

Social Exclusion and HIV

A Report

We need to break the silence, banish the stigma and discrimination and ensure total inclusiveness within the struggle against AIDS.

Nelson Mandela

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Foreword

Social exclusion can prevent individuals and groups of people from making their full contribution to our society through a variety of ways; poverty, poor education, prejudice and many others. This report shows the ways in which HIV and AIDS and the stigma attached to them can play a part in exacerbating or even creating social exclusion for a wide range of different people.

Being infected with, and living with, HIV should be no different from living with any other long term, life threatening medical condition for which imperfect and experimental treatment is available. Any chronic health problems can contribute to social exclusion, but HIV can cause particular difficulties due to the prejudice and, frequently, ignorance with which those of us who have the virus are too often treated.

For many people, the simplest apparent way to deal with such reactions may be to hide the condition, or even to deny the possibility of it. This, in turn, will have other exclusionary impacts, not least upon the long term health of the individual concerned.

This report covers a range of arenas in which HIV may cause, or add to the existing impact of, social exclusion. It lays out the need for Government to fully recognise HIV as a social exclusion issue. It offers a number of simple remedies to current injustices or inequalities which are a part of this. And, in conclusion, it calls upon both Government and civil society to actively collaborate and share responsibility for change, so that people with HIV become fully included within our society.

A handwritten signature in black ink that reads "Nick Partridge". The signature is written in a cursive style with a horizontal line underneath the name.

Nick Partridge OBE
Chief Executive Officer

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1. Introduction

1.1 Definition of social exclusion

Social exclusion is a shorthand term for what can happen when people suffer from a combination of linked problems, such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown. The issue of social exclusion is multi-dimensional and one form of exclusion will often lead to another.

For society as a whole, social exclusion can also have a major economic impact. It can lead to a higher social security bill, increases in crime and low productivity resulting from poor skills and wasted talent. It is important to prevent the exclusion of vulnerable groups within society by ensuring that mainstream services are not excluding them. Where social exclusion has already occurred, reintegration of those who have been excluded must be addressed. HIV has not traditionally been included as a factor contributing to social exclusion but, as this document shows, it can be a major contributor.

Gay and UK African communities, where prevalence of HIV is at its highest in this country, are minority communities which face a range of forms of discrimination. The difficulties that individuals from these and other affected groups face through a positive HIV diagnosis will only fuel the exclusion they already encounter. There is also good reason to suggest a correlation between social exclusion and low self-esteem.

Any form of social exclusion can affect someone's future life chances. HIV contributes specifically to such social exclusion in a range of ways, many of which are inter-related and compound the problems caused by others. This prevents people reaching their potential and becomes damaging, not only to them but also to society.

1.2 HIV in the UK – the facts¹

While HIV is less common in the UK than in many other areas of the world, it is increasing steadily and continues to be a serious threat to public and individual health. The year 2000 saw the highest number of new infections ever in the UK, 3,425; a 14% increase on the previous year. Currently, over 30,000 people in the UK are infected with HIV but around a third of these are untested and do not yet know they have the virus. By 2003, some 29,000 people across the UK are expected to know that they have HIV.

Within this growing population, the largest group living with HIV are gay men. There are now more new diagnoses amongst heterosexuals (48% of diagnoses in 2000), but much of this transmission has taken place abroad rather than in the UK.

Alongside these increased rates of diagnosis, people with HIV in the UK are generally living much longer because of improved treatments and care. Between 1995 and 1999 the death

rate fell by two thirds to around 500 deaths a year, but this appears to be levelling out. There are two primary causes; some people are being diagnosed very late, when it is too late for treatments to have any benefit; and there are people for whom the treatments have failed or proved ineffective. The only way to further decrease this death rate is likely to be by reducing the level of late presentation, which is primarily (though not solely) associated with African people (see below).

The estimated 40% increase in HIV between 1999 and 2003 is likely to impact disproportionately on London, with a predicted 54% increase in South East London, an area of considerable social deprivation and exclusion already for other reasons. This is linked to a rising rate of other sexually transmitted infections, particularly amongst young people in lower socio-economic groups and Black ethnic groups. The age of first intercourse for young people is continuing to decline, as the incidence of unprotected sex rises. There is also evidence that the level of awareness of HIV amongst young people is declining.²

Although in recent years the number of new diagnoses of HIV among drug users has remained relatively small, there is some concern over the increase in the incidence of high risk injecting activity.³ This coupled with an increase in the number of hepatitis C diagnoses among drug users suggests that a level of undiagnosed HIV infection may be present within this community.

All these facts contribute to a situation in which HIV is likely to increasingly interact with other social factors to increase exclusion and deprivation for certain populations and individuals in the UK.

