needs.

Goal 1: No person with HIV in the UK lives in financial poverty or destitution.

The financial poverty experienced by people with HIV in the UK varies markedly in terms of degree and nature. Some people with HIV are experiencing extreme financial poverty (mainly African migrants) and have difficulty feeding or housing themselves and their families. This is tending to eclipse the poverty we are more used to describing: that is relative poverty where uncertain health status leads to a reduction in income (experienced by most other people with HIV in the UK). In the short-term, the former group need help with extreme hardship (accommodation, furniture, clothes etc.) while the latter have other needs (which may include training and support to get out of a cycle of benefits dependency or unemployment). It is important that we attend to the poverty-related needs of both groups while resisting the tendency to create a hierarchy of poverty and need. In addition, it is helpful to distinguish between poverty leading to vulnerability to HIV acquisition and poverty as a direct consequence of having HIV.

Because HIV is a disease associated with poverty (and having HIV often makes people poorer), we should expect the population of people with HIV to experience greater levels of absolute and relative poverty than the wider population. However, patterns of poverty among people with diagnosed HIV also mirrors that of the general population. Absolute poverty is experienced more often by migrants, injecting drug users (IDUs) and sex workers with HIV. Women with HIV are likely to be poorer than men with HIV. People with HIV from Black and minority ethnic groups are likely to be worse off than White British people with HIV.

There are also situations commonly associated with HIV that exacerbate poverty in particular ways. For example, undocumented migrants and asylum seekers experience worse relative poverty than others with HIV inasmuch as they have no right to work or welfare benefits. However, variable health means that many people with HIV have an inconsistent employment record, which affects their pension entitlements and capacity to get and pay a mortgage. HIV-related employment discrimination makes it more difficult for people with HIV to gain (or keep) employment, and stigma associated with HIV excludes individuals from family and community networks, cutting off vital sources of economic and practical support.

Replace next paragraph with data from WDYN 2007/8

What Do You Need? (Weatherburn *et al.* 2002) reported that 31% of all respondents had experienced problems getting enough money to live on in the previous 12 months. The most commonly described difficulties centred on the ability to meet household bills, rent (or mortgage) and food. Individuals in all groups reported difficulties and all forms of income (pay, benefits, pensions, vouchers, sick pay, savings, student loans and salaries) were mentioned as insufficient to meet personal needs. A similar proportion (28%) reported feeling unhappy about their personal income. This unhappiness concerned debt, exclusion from financial services (mortgages, loans, insurance, pensions *etc.*) and with the administration of welfare benefits (delays, administrative mistakes, insensitivity and bureaucracy). Project Nasah (Weatherburn *et al.* 2003) reported that 77% of African people with HIV reported difficulties getting enough money to live on. Lack of money for basic survival needs was the most commonly reported problem among Africans with HIV and clearly exacerbated the majority of other needs.

These findings are supported by broader experiences within the HIV social care field. Crusaid's most recent report [12] on their hardship fund notes how they are being increasingly approached by people with survival needs (food etc.) and are witnessing extreme poverty among certain groups of people with HIV. Individuals with no income from work or benefits whatsoever now form the majority of applicants to Crusaid hardship funds (54% of applicants were in the asylum process with 6% having uncertain residency).

1. FINANCIAL POVERTY AIMS

- 1.1 No person with HIV in the UK (or their dependents) lives in absolute financial poverty or destitution.
- 1.2 An HIV diagnosis is never the cause of an individual (or their dependents) entering a state of financial poverty.
- 1.3 All people with HIV are able to develop the capacity to end their state of financial poverty and enhance their personal wealth.
- 1.4 Communities have the capacity and the motivation to counter HIV-related financial poverty.
- 1.5 All statutory education, health, social, custodial and legal services have the capacity and the motivation to counter HIV-related financial poverty.
- 1.6 All voluntary and community sector (VCS) services and charities have the capacity and the motivation to counter HIV-related financial poverty.
- 1.7 Central government policy and practice does not promote or exacerbate HIV-related financial poverty and should seek to end it.
- 1.8 Local government policy and practice does not promote or exacerbate HIV-related financial poverty and should seek to end it.

Goal 2: No person with HIV in the UK (or their dependents) lives in sub-standard accommodation.

Replace next paragraph with data from WDYN 2007

What Do You Need? (Weatherburn *et al.* 2002) reported that 18% of all respondents felt unhappy about their current housing or living conditions, 21% had experienced housing problems in the previous 12 months (including 4% who had experienced homelessness) and 16% had ongoing housing problems. The majority who reported housing problems described accommodation that was unsuitable because of damp, disrepair, inadequate heating, lack of equipment and problems with access or bath and toilet facilities. The immediate environment could also be debilitating, because of harassment and violence from neighbours and / or noise and vandalism. Difficulty meeting rent and mortgage payments, and problems finding adequate and affordable accommodation emerged as a significant issue affecting housing stability. The same research suggests that housing need is related to many other social care needs including eating and drinking, sleeping, self-care, mobility, financial security, anxiety and depression, self-confidence, job opportunities, caring for children and developing and maintaining relationships.

Project Nasah (Weatherburn *et al.* 2003) revealed far greater housing-related need among Black Africans in the UK. They were seven times more likely to report problems with housing and living conditions than the White British respondents. These findings reflect a general tendency in the

social rented sector with over-crowding and sub-standard accommodation significantly more common among Black and ethnic minority tenants than among white tenants [13].

Services to meet housing-related need of vulnerable groups are organised within the *Supporting People* framework, a Department for Communities and Local Government (DCLG) initiative administered through Local Authorities in partnership with PCTs, service providers and support agencies [14]. *Supporting People* aims to enable vulnerable people to live independently in decent and affordable accommodation (including owner-occupied and privately rented) through a flexible and client-centred service model. This approach is based on pre-emptive and ongoing support rather than crisis intervention. It concentrates both on the provision of housing and 'housing-related support' to help individuals and families to maintain their accommodation and increase independent living skills.

People with HIV are identified as one of eight target populations for *Supporting People* initiatives. The development of a 'floating support' service model is seen to be appropriate to meeting the needs of people with HIV (having the capacity to respond to need that varies over time and being able to identify periods of crisis and offer specific crisis intervention support). However, this concentration on individual needs does not tackle broader structural factors. First, there is little support for Local Authorities to identify and respond appropriately to the needs of their local populations. Second, *Supporting People* does not deal with the lack of decent housing stock and the fact that sub-standard housing is often assigned to asylum-seekers by arms-length social landlords. Importantly, there are no minimum standards or guidelines for public and private landlords around housing for people with HIV.

2. HOUSING AIMS

- 2.1 No person with HIV lives in accommodation that is not compliant with the standards set out in the Department for Communities and Local Government's Decent Homes Standards for 2010.
- 2.2 All people with HIV are empowered to represent themselves and take action as regards sub-standard housing.
- 2.3 All people with HIV have access to information, advice, support and advocacy around housing need.
- 2.4 All health and social care service providers are:
 - (a) aware of the impact that poor housing has on the health and adherence of people with diagnosed HIV in their care, and have the capacity to refer with regard to housing and accommodation needs.
- 2.5 All Local Authorities ensure that:
 - (a) current standards for directly managed and arms-length housing attends fully to the needs of people with HIV,
 - (b) that these are set into service level agreements, and
 - (c) that all contractors comply fully with these guidelines.
- 2.6 Police take seriously HIV-related hate crime within public and private housing.

Goal 3: All people with HIV have access to sufficient nutrition to maintain, as far as possible, an active and healthy life.

For people with HIV, access to sufficient and acceptable food is essential for protecting personal health and well-being, coping with illness and managing treatment regimens and their side effects. Food also fulfils important social and cultural functions. The ability to eat well, to prepare and enjoy food, to eat communally or as a family, and to eat traditional or culturally appropriate food is important. As well as having access to appropriate food, people with HIV also need the resources to store, prepare and consume food safely.

Malnutrition leads to immune function decline, making the body more vulnerable to infection. People with HIV who are asymptomatic require more energy than people who do not have HIV. This need for extra energy increases further during periods of illness and recuperation from illness. A high viral load, associated with a decline in immune function, will also significantly increase macro- and micro-nutrient needs. Children living with HIV face the same nutritional issues as adults but have to meet the added demands of growth and development. Failure to meet these needs can lead to growth stunting, failure to thrive, impaired cognitive development and wasting.

The nutritional needs of people with HIV tend to be most acute during periods of ill health. As personal energy needs increase, the individual's ability to meet these needs often decreases. The problems that illness brings, such as appetite loss, nausea, diarrhoea and eating difficulties, may reduce both the amount of food being taken into the body and the body's ability to absorb nutrients. In these circumstances, weight loss is a likely result. Weight loss is dangerous because it reduces the body's ability to fight off infections and recover. Nutritional support is crucial to prevent a vicious circle of decline where weight loss leads to vulnerability to infection, further illness and more serious physical deterioration. As people lose their strength and mobility, so they lose their ability to purchase, prepare and consume food, compounding this pattern of decline. Weight loss can also be caused, or exacerbated, by psychological problems or by lack of money to buy food.

Nutritional needs are often complicated by the demands of anti-HIV treatment regimens. These may include constraints on what can be eaten, if there is a risk of interaction with the medication, and on when food can be eaten: some medications must be taken at the same time as food, others at intervals before or after eating. Care may also be needed to eat or avoid certain foods to ensure that the medication is absorbed into the body. Treatment side effects can also have a significant impact on nutritional needs. Vomiting, diarrhoea, appetite loss and difficulties eating can lead to dangerous weight loss in the same manner as illnesses from other infections. Other side effects which impact on eating and nutritional needs include bloating, lean tissue wasting and lipodystrophy. Lipodystrophy does not always result in weight change but can seriously affect both health and body image.