2. Social exclusion contributes to the spread of HIV

2.1 Social exclusion can lead to poor self-esteem, which is implicated in HIV risk taking

As the epidemiology clearly shows, the groups primarily affected by HIV in the UK are also those who are marginalised or socially excluded by society. As a result of such exclusion, often coupled with direct discrimination, many people develop very low self-esteem that may in turn lead on to high-risk sexual behaviour.

For gay men, social and legal discrimination from school onwards can result in them learning a particularly low self-worth. The consequences of such discrimination and the denial of equal rights has led some to argue that this was a major contributory factor to the severity of the epidemic within this community.⁴ The recent increase in high risk sexual behaviour among some gay men⁵, together with evidence that up to a third of gay men do not access any kind of sexual advice service⁶, suggests that this is still a matter for concern. This is particularly the case among younger gay men who may well have recently experienced hostility, abuse and even violence both in the home and outside it.

Africans in the UK may also have self esteem issues due to social exclusion. Many are first generation migrants who have left a familiar society and culture for one which is difficult to understand and where racism against black people and migrants in general is common. Those who are asylum seekers may have fled torture or persecution at home, only to find themselves in detention camps or overcrowded conditions here. Many find it difficult to gain employment which makes full use of their skills and knowledge. According to the 1991 census, Black Africans in the UK had one of the highest proportions of post-school qualifications of any ethnic group, but also had the highest proportion of qualified people who were unemployed (14%, compared to 4% of white people).

2.2 Social exclusion may make sexual health a low priority for some people

For some people, there are more pressing concerns than HIV prevention or sexual health. For those who are worried about money and food for their family, coping with violence or living in a hostile environment, HIV can be a relatively distant concern. Many people, particularly women, are not in control of their sexuality; they may choose to prioritise keeping the family together, or keeping a roof over their head, rather than refuse unprotected sex.

For many gay men too, particularly younger gay men, HIV is only one of a number of issues that they must struggle with. Homophobic violence, continued discrimination and problems around 'coming out' can be far more relevant in their everyday lives than thinking about

safer sex. Unlike their heterosexual counterparts, few gay men grow up with positive images of how their lives can be led and many face conflicts and confusion about their sexuality.

Adam was harassed by students all through his senior school, even before he knew he was gay himself. He was victimised, bullied and had verbal abuse thrown at him. When he told his two best friends that he was gay, they turned their backs on him. He became severely depressed and was eventually referred to a child therapist. He left school at the age of 15 with no real friends and feels that although the teachers were aware of the situation they failed to act due to the scale of the problem.

2.3 Fear of HIV stigma can lead to denial of the importance of HIV and neglect of sexual health issues

Denial that HIV might be an issue at all for a community is a common occurrence across the world, and at its most extreme has led to major epidemics in some countries. This refusal to accept the presence of HIV for fear of community stigmatisation can also occur within the UK. HIV is often seen as something which affects “other people”: promiscuous people, gay people, black people, prostitutes or drug users. To admit that there may be a risk of HIV having been contracted could be to give the impression that the infected person was, or had been involved with, a deviant lifestyle. As a result, HIV is often not discussed openly, which serves to heighten the risk of transmission within a community.

Within the UK black communities in particular, HIV remains a highly emotive and complex issue⁷ and the possibility of a positive diagnosis can, for some people, be too great a burden to bear. Black Africans testing for HIV at a leading London hospital were found to be twice as likely as white people to be worried about future discrimination if they tested positive and four times more likely to be worried about meeting someone they knew there.⁸ This is undoubtedly related to the stigma which HIV holds within the black African communities.

African women, though relatively more likely to access a range of HIV services than African men, often express fear of discovery because they will be judged as having brought shame on their family and may risk abandonment by their husbands, with all the financial and social consequences.⁹ This leads some of them to delay or even to abandon seeking help for their concerns.

African men have a lower take-up of testing and treatment services for HIV than women and frequently present very late and unwell. This, in turn, makes treatment less likely to be of benefit and enhances the likelihood of early death. In addition, African men often view their position as “family breadwinner” as non-negotiable and a vital part of their identity and fear loss of work and/or community status. They may also fear that an HIV diagnosis will negatively impact on their ability to remain, or to keep their family, in the UK. Attitudes towards sex and sexuality, as in all cultures, are highly determined by religion and morals. Some African men may feel that a positive diagnosis, if known, will reflect on their morality or their masculinity.¹⁰

Recommendation A

Targeted work to tackle the stigma of HIV within particular communities should be supported and reinforced.

A campaign to challenge the stigma and prejudice which exists around HIV within the black African communities was launched by Terrence Higgins Trust in 2001. It is only through tackling the stigma attached to HIV within the African communities themselves that uptake of HIV testing can be increased. This, in turn, will lead to better treatment options should the test give a positive result.

2.4 A failure to tackle societal inequalities can lead to further social exclusion

Much of the social exclusion which gay men and, to a lesser extent, other groups experience can be traced directly back to the failure of the state and society to afford them equal rights.

2.4.1 Social exclusion in education

Many gay men are socially excluded from an early age as a result of prejudice and discrimination within the education system. Bullying because of their sexuality and a failure on the part of many schools to address the specific educational needs of gay men around sexual health issues in particular, lead many younger gay men to question the validity of much of the education being offered.

In recent years, young gay and bisexual men have been particularly identified as being in need of focussed HIV prevention work. There is little evidence to demonstrate how effective this has been, particularly among young men of school age. Evidence suggests that many younger gay men prefer to have their HIV prevention needs met as part of a more holistic approach to their health and well being.^{11 12}

The Institute of Education conducted some research in 1997 around the responses of secondary school teachers to lesbian, gay and bisexual pupils in relation to bullying, HIV education and Section 28.¹³ They concluded that a number of schools failed to address the sexual health needs of gay and bisexual male pupils and many failed completely to include sexuality discrimination within their equal opportunity policies. Even fewer schools included lesbian and gay issues within their confidentiality policy.

The failure on the part of teachers to take action against homophobic bullying serves to further socially exclude young gay men and to reinforce the message that homosexuality is blameworthy. In some cases this can lead to some gay men contemplating or even attempting suicide as discussed below. Such feelings of low self-esteem can continue in to adult life and may be a contributing factor to excessive alcohol intake, drug dependency and risky sexual behaviour.

The discrimination faced by gay men can affect their mental well being in a number of ways. It can lead to mental distress resulting in feelings of loneliness, anger and depression. There is also evidence that suggests that gay and bisexual men are 13 times more likely to attempt suicide than heterosexual men.¹⁴

Recommendation B

Sex education and health promotion in schools must include HIV prevention messages relevant to young gay and bisexual men. Section 28 of the Local Government Act should be abolished in England and Wales in order to combat the social exclusion which many young gay men feel at school.

2.4.2 Homophobia leads to social exclusion

In 1995 Stonewall conducted a survey of 4,200 lesbians and gay men around issues of homophobic violence and intimidation in the UK. The results showed that 1 in 3 gay men had experienced violent attacks, 32% had been harassed and 73% verbally abused because of their sexuality.¹⁵ This abuse resulted in the majority of gay men avoiding showing affection in public, thereby contributing to the lack of visibility of gay men in public life. A more recent survey has also shown that over 42% of gay men avoid showing affection to their partners in public due to fear of homophobic attack.¹⁶

Homophobic discrimination can also lead to other practical problems that serve to further socially exclude many gay men. The failure to recognise same-sex relationships, for example, can cause problems over immigration, inheritance, pension rights, housing and employment benefits that can lead to further stress, mental anguish and financial hardship.

A recent survey showed that almost 20% of gay men reported having had bad experiences when accessing sexual health services and almost 30% did not feel safe enough to discuss their sexuality with their own GP. This might explain why almost a third of gay men had never sought any kind of advice or help around their sex life or sexual health.¹⁷

2.4.3 Racism and xenophobia lead to social exclusion

Many black Africans also suffer social exclusion as a direct result of the racism and xenophobia endemic within society. Black people in the UK face a range of inequalities in employment, education and everyday life which can make sexual health issues relatively remote.

This is particularly the case for asylum seekers as a result of dispersal under the Asylum and Immigration Act (1999). They can find themselves placed hundreds of miles away from other members of their community, away from all support networks and everything that may seem familiar. For those asylum seekers with HIV, this can have very detrimental effects on their health and well being as many are unaware when they arrive that they have HIV, and are often dispersed to places where there is unlikely to be any sexual health information targeted at them. A delay in testing can often mean that there will be restricted or less effective treatment options available to them. It can also result in them unwittingly passing on the virus to sexual partners or future children.

Many black Africans do not have English as their first language and may find accessing HIV prevention and information difficult. Although Terrence Higgins Trust and a small number of other HIV organisations do offer information in French and other African languages, most are not able to do this. This is particularly the case with agencies outside London, which asylum seekers who have been dispersed will find themselves having to use – where they exist at all. In addition, much HIV information still being produced fails to grasp the need for prevention information to be culturally sensitive to the needs of minority target groups.