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Among the majority of UK-born people with HIV, lack of money is less of a problem than a lack of capacity to shop for, prepare and eat food. *What Do You Need* (2002) reported that 18% felt unhappy about their appetite and ability to eat and drink, 42% had experienced problems with

their appetite or ability to eat and drink in the previous 12 months and 24% had ongoing problems with their appetite or ability to eat and drink. Respondents described problems with appetite, taste, nausea, vomiting, bloating, constipation and mouth and throat problems such as thrush, sore gums and inability to swallow. Such problems are far more common for African people. Three quarters (77%) of respondents to *Project Nasah* study reported that they had difficulty getting enough money to live on, ten times the rate reported by White British people with HIV. People who do not have enough money to live on are unlikely to benefit from the well-balanced diet recommended for people living with HIV. Poverty forces choices between basic needs and, although food is too basic to forego altogether, the standard of an individual's personal nutrition is likely to drop when other demands press upon them.

Anyone who is living on welfare benefits may feel that their food choices are at times too limited, especially during periods of illness when nutritional needs intensify. People who are denied welfare benefits, such as refused asylum seekers, face a real risk of malnutrition. These people need the support of a wider range of professionals and services to ensure core nutritional needs are met, particularly social care and housing services. Clinical professionals who identify social and economic barriers to meeting nutritional needs must ensure that these barriers and needs are communicated to professionals who can address them effectively.

Those with the money and security to manage their diet appropriately need information and advice about nutrition to maintain their health, cope with illness and optimise their treatment-taking.

3. NUTRITIONAL AIMS

- 3.1 All people with HIV have the knowledge, understanding and resources to eat adequately in order to maximise their health and immune function; cope with illness and disability; and optimise their treatments.
- 3.2 All people with HIV have the opportunity and resources to meet their nutritional needs in a manner that is consistent, as far as possible, with their personal and cultural food preferences.
- 3.3 All health and social care providers are aware of the nutritional needs of people with HIV and the impact that poor nutrition can have on their health and well-being.
- 3.4 All health and social care providers understand the social and cultural issues that shape individual food choices.
- 3.5 All health and social care providers have the capacity to meet the nutritional needs of people with HIV, including psycho-social and economic needs.

Goal 4: All children with HIV can grow up in security.

For the purposes of this document, we define children as those who are under 18 years of age. In 2007 there were 972 children under 15 years living with HIV and seen for care. The majority (82%) of these children acquired their infection from their mother, and the majority of these mothers were African.

The UN Convention on the Rights of the Child [16] sets out the basic rights of children and stipulates that the best interests of the child must be the primary consideration, that children's survival and development must be ensured, and that children have the right to participate in decisions that affect them. The government policy, *Every Child Matters* [17] gives outcomes for children that include being healthy, staying safe, enjoying and achieving, making a positive contribution and achieving economic well-being. The health outcome specifies that children should be physically, mentally, emotionally and sexually healthy. However there are no HIV-related outcome indicators established.

The *Children Act 2004* [18] provides a framework for children's services in England and Wales. All relevant bodies must ensure that their functions are discharged with regard to the need to promote children's welfare. It also establishes Children's Commissioners for England, Northern Ireland, Scotland and Wales, who are responsible for raising awareness of the interests of children. Similar provisions are made under the *Children (Scotland) Act 1995* and the *Children (Northern Ireland) Order 1995*.

The *National Service Framework for Children, Young People and Maternity Services* [19] sets out objectives for disabled children and young people (including those with complex health needs such as HIV) which include that they receive "coordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and where possible, which enable them and their families to live ordinary lives".

There is a children focussed sub-section of the British HIV Association called the Children's HIV Association of UK and Ireland (CHIVA). It has published a range of protocols and guidelines, including those transitional services for young people with HIV. [www.chiva.org.uk/publications/PDF/2007/transition.pdf] CHIVA have also collaborated with the National Children's Bureau on good practice guidelines for schools on supporting children with HIV and those affected by it.

For children, HIV often brings with it a range of other social and emotional problems. The majority come from families where siblings and / or parents are also infected. Such children are likely to have to deal with bereavements or lack of parental or sibling support. In addition, they may find themselves having to become the main carer of a sick family member. These problems are often coupled with others such as uncertain immigration status, problems with housing and / or financial difficulties. These all constitute significant negative impacts on well-being. In addition, the process of growing up with HIV presents further specific challenges.

Living with HIV can place enormous strain on the emotional and mental health of children and adolescents. This manifests itself in emotional and conduct disorders in younger children and self-reported anxiety and depression among older children and adolescents. These difficulties are

usually connected with coping stresses rather than psychological disorders. Such stresses consist of conflicts within the family, difficulties at school, problems around disclosure and the management of information, concerns about personal appearance *etc.* Among older adolescents, these difficulties more often centre on managing intimate or sexual relationships. Children and their parents or guardians are likely to need significant psychological support in the management of disclosure, dealing with the stigma and secrecy surrounding HIV, developing intimate relationships and socially supportive networks. Furthermore, this group are likely to be reluctant to engage with services apart from those with specialist knowledge of HIV.

Schooling of children with HIV merits special consideration. Fear of stigma and discrimination at school can lead some parents not to disclose their child's HIV infection. As HIV is not a notifiable condition, there is no requirement to do so but non-disclosure can cause problems. The child may not be treated as having any medical needs, even when hospital appointments and illnesses demand frequent school absences and support with taking treatments and dealing with illnesses is required. School trips become difficult where treatments have to be hidden. As more young people with HIV reach school-leaving age, guidance on further education and employment is needed which takes into account managing health, disclosure and benefit entitlements *etc.*

The *Special Educational Needs and Disability Act 2001* [20] amended the *Disability Discrimination Act* [21] to make it unlawful to discriminate against disabled pupils in any aspect of school life (admissions, education and associated services). The *Code of Practice for Schools* [22] gives practical guidance on how to avoid discrimination against disabled pupils during their time in school, and describes the duties of the bodies responsible for this provision. In addition, the *National Healthy School Standard* [23] stresses the importance of investing in health to raise pupil achievement and improve standards. Ideally, schools play an integral role in the care and support network for the child with regular contact between school, parent, social and health services. HIV should be explicitly included in a list of medical conditions informing the various school policies (bullying, confidentiality, management of medicines, sharing information with health and social care colleagues *etc.*). These policies should be clearly communicated to all parents and supported by basic staff awareness about HIV transmission and HIV-related stigma. All schools should also consider reintegration plans for children who spend periods of time in hospital. In addition, as HIV is sexually transmitted, sex and relationships education (SRE) should educate children about prevention without stigmatising children infected or affected.

Improved diagnosis and treatment interventions have led to rises in the median age of the paediatric HIV infected population and increasing numbers of children with HIV infection are surviving into adolescence. This presents some unique challenges to those services hitherto delivered within family clinics. Adult services traditionally delivered within the ambit of sexual health need to develop specialisms to respond to the different needs of adolescents with HIV. In the UK, the majority of children with diagnosed HIV are African. As this population comes from a range of cultural backgrounds and as many are the children of migrants, questions of identity and cultural belonging are likely to be uppermost when considering social care and social support services. Transitional services are needed which take account of similarities and differences and learn from policies and service models developed in other chronic illnesses.

Finally, despite improved treatments HIV continues to impact through adolescence and adult life (including ambulatory and cognitive impairments, increased risk of lymphoma *etc.*). Knowledge

and expertise is needed in treating HIV in individuals going through puberty and reaching physical maturity (for example life-long chronic effects of HIV and treatments on developing and immature systems).

4. CHILD-CENTRED AIMS

- 4.1 All children with HIV are supported to achieve optimal health and well-being.
- 4.2 No child faces discrimination or reduced life opportunities because they have HIV.
- 4.3 All communities have the capacity to care for their children with HIV.
- 4.4 The welfare of children remains the paramount concern of all government policy and practice which impacts on, or concerns children and young people with HIV (including legislation and policy pertaining to child welfare, immigration, education, youth justice and poverty).
- 4.5 All clinical HIV services can offer or refer to appropriate paediatric services.
- 4.6 All clinical HIV services have transitional services in place.
- 4.7 All statutory health and social care providers can meet the needs of children and young people with HIV.
- 4.8 All voluntary and community HIV organisations have the capacity to meet the needs of children and young people with HIV and / or to make referrals to other services.
- 4.9 All voluntary and community children's agencies have the capacity to meet the needs of children and young people with HIV and / or to make referrals to other services.
- 4.10 All clinical mental health services have the capacity to meet the needs of children and young people with HIV and / or to make referrals to other services.
- 4.11 All voluntary and community mental health services have the capacity to meet the needs of children and young people with HIV or can refer appropriately.
- 4.12 All schools and educational settings have policies in place which are appropriate to children or young people with HIV and which include policies on confidentiality, management of medicines, pastoral support and reintegration after absences and sex and relationships education.
- 4.13 All schools and educational settings can access HIV awareness training for staff.

Goal 5: All people with HIV have access to employment, education and training.

Training is not simply a route to employment, and employment is not simply a route to financial security. The reasons that people seek employment and training are diverse, reflecting not only their material circumstances but also their priorities in life, interests and values. Some people feel an obligation to work and to contribute to society but others are happy not to work if they can support themselves in other ways. Some people see a career as a means to personal fulfilment whereas others would rather find this fulfilment elsewhere. Employment can give structure and purpose to life, enable social contact and build self-confidence but it can also become a burden and a cause of anxiety and ill-health.

Finding a job is never easy but for many people with HIV there are extra obstacles to overcome

when seeking employment. Anxieties about discrimination and mistreatment in the workplace are common. Many people with HIV experience periods of fatigue or general poor health (which can be managed in the work-place with a supportive and understanding employer). Those who choose not to disclose their HIV status, for fear of discrimination, are unlikely to enjoy this support. A return to work also risks increasing personal stress and so increases the likelihood of more serious health problems.

People with HIV who have not been employed for some time may find it difficult to account for gaps on their CVs. They may feel a loss of skills and confidence and so be wary of the challenges both of recruitment procedures and of working life itself. They may be worried about giving up the security of welfare benefits when success in employment is far from guaranteed. Many people with HIV choose to undertake voluntary work before seeking paid employment to address some of these problems but this also requires a supportive organisation.

A similar range of concerns affect attitudes and access to training and education: the potential impact on personal health and well-being, the risk of encountering discrimination or harassment, and personal ability to cope with new pressures. Many people with HIV seek flexibility and support from education providers in order that they can cope with these new pressures while also managing the wider issues they face in their daily lives, including treatment-taking, fatigue, poor health and child care.

Replace next paragraph with data from WDYN 2007

What Do You Need (Weatherburn *et al.* 2002) described the needs related to employment and training of people living with HIV in the UK. Of the 1,821 people with HIV taking part, 60% were not in paid employment, 27% felt unhappy about their opportunities in the job market and 39% were interested in learning new skills or retraining. Of those who identified specific training interests, 64% wanted to improve their computing and IT skills. Others identified languages (10%), management and business administration (5%), complementary therapies (5%), counselling (4%) and art and design (4%). Respondents also described their reasons for seeking training. Many wanted to get work or improve their opportunities in the job market: improving their income, getting off benefits and realising personal ambitions. But most described their motivation to learn as a desire to make the most of life and fulfil their personal potential. Some wanted to overcome boredom and dissatisfaction but others were more positive and emphasised the many benefits of learning.

The law does offer protection against workplace discrimination and harassment. The *Disability Discrimination Act* [21] now protects all people with HIV from discrimination in recruitment procedures, employment terms and conditions and chances for promotion and training. Unfair dismissal or unfavourable treatment is also against the law, confidentiality is protected and employers are expected to make 'reasonable adjustments' to enable people with disability or chronic illness to fully contribute.

The practical impact of the Disability Discrimination Act on people with HIV in employment is complex. It has been used successfully by people with HIV to fight unfair dismissal but such formal appeals to the law are uncommon. The greater impact of the legislation is to make employers review their procedures and improve their practice, sometimes with the encouragement of staff with diagnosed HIV. However people with HIV who do not have

confidence in their employers' willingness to take the law seriously may not disclose and consequently may not benefit from the 'reasonable adjustments' required by the law. Appealing to the law is not an easy option when you feel vulnerable.

The discrimination faced by people with HIV arises not just from their infection with a highly stigmatised disease but from the stigma sometimes linked to ethnicity and migration, and to sex, (homo)sexuality and other behaviours such as injecting drug use. It also relates to fear of infection and of terminal disease. Although all discrimination against people with HIV in the workplace is illegal, regardless of the trigger, this unusually broad context of discrimination complicates matters. Anxieties among people with HIV about discrimination in the workplace will remain if employers see their duties to the Disability Discrimination Act purely in terms of coping with physical impairment. Other anti-discriminatory legislation offers protection against racism, homophobia and sexism but the unusual convergence of these issues in HIV-related discrimination is not perfectly matched to the current legislation.

The Disability Discrimination Act affects colleges in their role as employers but not as providers of a service. However, public sector colleges are bound by the Disability Equality Duty which does concern the service provided to students and requires public bodies to have due regard for eliminating discrimination that is illegal under the Disability Discrimination Act and promoting positive attitudes to disabled people.

The UK government's denial of asylum-seekers' right to work has a major impact on the income, security, well-being and confidence of those affected. It adds to the disempowerment created by the dependent relationship with the Home Office: waiting in hope but often with little information about the progress of a claim. Reform of this policy would have an immediate impact on the poverty and exclusion of some of the most marginalised individuals living with HIV in the UK today.

5. EMPLOYMENT, EDUCATION AND TRAINING AIMS

- 5.1 All people with HIV have the same opportunities as other members of society to pursue education and employment.
- 5.2 All people with HIV are able to work and learn in environments free from discrimination and harassment of all kinds.
- 5.3 All people with HIV are able to pursue employment and education without fear of dismissal or exclusion because of problems relating to treatment-taking, fatigue and ill-health.
- 5.4 All people with HIV are able to disclose their HIV status to employers (and tutors) in the knowledge that their confidentiality will be protected and their needs respected.
- 5.5 All employers and education providers have a full understanding of anti-discrimination law as it relates to people with HIV, reflected in clearly defined corporate policy and practice to protect and support employees with HIV, including those who choose not to disclose their HIV status.
- 5.6 All employers and education providers have an understanding of, and respect for, the diverse needs of people with HIV and the particular challenges they face in sustaining employment and education. This should include an appreciation of the forms of discrimination, including social stigmatisation, which are not the primary concern of disability discrimination law.

- 5.7 All people with HIV have access to advice and information about careers, returning to work and opportunities for training and education.
- 5.8 All people with HIV have access to training opportunities to improve confidence and skills in seeking and applying for work.
- 5.9 All people with HIV have access to local, low-cost training and education opportunities which offer choice and flexibility in their terms of engagement and provide support for personal needs, including childcare.
- 5.10 All people with HIV have access to advice and information about the law and personal rights in the workplace and in education.
- 5.11 All people with HIV have access to support and advocacy in dealing with discrimination and promoting good practice.

Goal 6: All people with HIV have the information they need to make choices around their treatments, health and quality of life.

A diagnosis of HIV brings immediate information needs ranging from clinical questions about disease progression and treatments to psychosocial questions about transmission, discrimination and service provision. The extent of these needs varies: some people have a thirst for knowledge, others do not. Once initial questions have been answered, the ongoing extent of information need depends not only on personal circumstances but also on personal attitudes to HIV and living with the disease. Information needs are never satisfied once and for all. Although some people are happy to get on with life with relatively little information, everyone has new questions when their life circumstances change.

Key triggers of need may include deterioration in health, starting anti-HIV treatment, changes in personal and family relationships or employment status, travel, changes in immigration status *etc.* However, there are times when the need for information can be acute. For example, impoverishment, homelessness, failing health, treatment side effects and bereavement can raise urgent questions about what to do and where to seek support. The types of information needed by people with HIV varies widely and include topics such as the clinical impact of HIV, staying well and coping with illness, treatments and treatment-taking, services and benefits, peer support, the law, employment and training, immigration and asylum, sex and sexual transmission, pregnancy and child-bearing *etc.*

Many people with HIV face substantial problems in getting access to the information they need. The greatest difficulties are faced by people whose isolation is perpetuated by lack of contact with services and information providers. The most marginalised people with HIV are usually the least able to gain information. Poverty, discrimination, refusal of asylum, family rejection, ill health and disability can all contribute to this isolation, as can a sense of lack of entitlement to support. More immediate obstacles to meeting information needs include language barriers, disability (especially hearing, sight and speech disabilities), difficulties with reading and lack of confidence in dealing with professionals.

People with HIV gain information from a wide range of sources, including written resources (newsletters, leaflets, the internet) and talking with doctors and other health professionals, family, friends and other people living with, or affected by, HIV. A range of interventions are required to meet the full range of HIV information needs. However the value of this diversity in provision is only maximised if individuals are aware of what is available to them. Good signposting and referral across the sector is required to achieve this. Lots of information can be overwhelming; what matters is that individuals are able to identify and access the information that is most appropriate for their needs.

INSERT NEW paragraph with data from WDYN 2007 (not a need in WDYN 2002)

6. INFORMATION AIMS

- 6.1 All people with HIV have access to high quality accurate, up to date information about the full range of issues raised by living with HIV, in formats suitable to their own literacy and needs.
- 6.2 All people with HIV have opportunities to resolve their doubts and uncertainties about living with the condition through one-to-one communication with both professionals and other people living with HIV.
- 6.3 Communities affected by HIV have a shared understanding and appreciation of the impact and effects of HIV through community-based information and education.
- 6.4 Voluntary and community HIV organisations has the capacity to respond to the information needs of people living with and affected by HIV.
- 6.5 All providers and professionals can listen and respond to the concerns of their clients.
- 6.6 The role of people with HIV as providers of information and insight is fully valued.

Goal 7: All people with HIV have the highest attainable standard of health in relation to sexuality, including access to sexual and reproductive health care services.

This framework supports the definitions of sexual health and sexual rights specified by the World Health Organisation [24].

“Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.”

Sexual rights embrace human rights that are already recognised in national laws, international human rights documents and other consensus documents. These include the right of all persons,

free of coercion, discrimination and violence, to:

- the highest attainable standard of health in relation to sexuality, including access to sexual and reproductive health care services;
- seek, receive and impart information in relation to sexuality;
- sexuality education;
- respect for bodily integrity;
- choice of partner;
- decide to be sexually active or not;
- consensual sexual relations;
- consensual marriage;
- decide whether or not, and when to have children; and
- pursue a satisfying, safe and pleasurable sexual life.

There are many ways in which HIV impacts on sexuality and reproduction, and the management of the sexual and reproductive health of people with HIV poses many challenges to the NHS [25]. Symptoms and treatment side-effects as well as fear of transmitting HIV can all affect libido and sexual self-confidence. Men with HIV are more likely to report erectile dysfunction (ED) and retarded ejaculation (probably due to a mixture of physical symptoms, treatment side-effects and psycho-social factors). Drug treatment for erectile dysfunction is inhibited because treatments are contra-indicated with protease inhibitors. Women with HIV experience higher levels of Female Sexual Dysfunction (FSD) than other women. FSD is often attributed to psycho-social factors (changes to body, self-esteem, fear of disclosure and sexual or vertical transmission) but much less is known about the effects of HIV disease and treatments on women's sexual functioning and FSD among women with HIV often goes unreported and untreated.

Managing disclosure of HIV to sexual partners and responding to the risk of sexual transmission are among the most important factors governing the capacity for a fulfilled sexual life for people with HIV. An ability to deal effectively with these issues is generally developed over time. However, interventions are needed on a range of levels. There is a need for information about basic sexual transmission risk as well as interventions to support individuals in making choices around disclosure and sexual risk. Interventions to reduce the stigma associated with HIV are likely to have a beneficial effect in this area. Finally, interventions to minimize the harmful effects of recent policy developments (such as criminal prosecutions for sexual transmission of the virus) are essential.

Cervical cancer and the pre-invasive lesions are significantly more likely in HIV infected women and develop faster in immune-compromised women and frequent cervical cytology and HPV screening is recommended for women with HIV [25]. The presence of HPV may also be indicative of anal cancer. Rates of cancerous and pre-cancerous anal cell changes are higher in individuals with HIV than the rest of the population. Although it is important to acknowledge that anal cancer is a real health concern for people with HIV, the condition remains relatively rare. There are currently no data supporting the use of preventative HPV vaccines in HIV-positive individuals but studies are currently underway.