Recommendation C

People undertaking HIV prevention and information work should ensure that materials and methods are culturally appropriate to the groups they are to be used with, and that all groups at particular risk in their catchment area are targeted.

2.4.4 Public perceptions of drug use lead to social exclusion

As with other groups discussed here, many injecting drug users have suffered discrimination from all levels of society and remain highly socially excluded. Although such exclusion may be partly due to legal considerations, injecting drug users are also more generally discriminated against. This can range from access to health care (where many generalist staff are reluctant to deal with them) to housing opportunities. The assumption is often made that all drug users are chaotic in their social behaviour and linked with crime, leading to reluctance to interact with them from many people. This exclusion is an obstacle to personal and public health by discouraging people who use drugs from seeking support from anywhere but drug specialist agencies.

2.4.5 Social exclusion in the prison service

Prisoners are often at a heightened risk of HIV infection, whether from sexual relations with other prisoners or through sharing injecting equipment. Prison authorities, however, frequently deny the existence or commonality of these practices, because of their illegality. This denial of reality effectively colludes in the onward transmission of HIV, both within a prison and by those unknowingly infected on release.

Recommendation D

The Prison Service and Home Office should recognise the prevalence of risk activities within prisons and take steps to prevent transmission, including access to condoms and cleaning materials for injecting equipment.

3. Social exclusion increases ill health in people with HIV

In addition to contributing to the spread of the virus, social exclusion factors also increase the risk of ill-health amongst people with HIV. This can happen in a variety of ways, some of which are common to many groups of people with HIV and some of which are related to particular groups.

3.1 Some people who know, or fear, they have been at risk of HIV choose not to test for fear of the social exclusion they may face

Fear of what may follow is a factor for many people in deciding not to test for HIV. This may be expressed as a concrete fear of exclusion from a range of financial services such as insurance and house purchase; or it may be a fear that the person will be shunned within their family, relationship or community; or it may be a general fear of the stigma of HIV.

A significant number of people continue to present with late-stage HIV illness in the UK, and comprise a large part of the 500 or so people who continue to die each year with AIDS. Many of these are people who may know that they have been at risk of HIV through sexual or other transmission, yet their fear of the consequences of being found to have HIV has outweighed the prospect of untreated illness and death.

In a socially excluded minority community, where family and friends may seem your only allies, revealing a positive HIV diagnosis risks exclusion from even these, and from other forms of community support. There is a particularly strong stigma attached to HIV in most African communities and, often, a lack of accurate information in accessible formats. At one major London clinic, African patients presented with, on average, an immune system twice as damaged as gay men. They needed to start treatment only 31 days after testing, compared with a respite of two years for the average gay man at the same clinic.¹⁸

3.2 Social exclusion makes it difficult for some people with HIV to prioritise their healthcare

There are many problems caused by social exclusion and social disadvantage which may make health care a low priority in someone's life. Amongst these are homelessness, poverty, poor mental health and fear of persecution. Homelessness in particular makes it difficult to lead anything but a chaotic lifestyle and puts managing appointments and treatments beyond the reach of many.

People seeking asylum are, by the nature of their situation, particularly susceptible to all or most of these, and many asylum seekers in the UK have also come from countries where

HIV is prevalent. They are often physically or mentally harmed by their experiences; many do not speak English or understand British systems of healthcare and justice; they seldom have any financial resources; current media and public attitudes towards them are pejorative, demeaning and even physically threatening. In addition, many asylum seekers suffer social exclusion through racism, as discussed above.

Under the National Asylum Support System (NASS), asylum seekers are dispersed across the country, often to areas of low HIV prevalence with no clinical experience in treating families or African people. The experience of the Terrence Higgins Trust Advice Centre is that if they are dispersed, they may wait up to six weeks for food vouchers to be provided, and they are often housed in substandard accommodation which contributes to their health problems. If they remain there, their healthcare may suffer and they will experience considerable isolation with regard to HIV. Returning to London, where they would receive specialist care and community support, means losing most of their entitlement to state support and furthering their exclusion in order to maintain their healthcare – although this, in turn, may be damaged by the poverty and poor living conditions they face.

Florence, a pregnant asylum seeker with HIV was relocated to an area around seventy miles from London. Although there was a local HIV clinic, the doctor had never treated a pregnant woman and referred her back to London, but Florence was unable to pay the fares. The hospital eventually offered to give her the fares rather than treat her locally. However, they would not pay for her husband to attend consultations with her for support.

NASS provides asylum seekers mainly with food vouchers rather than cash. Terrence Higgins Trust has supported clients who have been singled out for abuse and even physical attack after being identified by their use of vouchers in supermarkets, but this can happen to any asylum seeker. There is no provision in the voucher system for the special dietary needs of anyone with chronic long term illness, although wasting disease and loss of appetite are common symptoms of HIV disease.