Many people with HIV have unprotected sex with other HIV-positive individuals. Accurate information is needed about the likely health consequences of such behaviour. The latest

research suggests that HIV super-infection is rare. At present approximately 30 cases have been reported worldwide, the majority of which appear in individuals who acquired their initial HIV infection within the last three years (but cases of super-infection in patients with chronic HIV have recently been reported). No cases of super-infection involving patients taking virologically effective anti-retroviral therapy have been reported and the clinical significance of super-infection remains unclear.

The presence of other STIs increases viral load, suppresses immune functioning and facilitates sexual transmission of HIV to others [25] and both hepatitis and the drugs used to treat it affect the efficacy of anti-HIV drugs dependent on liver metabolism. STI prevention, screening, identification and prompt treatment are important for people with HIV.

The growing population of young people with HIV reaching sexual maturity bring a range of challenges. Accurate information is needed regarding sexual health, STIs, contraception and reproduction for young people with HIV. In addition, young people need access to condoms and other contraceptives. Support and advice are also important. Social care services need to be aware of the unique challenges and dilemmas facing adolescents with HIV. Having HIV complicates what is already a confusing time. Possibly the most difficult aspects include initiating a first sexual relationship. There is a need for a safe environment where adolescents can discuss a range of sensitive issues, and receive accurate information and support. Staff of clinical and social care services must be equipped and ready to talk about these issues when necessary. In addition, parents and families might need support in this period. Young people on anti-HIV treatments may need additional support to cover issues such as body image and self-confidence.

Replace next paragraph with data from WDYN 2007

40% of all respondents to the *What Do You Need?* survey (Weatherburn *et al.* 2002) felt unhappy about their sex lives with half of the entire sample reporting problems with sex in the previous 12 months. The most frequent problems were having little or no sex, loss of libido or interest in sex, erectile dysfunction and problems relating to illness, treatments and anxiety (worries about passing on HIV and disclosing HIV status to partners predominated along with problems with self-image).

7. SEXUAL HEALTH AIMS

- 7.1 All people with HIV can pursue a satisfying, safe and pleasurable sexual life.
- 7.2 All people with HIV have the capacity to deal with dilemmas and issues concerning disclosure and transmission during sex.
- 7.3 All people with HIV can have a consensual sexual life without fear of prosecution.
- 7.4 All people with HIV have free access to the full range of clinical sexual health services for treating and managing their HIV infection, and these services are administered according to nationally agreed guidelines (from the British HIV Association and the British Association for Sexual Health and HIV).
- 7.5 All people with HIV have access to a range of other medical interventions including the diagnosis of sexually transmitted infections, vaccinations (such as Hepatitis A and B) and other medical technologies to increase their confidence, capacity and enjoyment regarding sex and reproduction.
- 7.6 All people with HIV have access to a range of information and advice interventions,

- including written and talking interventions, to increase their confidence, capacity and enjoyment regarding sex and reproduction.
- 7.7 All people with HIV have access to free high quality counselling and support to ensure good sexual and reproductive health.
 - 7.8 All people with HIV have access to free information and treatments for sexual dysfunction.
 - 7.9 All people with HIV have access to free information about the effects of super-infection, drug-resistant infection, infection with STIs and hepatitis, including how to avoid these infections, where and how to test for them, how to identify symptoms and the range of treatments available.

Goal 8: All people with HIV can decide whether or not, and when, to have children.

For some people, having children is integral to their social identity and sense of self. As people with HIV live longer and healthier lives, the capacity for parenting increases along with the desire to have children. In attending to reproduction, this framework supports reproductive rights as defined by the World Health Organisation and the United Nations Population Fund [26].

Reproductive rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. They also include the right of all to make decisions concerning reproduction free of discrimination, coercion and violence.

There are a range of factors which complicate reproduction and possibly impede reproductive rights for people with diagnosed HIV. The need to avoid sexual transmission within sero-discordant couples and to avoid transmission to the child is likely to have a significant impact on the reproductive capacity and decisions of people with HIV. In addition, there is evidence to indicate that advanced HIV disease decreases fertility in both women and men. There are also a range of psycho-social factors attending reproduction, pregnancy and parenting for people with HIV. For example, fears for their future health are likely to be a factor for people considering parenthood.

Prior to attempts at conception information and support is needed which is appropriate to the HIV sero-status of both parents. These should enable parents to weigh-up the risks associated with conception and pregnancy and consider factors such as sexual and vertical transmission risks, the effects of pregnancy and parenthood on long-term health, the use of anti-retrovirals during pregnancy, and the capacity to parent in the presence of HIV. In order to reduce the risk of sexual transmission during conception, sero-discordant couples should have access to the full range of information (such as the likelihood of transmission), support for their chosen risk-reduction strategies (for example, timed intercourse, self-insemination), and access to all the medical technologies (such as sperm washing) currently available. To reduce the likelihood of vertical transmission, women need access to information and support, treatments, clinical procedures (such as caesarean birth) and feeding / care guidance after giving birth. Couples

experiencing difficulties with conception need fertility evaluation and access to the full range of assisted reproduction technologies (super-ovulation, IVF *etc.*).

Ante-natal services usually have the capacity to deal with the range of issues raised by a pregnant woman with diagnosed HIV, including termination, HIV treatments, birthing methods, capacity to care, partner testing, avoidance of breast-feeding *etc.* However, there is a need to attend to the needs of fathers in this respect. Also, the reproductive desires of gay men with diagnosed HIV remain little known and not catered for within clinical environments.

For HIV positive heterosexual couples the risk of conception need to be balanced with risk of HIV transmission. HIV treatments affect the efficacy of some contraceptives and hence the range of contraceptive methods available. HIV provision in family planning and termination settings probably lags behind that of ante-natal provision. This may lead to inappropriate provision of services to people with HIV requiring contraception. All individuals with HIV should have access to information on all available methods of contraception (including any contra-indications with HIV treatments both in terms of health risks and reductions of efficacy). Where efficacy is reduced, information on dual contraceptive methods is especially important. As HIV treatments affect the choice and dosage of emergency contraceptives, women need access to sufficient information at the right time. Finally, all information and support should be sensitive to cultural difference and religious beliefs.

8. REPRODUCTIVE HEALTH AIMS

- 8.1 All people with HIV and their partners have the capacity to make informed choices about transmission and contraceptive risk and the skills to minimise these risks while pursuing a fulfilling sex life.
- 8.2 All services providing STI, reproductive, contraceptive and termination services are able to respond to the sexual health and reproduction needs of people with HIV.
- 8.3 All people with HIV wishing to conceive are able to access a full range of information, advice, strategies and technologies around conception including: pre-conception counseling on sexual and vertical transmission risks, risk reduction strategies and technologies, long-term health and the effects of anti-retro-virals on the foetus, reduced fertility, fertility evaluation *etc.*
- 8.4 All people with HIV having difficulty conceiving have free access to the full range of assisted reproduction technologies appropriate to their needs and delivered according to nationally agreed guidelines (BHIVA & BASHH).
- 8.5 All people with HIV have free access to contraception and termination services appropriate to their needs, delivered according to nationally agreed guidelines (from the British HIV Association and the British Association for Sexual Health and HIV).
- 8.6 All people with HIV have free access to antenatal, neonatal and birthing care appropriate to their needs.

3. Health and social care services

Our Welfare State is based on the tenet that health care and social care be available free to all eligible people in the UK. The government has recently announced its intention to ensure that health and social care services are tailored and responsive to the needs of the individual. Although specialist health services are configured to meet the needs of people with HIV, with a set of standards against which performance may be audited, this is not the case for social care.

Local Authorities are supported in their provision of social care for people with HIV by the AIDS Support Grant (ASG) which in 2007/8 totaled £19.8 million, approximately £350 per person living with HIV and in touch with services. As well as direct social care to people with HIV, this grant is also intended for services to people affected by HIV, such as partners, children and carers of people with HIV, as well as the cost of undertaking needs assessments, strategic planning and HIV training for local authority staff. The size of the ASG is determined centrally and local authorities are automatically eligible for it.

In 2008/9 the Department of Health introduced an additional £3.1 million for the provision of housing for people with HIV and other capital expenditure. This is called the HIV Capital Grant and local authorities must bid for it. Other funds that HIV social care providers may be able to draw on including Supporting People Grants (administered by the Department of Communities and Local Government) and the Promoting Independence Grants (administered by the Department of Health and having similar aims and objectives as the earlier Prevention and Partnership Grants).

Goal 9: Social care services are appropriate to the needs of people with HIV.

Definitions of 'social care' are shaped by historic institutional responsibilities rather than by the reality of individual needs. They tend to be lists of services. The following definition is from the website of the Department of Communities and Local Government [27].

The term 'social care' covers a wide range of services, which are provided by local authorities and the independent sector. Social care comes in many forms, such as care at home, in day-centres or by way of residential or nursing homes. The term also covers services such as providing meals on wheels to the elderly, home help for people with disabilities and fostering services.

The Commission for Social Care Inspection [28], the government body that checks the quality of both public and private social care providers, uses a similarly vague definition.

The term social care covers a huge variety of services. These range from care homes and meals on wheels to drop-in centres for disabled people. There are many different types of social care services available.

Government policy in this area is driven by the priorities in the 2006 white paper *Our health, our care, our say: a new direction for community services* [29]. This document's vision for social care is "high-quality support meeting people's aspirations for independence and greater control over

their lives, making services flexible and responsive to individual need". It includes a promise of more support for people with long-term needs who "will be supported to manage their conditions themselves with the right help from health and social care services".

Although this policy has led to greater investment in Expert Patient Programmes, there is little evidence that people with HIV are receiving more flexible or appropriate social care services. National policy drivers inevitably focus on traditional social care client groups, so the 'long-term needs' considered in this policy do not match the needs of (say) an African woman with HIV awaiting a decision from the Home Office, unable to work and coping with treatment side-effects. The lack of a clear policy statement on the social care needs of people with HIV keeps people with HIV marginalised in both policy and practice.