In particular, women who are responsible for looking after a family frequently put their own needs, including health needs, last. Where they have not disclosed their HIV diagnosis due to fear of stigma, they may also find themselves unable to access or manage treatments for fear of discovery by others in the family.

Recommendation E

The Home Office should reform the current asylum arrangements to take account of the needs of people with long term or specialist health conditions, including HIV. These reforms should include the abolition of the current voucher system.

3.3 Social exclusion may prevent some people from accessing appropriate healthcare at all

Asylum seekers with HIV, as discussed above, may have to choose between appropriate healthcare and other basic needs. But many may not even acknowledge that they have the virus because of fears of being refused leave to stay in the UK. There is little or no information provided by NASS about HIV, even to people arriving from countries known to have a high incidence of the virus. Many people seeking asylum assume that an HIV diagnosis will lead to being expelled from the UK.

For people within the prison system, accessing appropriate HIV care may be very difficult. Although in theory any prisoner should be able to get treatment for HIV, many may choose to hide their diagnosis for fear of stigma amongst their peers. If they do access treatment, they are unlikely to have control over their medicines and poor staffing levels may mean a prison regime which makes it difficult or impossible to take the proper treatments at the right times of day. If they are moved between jails, they will face interruptions to their treatment of up to several days at a time.

Although Britain has a free healthcare system, many migrants and asylum seekers are unaware of their entitlement to treatment or how to access it. Information on services may only be available, if at all, in English – and then often in a kind of English unfamiliar to anyone without a clinical background. Black African people in particular have a lower take-up of testing and treatment services for HIV than others and frequently present very late and unwell.¹⁹ This, in turn, makes treatment less likely to be of benefit and enhances the likelihood of early death.

3.4 Social exclusion and discrimination are factors in some people choosing not to access some healthcare

As more people live longer with HIV and treatment costs continue to rise, clinic budget constraints mean that, increasingly, people are being directed towards their GP and other generalist primary healthcare services for general prescriptions, dentistry, health visiting, etc. The growing number of people with HIV who live outside high prevalence areas are also dependent upon generalist services for much of their care. Additionally, Government emphasis on devolution of planning within the health services to local level is likely to lead to less specialist and more generic healthcare services locally for many people with HIV in the future.

Given all the above, it is of vital importance that people with HIV feel confident that they will not suffer exclusion or stigma in healthcare. A basic level of healthcare is often seen as a human right in the UK, and yet people still report difficulties in accessing services such as dentistry because of a positive HIV diagnosis.²⁰ Although the majority of people with HIV in London have disclosed their HIV status to their GP^{21 22}, many others have not, for fear of how the information may be held and used, or fear of prejudice.²³ This inhibits their ability to use ordinary healthcare services, or inhibits the usefulness of those services when accessed, if they do not disclose their status.

Many of the communities most affected by HIV are also those which may face day to day discrimination or simple ignorance in the way they are treated by our healthcare system. This creates a reluctance to engage with those services, which may in turn be damaging to the health of someone with HIV.

As mentioned earlier, many gay men are reluctant to discuss their sexuality with their own GP due to uncertainty as to the response that they will receive. Many others have never accessed any sexual health service, partly due to a concern over how they will be treated.²⁴ Clearly, in terms of primary care there may be a need for a GP to be aware of a patient's HIV status and yet if they are not even aware of their patients sexuality, it is unlikely that this will be the case.

Recommendation F

The NHS should ensure that health authorities and practitioners throughout the United Kingdom are reminded that asylum seekers and other socially excluded groups are entitled to their services on an equal basis with others.

Injecting drug users often have difficulty in accessing any health care which is not specialist to them, due to stigma and reluctance to work with them. Even within HIV-specific services, drug users often face discrimination and suspicion from both staff and other service users.

3.5 Some people may have difficulty in managing their treatment or accessing support services because of social exclusion

While many people overcome the barriers described above to access treatment, they may still face difficulties in adhering to their treatment regime or in finding the social support they need. This is of particular importance in the field of HIV, where the treatments are still new, often experimental and demand a very high level of adherence compared to other medications. Research presented at the World AIDS Conference in Geneva (1998) showed that adherence to treatments can be affected by a range of social exclusion factors. These include poor mental health, poverty, poor social support mechanisms and language problems; understanding of the reasons behind treatment and faith in its efficacy are primary motivators for adherence.