Social care is also constrained by the practice of social care assessment which, again, is designed for client groups with stable, on-going needs. People with HIV who do not qualify for services under local authority assessment procedures may nonetheless experience intense social care need, especially at times of change or crisis. Sustained periods of ill-health, weakness and exhaustion can be difficult to manage, especially if wider problems related to employment, immigration, poverty and housing are unresolved.

At present, a great deal of social care is focused on personal care: helping people with the daily tasks of bathing, eating and basic mobility. One step back from this level of intimacy are home help services which include cleaning, shopping, cooking (or meals-on-wheels) and managing household chores. Childcare and family support are also integral to the services offered by social care professionals. Broader aspects of social care include information and advice, emotional support, help accessing housing and welfare benefits, and other forms of advocacy. The demand for these forms of social care is substantial.

People with HIV have always faced needs across this spectrum. Improvements in HIV treatments have reduced needs for personal care and home support but illness, fatigue, weakness and treatment side-effects can still have a profound effect on an individual's ability to cope with basic daily routines. Wider social care needs are shaped by the reality of living with HIV: isolation, discrimination, family rejection, impoverishment, bereavement, uncertainty and loss of self-esteem all continue to take their toll.

However, the distinctions made within Local Authority social care departments are not helpful in ensuring that they respond flexibly to the diversity of need experienced by people with HIV. As few people with HIV live in care homes, 'day care' is a poor description of the peer support drop-in services many people with HIV could access through much of the 1990s. The standard offer of domiciliary care is of limited use in addressing the potentially complex needs people with HIV face in sustaining their daily routines. Arguably as important in the lives of people with HIV is the 'social work' or advocacy element of social care. People with HIV may need help with identifying and accessing benefits and housing, obtaining modifications to their homes, or dealing with a range of difficulties caused, or exacerbated by HIV infection (debt, gaining employment, childcare, dealing with discrimination etc.). The prominent role that voluntary and community sector organisations have played in meeting the health and social care needs of people with HIV reflects the idiosyncrasy and complexity of these needs.

There is a long history in the UK of specialised social work for people with HIV. However, the specialism is increasingly being mainstreamed back into generic social services departments. Hence, a full appreciation of the complexity of HIV-related social care need is being lost along with a range of specific skills.

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What Do You Need? (Weatherburn *et al.* 2002) described the needs related to household chores and self-care of people with HIV in the UK. Of the 1,821 people with HIV taking part a third (35%) had experienced problems doing household chores or looking after themselves, in the previous 12 months and a fifth (22%) had ongoing problems doing household chores or looking after themselves and felt that further help or support would be useful. The main reason for these problems was fatigue and lack of energy, often closely linked to loss of mobility and physical strength, illness, or lack of motivation. Debilitating illnesses included opportunistic infections of HIV disease and the demands of other chronic illnesses such as haemophilia (also reflected in joint problems), asthma and arthritis. However, illness was usually described in more general terms: fevers, nausea and feeling unwell. The impact of illness, pain, neuropathy and side effects was clear not only in the extent of reported fatigue but, more profoundly, in the losses of strength and mobility.

Many of the other needs examined in the survey (Weatherburn *et al.* 2002) were also relevant to an assessment of social care needs:

- 67% had experienced problems with anxiety or depression in the last 12 months.
- 59% had experienced sleep problems.
- 48% had experienced problems with self-confidence.
- 42% of those living with children had experienced problems looking after them.
- 42% had experienced problems with their appetite or ability to eat and drink.
- 31% had experienced problems getting enough money to live on.
- 29% had experienced mobility problems.
- 21% had experienced housing problems.

Levels of need were much higher among the African people with HIV in the subsequent Project Nasah survey (Weatherburn *et al.* 2003). For example, 42% had problems with household chores and self-care, 77% had problems getting enough money to live on and 54% had housing problems. It is this breadth of HIV-related needs that challenges social care services. Many people have basic needs for shelter, security and nutrition which can exacerbate all other needs. Others are struggling to cope with the demands of treatment-taking and its side effects, uncertainty and loss of opportunities. Experiences of discrimination and marginalisation complicate these needs even further.

Social care professionals must respect the complexity of the needs of people with HIV and respond flexibly, looking beyond the priorities that guide practice in their more established client groups.

9. SOCIAL CARE SERVICE AIMS

- 9.1 All people with HIV are supported and resourced to maintain independent lives in their own homes and other settings, including managing their own personal care, domestic chores and daily needs, with support when necessary.
- 9.2 All people with HIV are supported and resourced to cope with the impact of illness, treatment-taking and disability on their daily lives.
- 9.3 All people with HIV are supported and resourced to cope with the impact of discrimination, poverty and social exclusion on their daily lives.
- 9.4 All people with HIV are supported and resourced to maintain and improve personal well-being and mental health.
- 9.5 All people with HIV are supported and resourced to support and nurture their families and relationships.
- 9.6 All informal carers of people with HIV (and care networks) are supported and adequately resourced.
- 9.7 All social care providers are aware of the complexity of the social care needs of people with HIV and of the diverse needs of the communities affected by HIV.
- 9.8 All social care providers are aware of the impact of discrimination on people with HIV, particularly in marginalising individuals and communities and limiting their access to services.
- 9.9 All social care providers are able to respond quickly and appropriately to people with HIV, particularly at times of crisis, recognising the variability of HIV-related need over time.
- 9.10 All social care providers work closely with clinicians and other health professionals so that social care services can optimise the conditions for effective treatment.

Goal 10: All primary care services are appropriate to the needs of people with HIV.

Primary care describes community-based health services that are usually the first point of contact that patients make with the health service. It covers services provided by family doctors (GPs), community and practice nurses, community therapists (such as physiotherapists and occupational therapists), community pharmacists, optometrists, dentists and midwives. Primary care also includes NHS walk-in clinics and NHS Direct.

Because HIV is mainly sexually transmitted, medical HIV expertise grew out of those acute services where patients first presented (GUM, communicable disease departments, thoracic medicine *etc.*). In addition, as HIV is a stigmatised condition, there has been a marked tendency to set apart its treatment within these specialist areas. Therefore, traditionally, primary care has had relatively little to do with HIV treatment and care with the result that such settings are often not equipped to deal with patients with HIV. While much of the treatment of HIV infection remains specialised, general practice and primary care have increasingly important roles in caring for patients with HIV as care pathways based on chronic disease management are formulated. It is important to ensure that primary care standards are consistently high.

Although primary care personnel may have limited expertise on the treatment of HIV, they traditionally have a fuller understanding and insight into the patient's overall medical and social problems and needs and so are an essential component for the provision of medical care. The GP and community nurse also have central roles within community care or home support teams. In addition, GPs and community nurses can be more accessible than HIV services, sometimes seeing the patient in the evening or at home. Finally, both can help co-ordinate the local services needed for palliative care at home and if necessary arrange admission to a hospital or hospice. They can help with the prescription of drugs and treatments that hospitals may be unwilling to provide. Shared care between the specialist centres and primary care staff can prove successful and fruitful.

Effective and appropriate dental care is essential to maintaining health and quality of life and in dealing with a range of symptoms associated with HIV. It is important therefore that dentists treating people with HIV are aware of their patient's HIV status and what medications they are on. This knowledge is also vital in diagnosing and treating a range of HIV-related symptoms.

Midwives have a vital role to play in the management of HIV during and after pregnancy. As many women with HIV are first diagnosed prenatally, the midwife can provide vital support in managing what is often an extremely challenging period for those women who go ahead with their pregnancy. Like GPs, midwives often have a more holistic picture of the health and social care needs of the woman in their care. It is therefore vital the midwives are competent to care for women with HIV. Not only does this involve sensitivity in service delivery, but also knowledge of the range of factors and risks attending pregnancy and childbirth for women with HIV and an ability to work collaboratively with HIV specialists.

Pharmacists need to be able to manage disclosure of information about HIV from patients or customers as well as have competencies around prescribing and contra-indications of a range of prescription and over the counter treatments with HIV treatments. Pharmacists also manage methadone dispensing for people with HIV who have used intravenous drugs. Therefore, it is vital that all people with HIV have confidence in their pharmacist both to provide appropriate information and advice and to treat them with respect.

There is evidence that people with HIV have experienced discrimination and inappropriate treatment in primary care settings, ranging from refusal to register patients to stigmatising comments or attitudes to excessive infection control measures. People with HIV therefore face substantial disincentives to use primary care services or to disclose to providers if they do. The main disincentives are concerns about the quality of care and the competence of primary care personnel to deal with HIV-related symptoms, fear of discrimination and stigmatising attitudes from primary care personnel and finally fears for confidentiality. Primary care providers and their regulatory or professional bodies need to work hard to overcome these fears and ensure standards. The main professional and regulatory primary care associations (The Royal College of General Practitioners, The Royal College of Midwives and The Royal Pharmaceutical Society) have all issued guidelines or policies regarding the treatment of patients with HIV [30]. These cover skills and competencies, confidentiality and infection control procedures *etc.* However, the extent to which these guidelines are regularly updated, disseminated and adhered to is variable.

Finally, it is by no means clear that all people with HIV in the UK have free access to primary care services. Department of Health guidance states that all people who have formally applied for asylum are entitled to primary care without charge for as long as their application (including appeals) is under consideration. The same is true for those granted refugee status, given discretionary leave to remain or granted humanitarian protection. Like UK citizens, they can register with a GP but have to pay certain statutory NHS charges (e.g. prescription charges) unless they also qualify for exemptions.

However, guidance is confused on the case of refused asylum seekers (including those getting Border & Immigration Agency (BIA) Section 4 support while awaiting departure from the UK). Guidance currently states that refused asylum seekers should not be registered with GPs, but equally, GP practices have the discretion to accept such people as registered NHS patients [31]. However, a recent high court ruling now means that anyone showing that they are "ordinarily resident" in the UK should now have access to all NHS treatments (including primary care services). This should include refused asylum seekers, Article 3 (Human Rights) applicants and those who have entered on a valid visa or are applying for visa extension. Under this ruling, the only persons who still do not qualify for free primary care services are those who have overstayed their visas and not made an application (e.g. under Article 3) or people who are completely undocumented (i.e. people who have never presented themselves to the immigration authorities, nor made any application for leave to remain). The government has been granted leave to appeal this ruling in the House of Lords and are likely to do so.