There are particular barriers to accessing HIV services for African people. These stem from cultural differences, fears about confidentiality, language difficulties, a lack of understanding of how to access free healthcare and, often, fears that to do so may involve other authority figures such as the Home Office or Social Services. Many general health services, including antenatal clinics where many women are now diagnosed, are often not tailored to the culture or language of African women²⁵. Additionally, some health practitioners do not always refer people to appropriate social support.

Lilian, an African woman, visited her GP with an unspecified illness. The GP tested her for HIV without any information or preparation for the result, and told her over the phone that she was positive. The GP had no previous experience with HIV, and referred her only to a clinic, at some distance. The clinic offered treatment, and she found Terrence Higgins Trust only through a poster there.

Following the Immigration and Asylum Act (1999), asylum seekers entering or already in the UK are being dispersed across the country. Terrence Higgins Trust lawyers have dealt with many cases where a person has been placed somewhere with no specialist HIV services within reasonable travelling distance, or in towns where the HIV clinic has no experience of caring for Africans (who may have differing health beliefs, differing types of HIV, and differing responses to some interventions from most Europeans) or for children, who require very different treatment and care. HIV pregnancy care is a specialist area which is evolving very quickly and standards of support vary considerably between different clinics, with almost all the specialists in London or Edinburgh. Additionally, almost all community support services for African people with HIV are located in London, adding greatly to the social exclusion of African asylum seekers with HIV placed elsewhere.

People with HIV often need to combat wasting disease and digestive problems, but asylum seekers with HIV are unable to get food which they are accustomed to or able to tolerate at the limited outlets which take vouchers. Some treatments need to be taken with food, and Terrence Higgins Trust has experience of people who have been unable to stick to their drug regime because of difficulties with vouchers; failure to adhere to the correct treatment regime can lead to drug resistance, loss of efficacy and early death. There is no provision within the current arrangements for baby milk vouchers, which leads women with HIV to occasionally breastfeed, in order to stretch the vouchers further, when they should avoid doing so.²⁶

Joseph is an asylum seeker who was diagnosed late and with AIDS. He was immediately put on a complex regime involving rather toxic drugs which needed to be taken with particular types of food. However, because he was inexperienced in managing vouchers (and possibly because of the level of illness and the mental distress caused by such a severe diagnosis), he ended up trying to survive on a loaf of bread for four days before seeking help, thus threatening the effectiveness of the treatments and his own health.

Recommendation G

NASS should cease to disperse asylum seekers with HIV to areas where there is little or no appropriate support available to them and should provide training for their staff in understanding the needs of people with HIV and other long term medical conditions.

4. HIV itself causes further social exclusion

4.1 Family and community

The majority of people with HIV in the UK have not told some or all of their family. This often includes people with whom they are living, leading to problems in managing treatment or accessing support.²⁷ In the experience of Terrence Higgins Trust and Lighthouse, their fears of rejection can be based on reality.

Margaret was tested for HIV while pregnant. Her GP visited her at home and disclosed her diagnosis in the presence of her husband. Blaming her, her husband walked out and left the family without any means of support. In distress, she agreed to an unwanted abortion because of this.

The stigma of HIV can be as strong within affected communities as within the general public. Although the fear of disclosure is particularly experienced within some African communities²⁸, causing people with HIV to travel long distances to access services without being seen, it may also be present within other communities, e.g. gay men and within tight-knit localities.

Catherine was diagnosed with HIV in the 1980s. When this became known, her home was daubed with graffiti and she was forced to move. Her young daughter was persistently assaulted at school, as it was assumed that she too had HIV. Some years later when colleagues in the daughter's first workplace discovered her mother's HIV, the girl was forced to leave her job for the same reason.

As can be seen from the case study above, the stigma of HIV within a school – even by association – can lead to exclusion. Many people prefer to isolate themselves and hide HIV within their family for fear of bullying, threats and public prejudice. This means that they are unable to obtain the social care and support they may need from the social services and local education system. Where HIV is disclosed at school, families have often felt forced to move. This, in turn can impact on employment and housing.

The public stigma of HIV is so strong that, once someone's diagnosis is known in a neighbourhood, they may be subject to considerable pressure to move, including threats of violence. Where they are in public housing, with an unsympathetic or inexperienced authority, this can lead to loss of housing.

Donald had lived in a council flat in a small block which he had furnished and decorated. Somehow his HIV diagnosis became known to other people locally. After written threats and paint on his door failed to make him leave, someone

tried to burn him out with rags and petrol through the letterbox. He fled the area to sleep on a friend's sofa, but the local authority tried to say he had made himself intentionally homeless and to refuse rehousing.

4.2 Health and social care

Terrence Higgins Trust has dealt with many causes where, despite apparent hygiene precautions, dentists have been unwilling to treat people with HIV. Where treatment is offered, people with HIV are often asked to wait to the end of the day.