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10. PRIMARY CARE AIMS

- 10.1 All people with HIV living in the UK have access to the full range of primary care services.
- 10.2 All people with HIV feel confident in disclosing their HIV status to all primary care practitioners.
- 10.3 No person should experience discrimination in primary care settings as a result of their HIV status.
- 10.4 All people with HIV should be treated with respect by all primary care staff.
- 10.5 All people with HIV know about and can use complaints and grievances procedures with regard to primary care.
- 10.6 All primary care providers are able to respond to the healthcare needs of patients with HIV and to refer to other services.
- 10.7 All primary care providers are aware of the impact of discrimination in healthcare settings on people with HIV, particularly in marginalising individuals and communities and limiting their access to services.
- 10.8 All primary care providers work closely with clinicians and other health professionals to optimise the conditions for effective treatment, health and quality of life.
- 10.9 All primary care regulatory and professional bodies (such as the Royal College of General Practitioners, the Royal College of Midwives, the Royal College of Optometrists, the British Dental Association) regularly review and update procedures and guidelines on the treatment of people with HIV.
- 10.10 All PCTs ensure that the primary care services that they commission and manage can

- deliver an effective and acceptable service to people with HIV.
- 10.11 All PCT complaints managers respond promptly and appropriately to complaints lodged by people with HIV.

Goal 11: Mental health services are appropriate to the needs of people with HIV.

Good mental health is an integral part of good overall health for people with HIV. However, mental health is often severely affected by HIV. Issues such as uncertainty about the future, treatment side-effects, pain, and fear of disease progression can cause emotional strain and undermine mental health. A significant proportion of people with HIV experience mental health problems.

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The causes of elevated mental health morbidity among people with HIV are numerous. Some mental health symptoms are caused by HIV disease itself. Although advanced HIV disease can cause dementia and mania, because of successful anti-HIV treatments, new cases of dementia and mania are now rarely seen.

There is evidence to suggest that depression and anxiety occurs much more frequently in people with HIV than in the general population and that other mental health problems can be caused by the strains of living with HIV. Particular events, such as being diagnosed with HIV, bereavement, being ill, dealing with treatment side-effects, or work problems can cause feelings of deep unhappiness and emotional distress. In addition, mental health symptoms can occur as side-effects of HIV treatments. For example, efavirenz (*Sustiva*) has been associated with depression and sleep problems and to a recurrence of pre-existing mental health problems. Interferon treatments for hepatitis C co-infection can cause depression and treatment side-effects (such as lipodystrophy) can also lower self-esteem and lead to anxiety and depression.

Undesirable in itself, mental health morbidity may lead to a range of detrimental outcomes for people with HIV in terms of health, social need, financial stability, physical health and adherence to HIV treatments. Individuals may self-medicate with recreational drugs or alcohol, often leading to other health concerns. Conversely drug use (whether recreational or because of dependence) can compound or initiate mental health symptoms ranging from depression and anxiety to psychosis.

Increased need around mental health for people with HIV has long been recognised and most large HIV treatment centres have specialist mental health teams including psychiatrists, psychologists and mental health nurses. Social support interventions are valuable in promoting mental health maintenance among people with HIV as are complementary therapies (massage, acupuncture *etc.*).

The Department of Health strategy *Modernising mental health services: safe, sound and supportive* [32] makes several recommendations regarding minimum service standards for

mental health services. Services should:

- involve service users and their carers in planning and delivery of care;
- be well suited to those who use them and non-discriminatory;
- be accessible so that help can be obtained when and where it is needed;
- offer choices which promote independence;
- deliver continuity of care for as long as this is needed, and;
- be properly accountable to the public, service users and carers.

The *National Service Framework for Mental Health* [33] specifies five areas where interventions are needed. These are tackling discrimination and social exclusion associated with mental health, improving mental health promotion and treatment of common mental health conditions through primary care, developing effective services for people with severe mental illness, supporting those who care for people with mental health problems and reducing the population suicide rate.

As people with HIV belong to groups disproportionately affected by mental health morbidity, it is important that services oriented to these groups take account of the additional needs of those clients with HIV. As services for common or mild mental health problems are often delivered through, or triaged from, primary care services, it is important that primary care services are appropriate to the needs of people with HIV. Also, as stigma associated with mental health problems is likely to affect groups with significant numbers of people with HIV, it is important that mental health promotion services as well as community mental health services are competent to meet the needs of people with HIV. Community mental health promotion must take care not to compound or exacerbate HIV-related stigma.

11. MENTAL HEALTH SERVICE AIMS

- 11.1 The UK government commits to countering stigma and discrimination that leads to, or exacerbates mental health morbidity among people with HIV.
- 11.2 All people with HIV have access to peer support to maintain mental health.
- 11.3 All people with HIV have access to mental health assessments.
- 11.4 All people with HIV have access to information and advice around mental health maintenance and symptom diagnosis.
- 11.5 All people with HIV have access to a range of high-quality and free mental health services.
- 11.6 All people with HIV are knowledgeable about the range of mental health services available and the means to determine which are appropriate for them.
- 11.7 All people with HIV are aware of any contra-indications between both pharmaceutical and herbal (for example, St John's Wort) anti-depressants and HIV treatments.
- 11.8 All people with HIV have access to information and support around stress management.
- 11.9 All voluntary and community sector (VCS) and statutory mental health services are competent to provide services to clients / patients with HIV and to refer to other services.
- 11.10 All VCS and statutory HIV clinical, treatment, support and care services are competent to provide services to clients/patients with mental health problems and to refer to other services.

Goal 12: Drugs services are appropriate to the needs of people with HIV.

Elevated and problematic drug use is associated with certain groups of people with HIV (for example, gay and bisexual men, injecting drug users, sex workers and those in custodial settings). Such use is associated with a range of negative factors such as poverty, exclusion, and mental and physical health problems. However, a significant proportion of people who use illegal recreational drugs take pleasure in their drug use and consider that it causes little harm.

The key distinctions when thinking about drug services for people with HIV are those between recreational, problematic and chaotic drug use. Recreational drug users mainly use stimulants and do not usually regard their drug use as problematic though it is likely to impact on their health and well-being. Problematic drug users often identify their use as having a significant detrimental effect on their lives. However, when drug service providers think of problematic drug use, they are generally referring to opiates (heroin *etc.*). Chaotic drug use is generally assumed to mean poly-drug use (for example, methadone, heroin, crack, alcohol and benzodiazepines). The needs and concerns of people in these three different groups differ markedly as should the service response.

The majority of drugs services are designed to meet the needs of problematic opiate users. Although this should bode well for meeting the HIV care needs of this group, drug users with HIV can find themselves excluded from HIV social care services because their drug use is not manageable. On the other hand, those who use recreational drugs (for example gay men) are not well served by drugs services because they tend to use stimulant rather than opiate drugs.

It is necessary to clarify the care needs of all people with HIV who use drugs and assess the capacity of current services to meet that need. Currently, the drug treatment needs of people with HIV are not adequately addressed. There are insufficient treatment and support services for gay men with HIV using recreational drugs. In addition, it is necessary to understand the interaction of drug treatments (for opiate or stimulant addiction) with HIV and hepatitis infection. For example, methadone interacts with many HIV drugs and can build up in the liver so it is not necessarily appropriate for people with HIV. More appropriate morphine treatments are much less available. Likewise, for interferon treatment to work for hepatitis, patients must be drug-free and (like methadone), interferon also interacts with many HIV treatments. What is necessary here is a range of services to suit the various needs and tolerances of the individual.

12. DRUG SERVICE AIMS

- 12.1 All people with HIV have access to a full range of information and advice about illicit drug use.
- 12.2 All people with HIV who are experiencing problematic or chaotic drug use have access to support and treatment.
- 12.3 Standards for drug treatment and support services for people with HIV are developed and adopted.
- 12.4 All drugs services are competent to deliver services to people with HIV and to refer to other services.

- 12.5 All HIV treatment, care and support services are competent to deliver services to clients who use drugs recreationally, experience problematic or chaotic drug use, or who are in drug treatment programmes.

Goal 13: Alcohol services are appropriate to the needs of people with HIV.

There is no evidence to suggest that moderate drinking harms people with HIV. Indeed, it can offer benefits. Alcohol relaxes the brain and body, can increase well-being and reduce stress as well as acting as an appetite stimulant.

Like other recreational drugs, elevated and problematic alcohol use is associated with certain groups of people with HIV (for example, gay and bisexual men and sex workers). Increased or problematic alcohol use is associated with a range of factors such as poverty and exclusion as well as mental and physical health problems. Excessive or dependent alcohol use can have detrimental physical, psychological and social effects which may interact with pre-existing problems common in people with HIV. For example, excessive alcohol use lowers immune system function and can lead to poor diet. As alcohol is a depressive drug, it can worsen mental, psychological or emotional problems. Heavy alcohol use can have potentially serious consequences for people taking anti-HIV drugs. Alcohol can damage the liver and a healthy liver is necessary for the body to process medicines effectively. The blood fat increases caused by some anti-HIV drugs can be made worse by heavy drinking. People whose liver has been damaged by drinking alcohol (especially if they have hepatitis) may be more likely to experience side-effects from anti-HIV drugs, particularly protease inhibitors.