Christopher questioned his dentist about hygiene in the surgery and was assured that he didn't need to worry about it. He then told the dentist that he had HIV. Before his next appointment, he was rung and told the time had changed to the last appointment of the day, with no explanation. This happened twice and, when challenged, the dentist explained that it was so that instruments could be more thoroughly cleansed after his visits. Christopher felt angry that staff had not been honest about reasons for changing the appointment, and worried that, had he taken the dentist at his word about safety and not disclosed, he might have been putting other people later on the day's list at risk.

People with HIV have reported that they are reluctant to use non-specialist health services because they fear being met with ignorance or prejudice.²⁹ This poor reception, often coupled with misconceptions about gay men or Africans, can lead to self-exclusion of some people with HIV from the health care they need. Where they do need to use services, they may be asked to wait to the end of the day or be repeatedly postponed to the end of the 'list'. In extreme cases, this has caused damage to their health.

Recommendation H

Health and social care professionals should receive information and training to ensure that they understand the current reality of living with HIV and are able to respond appropriately to people with HIV who need their services.

People with HIV, as with any life threatening condition of uncertain prognosis often report a range of mental health problems ranging from mild depression to more serious conditions such as mental breakdowns.³⁰ However, this can lead to a situation whereby HIV agencies are ill-equipped or unwilling to meet their mental health needs and mental health agencies cannot see beyond their HIV referring them back. HIV services may misinterpret mental health problems as bad behaviour and simply exclude a difficult service user rather than working with local mental health services for them. This can lead to 'revolving door' situations whereby a person may persistently re-present with minor immediate needs but their underlying difficulties are never tackled.

Ed was a 27 year old gay, HIV positive man with a number of mental health problems and a history of depression and drug and alcohol misuse. In the past, his own GP had reacted to Ed's mental health problems by blaming his being gay. He has attempted to use a variety of support services around mental health and HIV, but had had repeated experience of what he describes as 'falling through the gaps' as HIV support services were unable or unwilling to deal with his mental health problems. In addition, mental health services felt unable to deal with his HIV issues.

Children whose parents have died with HIV may have difficulty in finding appropriate fostering or adoption placements, but some families with HIV, particularly those unfamiliar with social services, avoid involvement with the local authority for fear of disclosure of their HIV, or fear of their children being taken into care. This can make planning for the future of the children even more difficult.³⁷

4.3 Employment

Many people with HIV seeking employment are in a Catch 22 situation. If they disclose their diagnosis at interview, they may well be refused the job through prejudice about HIV; if asked a question about health where they fail to mention it, their employer may take the view that they have concealed a material fact.

Raul is gay and a Spanish national living in London. He went for a job as a receptionist at the offices of a Spanish organisation and appeared to be having a very good interview. Indeed, Raul felt it was going so well that he decided to reveal his HIV positive status to the interviewer. The atmosphere changed immediately and Raul was told he would need to sit an exam even though no mention of this had been made earlier. He was not offered the job.

Most people with HIV nowadays prefer to remain in employment and others are interested in returning to work where HIV treatments have stabilised their health. However, concerns around the possible results of revealing an HIV diagnosis to employers and colleagues or to prospective employers remain very real. This is despite a number of high profile cases where employers who have blatantly discriminated against people with HIV have had to pay large amounts to settle.

Mark told his employers, a major supermarket chain, that he had HIV shortly after diagnosis. He was initially given time off from his job in order to start HIV treatment. When he felt ready to return he was told that it would not be possible as it was felt that his condition would cause offence to other staff and customers. Following the threat of legal action, his employers subsequently settled out of court rather than allow him to return.

Recent research suggests almost a third of people with HIV fear the discrimination they could face from colleagues and employers if it was known at work that they were

positive.³² Research into patterns of disclosure usually shows that less people with HIV have felt able to tell others in their workplace than any other regular source of social contact. Such concern over discrimination is understandable, as HIV remains a highly stigmatised and feared condition.

Some employers, aware that they may face difficulties if they openly mistreat an employee with HIV, attempt to cover this by forms of constructive dismissal. In the experience of Terrence Higgins Trust employment advisors, this has included drastically altered and unacceptable shift patterns and requests to wear inappropriate clothing such as gloves or masks which would mark the person out. Some employers have simply failed to stop victimisation by other staff, making continued work impossible. Although the majority of employers do not behave in this way, many people are unwilling to risk their jobs to find out. This secrecy, in turn, excludes them from a potential source of support, contributes to isolation and exclusion and may lead to difficulties if they become ill or need time off to cope with new treatments.