Alcohol policy and services probably do not currently meet the HIV-related needs of people with HIV who experience problematic alcohol use. Many alcohol treatment and support services are not appropriate for gay and bisexual men or ethnic minorities and are ill-equipped to deal with the specific needs of clients with diagnosed HIV. Specifically, there is little information available about interactions between HIV treatments and alcohol (specifically lipids and liver function), the effects of sustained alcohol use on immune functioning, and the potential effects of problematic alcohol use on adherence *etc.*

13. ALCOHOL SERVICE AIMS

- 13.1 All people with HIV have access to information and advice about alcohol use.
- 13.2 All people with HIV who identify their alcohol use as problematic have access to support and treatment.
- 13.3 Standards for alcohol treatment and support services for people with HIV are developed and adopted.
- 13.4 All alcohol services are competent to deliver services appropriate for people with HIV and to refer to other services.
- 13.5 All HIV treatment, care and support services are competent to deliver services to clients whose use of alcohol is problematic or who are in alcohol treatment programmes.
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4. Government, society and community

None of the goals described in chapters 2 and 3 are achievable in the absence of a nurturing social and political environment. Government determines many of the conditions within which we all live. A government's performance on the economy to a large extent determines our individual and collective wealth and standard of living. A government's record on human rights makes the difference between a repressive society and one based on openness and tolerance. A government's commitment to social reform and the health and well-being of its citizens determines the standard of public services we are entitled to and the degree of poverty, ill-health and degradation acceptable in society.

There are several ways in which government influences the health and well-being of people with HIV. On a basic level, government is responsible for creating the services available to people with HIV in the UK. However, government also sets the social climate within which people with HIV live. For example, the nature and extent of anti-discrimination legislation and policy have a direct influence on how people with HIV are treated by others in work and education settings, as well as in the delivery of goods and services. This legislation coupled with the kind of leadership government displays in combating HIV-related stigma influences the extent to which our society supports or stigmatises people with HIV and the extent to which communities and individuals are enabled to empower themselves. Arguably the most important goal of this framework must be an integrated and supportive government response to HIV social care need. Therefore, this framework seeks to engender better social attitudes towards people with HIV and better community support by calling for better government.

Goal 14: No government policy is detrimental to the health and well-being of people with HIV.

Our current government has shown a clear commitment to social reform and to supporting and reforming the welfare state (specifically the NHS). For the majority who qualify, free HIV clinical treatment and care is excellent. However, in many other important areas the interests of people with HIV have been damaged by legislative and political change. For the most part, this is due to government acting in ignorance of the impact of policy or legislative change on people with HIV. However, in other cases government policy in specific areas have a disproportionate effect on the weakest groups of people with HIV (specifically immigration policy).

Our present government has the capacity to present a model of good practice throughout Europe. The government's social reforms have improved the lives of a substantial proportion of people with HIV in the UK (namely, those born here and those who have a right to free services, benefits and work). However, for migrants with HIV, for those from Black and minority ethnic backgrounds, for those who are not responding to treatments and for poorer people with HIV, current government policy is arguably worsening quality and quantity of life. Government policy has divided the population of people with HIV by firmly distinguishing the haves from the have-nots.

14. AIMS FOR GOVERNMENT

- 14.1 All current and future policy and legislation is fully compliant with the Disability Discrimination Act and the Human Rights Act [21,22].
- 14.2 Public Health Impact Assessments are carried out on all current and future policy and legislation to take full account of all impacts on people with HIV and all policies and legislation are consistent with the health and well-being of people with HIV.
- 14.3 The UK government takes an international lead regarding best practice in HIV social care.
- 14.4 The UK government appoints an HIV and AIDS champion.

Goal 15: All people with HIV are free from discrimination.

HIV-related discrimination is common and has a profound negative effect on the well-being of people with HIV. The majority of people with HIV in the UK report experiencing discrimination in a range of settings.

For the purposes of this framework, we define discrimination as individuals or groups being denied equal rights, goods, services or opportunities and / or are treated prejudicially because they belong to that group. This form of discrimination emanates from negative attitudes or beliefs about individuals or groups and can be described as an enacted or institutional dimension of social stigma.

Discrimination is not only something done by individuals. Governments can be discriminatory (by drafting legislation or policy which treats certain groups detrimentally) as can businesses (by refusing services to individuals or groups based on prejudicial beliefs) as can community or faith organisations (by excluding or demonising specific groups or individuals). For our purposes, the most relevant result of discrimination is that it deprives individuals or groups of equal rights, services or goods. That is, we are concerned primarily with the discriminatory actions of the government, businesses, service providers and community organisations.

Discrimination is based on a range of characteristics (ethnicity or race, gender, age, disability, sexuality *etc.*) which are often inter-related in quite complex ways. Discrimination associated with HIV depends on a range of prejudicial beliefs or attitudes. These include fear of disease or contagion, but may also be based on what having HIV indicates about the individual or group (being gay, being Black, being a migrant, being promiscuous *etc.*). As pernicious as experiencing discrimination is the fear of discrimination. Such fear can severely limit an individual's horizons discouraging him or her from applying for jobs, moving home, socialising or seeking support.

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Roughly one-fifth of people with diagnosed HIV have experienced some form of discrimination in the last year (Weatherburn *et al.* 2002). Among the *What Do You Need?* sample, discrimination on the basis of HIV status was widely identified, but respondents also described discrimination on grounds of sexuality, ethnicity, disability, physical appearance, age, drug use and gender. A quarter of those experiencing discrimination did so when using public services (especially when they accessed health and social services for reasons other than HIV treatment and care). Discrimination was also encountered from other 'generic' service providers (for example housing

department staff, general practitioners and dentists). 15% had experienced discrimination at work, while 6% had experienced discrimination while seeking employment. Others reported discrimination while seeking financial services, insurance or while traveling internationally.

The last decade has seen a considerable amount of legislation that outlaws discrimination on a range of grounds in a range of contexts. This includes the *Disability Discrimination Act 2005* which provides protection from the point of diagnosis for people living with HIV in employment, education, housing, trade union membership and in the provision of goods and services. However, there is a need to ensure this legislative protection is complied with and accessed. This must be through effective dissemination of the relevant rights and responsibilities, with effective remedies available and monitoring of compliance.

15. DISCRIMINATION AIMS

- 15.1 All people with diagnosed HIV have the information and capacity to resist the harmful effects of HIV-related discrimination.
- 15.2 Families, friends and communities of people with HIV have the information and capacity to counter HIV-related discrimination.
- 15.3 Businesses, including the press and providers of goods and services, do not discriminate against people with HIV.
- 15.4 Statutory education, health, social, custodial and legal services do not discriminate against people with HIV as required by the Disability Equality Duty.
- 15.5 Statutory education, health, social, custodial and legal services counter HIV-related discrimination.
- 15.6 Voluntary and community sector (VCS) services and charities do not discriminate against people with HIV.
- 15.7 VCS services and charities counter HIV-related discrimination.
- 15.8 Central government policy and practice does not promote or exacerbate HIV-related discrimination, but rather acts wherever possible to eliminate HIV-related discrimination and promote equality of opportunity and positive social attitudes.
- 15.9 Local government policy and practice does not promote or exacerbate HIV-related discrimination, but rather acts wherever possible to eliminate HIV-related discrimination and promote equality of opportunity and positive social attitudes.

Goal 16: All people with HIV should be able to find appropriate support within their communities.

The support of friends, family and the wider community is essential to health and well-being. However, for many people with HIV, this support is not guaranteed.

Many people with HIV belong to stigmatised social groups (gay and bisexual men, African migrants, injecting drug users, sex workers). Such stigma often leads to a rejection from broader society as well as family and local community. In the face of such stigma, alternative supportive communities come into being (gay community, diasporic communities *etc.*) where individuals find social support and affirmation. However, an HIV diagnosis not only increases broader societal stigma but can often lead to the individual being stigmatised within their community of support.

Gay men may have already experienced rejection from family and community when they came out and may rely on gay community support. However, gay communities often harbour significant stigma around people with HIV who are sometimes characterised as irresponsible, unworthy and unproductive [1]. In addition, gay men with HIV can hold significant negative attitudes to one another. Some gay men may find themselves dependent on a biological family that already has antagonistic feelings towards them or have rejected them in the past. Many gay men report relationship break-ups and a loss of social contact when they are diagnosed with HIV.

Like many migrants, African people are likely to rely heavily on expatriate communities for support. However, among African diasporic communities in the UK there is significant stigma against members with HIV [2]. An HIV diagnosis calls into question the sexual and moral conduct of the individual and indeed his or her role in the social group. Therefore some woman who test positive for HIV during an antenatal screen find themselves rejected by partner and family and many African people with HIV report rejection from wider family, local community and from their church.

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Among respondents to *What Do You Need?* (Weatherburn *et al.* 2002), rejection from friends, families and neighbours accounted for 20% of the rejection reported. This included explicit rejection (such as family members who refused to have any contact or friends who turned away) as well as more subtle forms of exclusion, particularly the attitudes and ignorance that breed gossip, suspicion and rejection both in specific communities (gay, African) and in society as a whole. More direct and violent forms of social rejection – verbal and physical abuse – came next accounting for 17% of the rejection suffered. This was mainly homophobic in nature coming from both neighbours and strangers.

Family and community rejection is one outcome of HIV-related stigma. HIV-related stigma serves to increase power inequalities between those who are infected and those who are not. It undermines the vital social support networks on which so many people with HIV depend. Stigma is a process in which all members of society are implicated, whether through compliance or resistance. Once we know how stigma works, we can choose to act in a way that increases or decreases it. People can resist stigma only if they have knowledge of how stigma works, and have the capacity to do so.

16. COMMUNITY SUPPORT AIMS

- 16.1 All people with diagnosed HIV have the capacity to resist the harmful effects of family and community rejection.
- 16.2 Families, friends and communities of people with HIV are supportive of members with HIV.
- 16.3 Families, friends and communities of people with HIV counter HIV-related stigma and discrimination.

Goal 17: No person with HIV suffers decreased health or well-being because they are a migrant to the UK.

Immigration policy and policing, social discrimination and stigma coalesce to have a disproportionately harmful effect on the health and well-being of people who migrate to the UK with HIV. People from black and minority ethnic backgrounds make up 49% of people with diagnosed HIV in the UK and among this group, 89% are black African [15]. Hence, although people with HIV come to the UK from many countries, African people make up the vast majority of UK-residents with HIV infection which was “acquired abroad”.

Migrants (especially refugees, forced migrants or those seeking asylum) often have complex pre-existing social care, support and health-related needs. Health is severely compromised by pre-existing poverty, trauma, the presence of communicable diseases in the country of origin, and is exacerbated by conditions on arrival such as poverty and inadequate housing [34, 35]. Maternal death and paediatric conditions are significantly more common among refugees and asylum seekers, than in the general UK population [36, 37]. In addition, the conditions of departure and the conditions that people are forced to live in when they arrive in the UK lead to greater mental health morbidity.

The question of asylum-seeking and irregular and undocumented migration to the UK has been politically charged for some time now [34, 35]. This has led to policies focused on tighter border controls, distinguishing migrants based on their value to the UK, and the removal of those who have been refused permission to stay in the UK. For the purposes of this framework, we classify migrants under the headings of documented migrants, undocumented migrants and asylum seekers.

Documented migrants

Migrants who have a right to stay in the UK (documented migrants) often experience periods of instability, especially on arrival. This can be exacerbated by language difficulties, confusion over qualifications and benefits or lack of accommodation which are compounded if the person has HIV. A more recent problem concerns migrants from recent EU accession countries who must have worked for 12 months in the UK in a job after they have correctly registered with the Home Office in order to be entitled to benefits. Those who have not done so (who have worked cash-in-hand or casually) can often find themselves in difficulties should they become unwell and unable to claim benefits or treatment.

Undocumented migrants

Little is known about the lives of undocumented migrants. Voluntary and community sector (VCS) agencies tend to be silent on their needs and reluctant to draw attention to their presence for fear of precipitating arrests and deportations. Undocumented migrants are reluctant to draw any attention to their own plight for the same reason. Many have powerful reasons for wishing to remain in the UK. Some fear for their safety or health if they return home. Others may be able to apply for asylum but are dissuaded from doing so by expectations of a protracted procedure and a long period of limbo possibly involving detention and restrictions on the capacity to work. Some may have tried and failed in their asylum applications and have chosen a life “undocumented” to avoid being sent back to their home country.

Undocumented migrants live in what has been called a 'rightless' state outside the legal and tax system. Life in the UK for undocumented migrants is precarious. Legislative changes from the mid-1990s onwards mean that undocumented migrants are now entirely dependent on the private or charitable (church) sector. Lack of redress to a legitimate support framework leaves people especially vulnerable to exploitation (sexual exploitation or servitude, and sub-standard accommodation). They have no recourse to welfare benefits, although there may be some emergency provision through Local Authority *No Recourse to Public Funds* (NRPF) programmes. Hence, the majority of undocumented migrants must quickly get (cash-in-hand) work and keep it. The imperative to keep working at all costs is stressful and detrimental to health.

Undocumented migrants have no access to free NHS secondary health care (with only a limited number of conditions or healthcare settings exempted from NHS charges). They literally cannot afford to be ill or incapacitated. They are likely to suffer similar levels of mental health stressors and morbidity as refugees and asylum seekers. However, unlike the former, they have no access to mental health services. Little is known about the extent to which undocumented migrants with HIV manage to obtain clinical treatments in the UK.

Asylum seekers

Asylum seekers are likely to have complex pre-existing social care, support and health-related needs [38]. However, the process of lodging and defending an asylum application often has a detrimental effect on the mental and physical health of applicants by over-stretching their limited resources.

The Home Office's current policy on asylum seeking has been described by refugee and asylum charities as a "policy of destitution" [34, 35]. The application and appeal process is difficult and support is withdrawn from individuals whose application for asylum has been turned down. Many people with HIV make additional applications under Article 3 of Human Rights Act 1998, based in part on a lack of access to anti-HIV treatments in their country of origin. While an asylum application is considered, the applicant receives benefits through the Home Office Border and Immigration Service. If an asylum claim is rejected, the individual loses all support (though families with children continue to be supported under section 94(3A) of the Immigration and Asylum Act 1999). Individuals can then apply for Section 4 'Hard Cases' support (£38 in vouchers or grants and access to temporary accommodation). The process of assessment for, and decisions on, Section 4 support have some serious flaws. Those whose applications have been rejected but who remain in the UK often become destitute, defined in section 95 of the Act as unable to access adequate accommodation or meet essential living expenses for themselves or their family for the next fourteen days. There is now a substantial population of destitute or near destitute people in the UK.

The practice of dispersal of asylum seekers (moving individuals and families out of London and the Southeast to other areas in order to relieve pressure on social services) disrupts service networks and legal representation. Individuals are often placed in areas where they are cut off from social care, health and legal expertise, and also from the support of expatriate communities. Fortunately there are guidelines around dispersal of asylum seekers with diagnosed HIV which should ensure adequate time to prepare for dispersal and handover of clinical care. However, such guidelines these are much less robust for the safe transfer of social care.

Of particular concern is the restriction and denial of access to free secondary healthcare to refused asylum seekers since 2004 (NHS Overseas Visitor Hospital Charging Regulations 2004). At present, refused asylum seekers have a right to continue on treatment that commenced before their cases were decided. All other secondary care can be charged, with some trusts seeking deposits before treatment commences. Exceptions to this include accident and emergency services, family planning, GUM (diagnosis and treatment of STIs excluding HIV) and compulsory mental health treatments. Under these regulations, trusts must assess whether a patient is 'ordinarily resident in the UK'. Patients who do not meet the criteria can be billed for all but emergency services. However, as Section 4 recipients live in a cashless state (receiving only accommodation and vouchers), they are unable to pay any medical bills. There is evidence to suggest that some Trusts may not be using discretion or taking into account the poverty, vulnerability or destitution of the patient when they issue bills for treatment. At the time of writing, these regulations have been ruled as unlawful in the High Court as applied to refused asylum seekers, but do still apply to illegal migrants and visa over-stayers [31].

In order to improve this situation, the asylum process received the last of a series of overhauls in July 2006, including the absorption of NASS into the Asylum Resources Directorate, the development of a New Asylum Model (NAM) and the funding of the Voluntary Assisted Return and Reintegration Programme. However, the policy of destitution remains.

Migration and impact on health

Current government policy on undocumented migrants, refugees and asylum seekers runs contrary to good public health and is detrimental to the health and well-being of a significant proportion of the UK HIV infected population. There is a clear public health argument for providing HIV treatment, healthcare and social support to all people currently resident in the UK regardless of immigration status. Four practices are especially problematic.

First, the policy of destitution is likely to have a massive detrimental impact on the general health and well-being of asylum seekers with HIV. There is no question that destitution harms health. Second, the practice of dispersal currently makes little attempt to ensure continuity of social care, and creates burdens on PCTs with little or no specialist services or expertise. Third, some people are incorrectly denied healthcare, benefits and support because of a complex set of regulations and expectations. Fourth, the policy of refusing HIV treatments to asylum seekers who have been refused is inconsistent with government policy, as HIV is both communicable and sexually transmitted.

Children of migrants

The children of migrants with insecure immigration status constitute a particularly vulnerable population. Current estimates suggest that there are 200 to 250 HIV-infected children with insecure immigration status living in the UK [34]. Governance and policy which affects children in this group is fragmented. For example, while immigration policy is a responsibility of the Westminster government, children's social care is devolved to the four nations and children's health services are organised differently in each of them.

The UN Convention on the Rights of the Child (UNCRC) [16] included articles that extend the right to healthcare to all children regardless of their immigration status. It stated that children seeking asylum (whether accompanied or otherwise) should receive protection and humanitarian

assistance and enjoy all applicable rights (including access to health care) set out in the convention. However the UK has a reservation on these articles which effectively allows immigration law to take precedence over child welfare legislation.

The duties imposed by the 2004 Children Act [18] do not apply to the Home Office, immigration removal centres or immigration officers at a port of entry. The justification is that attending to welfare of children could compromise the capacity to maintain strong immigration control. However, the Act also establishes a Children's Commissioner for England (and separate Commissioners for Northern Ireland, Scotland and Wales), who has responsibility for promoting awareness of the views and interests of children. Their role is to undertake inquiries, but not to take up individual cases. The Children's Commissioner for England has responsibility for reserved issues, such as speaking out on immigration and asylum.

Unaccompanied children seeking asylum fit, by definition, the criteria for being looked after by a Local Authority under Section 20 (1) Children Act 1989. They should be entitled to the same services as other looked after children (needs assessment, care plans and access to all health and social care as well as support on leaving care). One of the criteria set out for assessing asylum applications applies to minors who claim asylum in their own right. This is likely to increase the number of cases where the government contests an asylum claim for a minor, usually on the grounds of disputing age.

Currently children are left in the care of their parents. However, a family refused asylum and not complying with arrangements to remove them forfeit the right to Border and Immigration Service support. In line with the duty of care under the Children Act (1989), children under the age of 18 can be taken into the care of the Local Authority. Such an action is highly contentious with some Local Authorities refusing to take any child into care. The government is currently consulting on bringing about better outcomes for both unaccompanied children seeking asylum and the children of asylum seekers. Currently, the priority remains the immigration outcome rather than child welfare.

Overall therefore, there is an inconsistent policy environment governing child or young migrants with HIV and the prime imperative of children's legislation (the welfare of the child) is compromised by immigration legislation. This is likely to lead to inconsistencies, double standards and confusion in terms of service access and entitlements as well as tensions between health and care professionals and immigration services.

17. IMMIGRATION AIMS

- 17.1 All migrants to the UK (documented and undocumented migrants and asylum seekers) with HIV have the capacity to negotiate the immigration and asylum system appropriate to their situation.
- 17.2 All migrants to the UK with HIV have access to free health care.
- 17.3 All migrants to the UK with HIV have access to benefits and social care.
- 17.4 All migrants to the UK with HIV have access to community support.
- 17.5 All asylum seekers to the UK with HIV have access to employment after six months residence.
- 17.6 No business, employer or service provider discriminates against someone or provides inferior goods or services to them because they are a migrant.

- 17.7 Current government policy and practice on immigration and asylum is made consistent with good public health practice and enhances the health and well-being of migrants or asylum seekers with HIV.
 - 17.7 The welfare of the child should be the sole and paramount concern of all government policy and practice which impacts on, or concerns children and young people with HIV (including legislation and policy pertaining to child welfare, immigration, education, youth justice and poverty).
 - 17.8 All statutory and VCS migrant and asylum support agencies have the capacity to provide services to people with HIV and to refer to other services.
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