Although the Disability Discrimination Act 1995 made discrimination in the workplace against someone with HIV illegal once they become sick, it currently offers no protection from discrimination based purely on an HIV diagnosis. In 2000, Terrence Higgins Trust called on the Government to amend the legislation to offer protection from the point of diagnosis with HIV.³³ This would effectively give everyone with HIV protection from the discrimination in the workplace which is still common. The announcement by the Government in 2001 that it intended to make these changes is to be welcomed.

The current benefits system is also problematic for people with HIV, or indeed any episodic chronic condition. Current regulations are inflexible and can make it extremely difficult for someone who wants to work but is unsure of their stamina or capacity to “try out” work without losing their place in the system and having to start again from scratch if they are unable to sustain work. Many people with HIV are unsure of their ability to maintain regular or full time work.

Additionally, many people diagnosed with HIV when there was little or no treatment available now have a history of unemployment which makes them unattractive to employers and causes great difficulty in re-entering the job market. Research shows that people are afraid of becoming ill, and worried about the impact of employers or colleagues finding out about their HIV.³⁴ This places people in a vicious circle where their HIV damages their ability to work, their unemployment contributes to their social exclusion and their social exclusion, through poverty, depression and isolation, impacts further on their health.

Recommendation I

The Department of Work and Pensions should review benefit regulations to make them more flexible for people with long term chronic medical conditions and the Department of Education and Skills consider ways of supporting those people with HIV who are able to work to do so.

5. What role for Government?

5.1 Co-ordination and collaboration within government and the voluntary sector

To break any cycle of HIV and social exclusion, people with HIV must be put before the separate departmental and organisational agendas of government departments, health authorities, social services and voluntary groups. The lack of joined-up thinking by those in authority is a key component in contributing to social exclusion.

As can be seen in work undertaken by the Social Exclusion Unit of the Cabinet Office on areas such as rough sleeping and teenage pregnancy, cross-cutting Government work is vital to bringing about any real long-term change. Currently, the Departments of Health, Work & Pensions, Education & Skills and the Home Office all have a distinct role to play but the lack of co-ordination between them on HIV is conspicuous. Even within Health, there is no clear co-ordinated lead on the issue. Closer working ties need to be established in all relevant areas with a lead on HIV health strategies and services from Health, educational initiatives and employment programmes from Education & Skills, a more flexible approach to benefits systems for people with long term chronic conditions from Work & Pensions and more appropriate asylum and immigration regulations and practice from the Home Office. Unless these areas are co-ordinated in a similar manner to teenage pregnancy work, clear messages and workable solutions will not happen and the direction of work in one Department will continue to cut across the strategic plans of another.

Similarly, there needs to be a renewed commitment to genuine collaboration within the HIV voluntary sector, to ensure best use of limited funding and less duplication and rivalry. Competitive tendering to provide services, while one way of decreasing the large number of HIV organisations and their associated duplication of costs in certain towns, should not be allowed by those organisations to come before meeting the needs of people with HIV. The undoubted expertise within the sector needs to be more efficiently harnessed to meet these needs. However, it is clear that, as with rough sleeping and teenage pregnancy, a lead from the Government in cross co-ordination would cascade into and motivate the voluntary sector to work in genuine partnership.

Recommendation J

The Government should establish a cross-departmental coordinating mechanism to oversee the legislative and other changes needed to combat social exclusion through HIV

5.2 A public awareness/de-stigmatisation campaign

Though some people have called for a renewal of the public information campaigns of the 1980s, it would be misleading to run campaigns suggesting that everyone is at equal risk of HIV, or equally affected. There is, though, an urgent need for robust, Government-endorsed messages to break the barriers of HIV stigma and combat the prejudice which actively hinders the full social inclusion of people with HIV.

Government needs to be seen to be leading the way in encouraging the public and media to be more sensitive to the realities of life for people with HIV, especially in reducing sensationalism and stereotyping. A new Government public information campaign, especially one developed with people with HIV and the organisations supporting them, could be crucial in promoting a better public understanding of current situations.

Other countries have addressed this successfully; for example, the Australian Government's public education campaigns of the early 90's called "HIV doesn't discriminate, people do" and " Don't judge what I can do by what you think I can't". There is a similar need in the UK, clear from all the above evidence, to challenge and break down public fears and misconceptions which contribute to a range of forms of social exclusion for people with HIV in this country.

Recommendation K

The Government should fund and endorse a national public information campaign to reduce stigma and prejudice about HIV, which should involve people with HIV and those who support them.

6. Recommendations for improvements in the social inclusion of people with HIV:

- A. Targeted work to tackle the stigma of HIV within particular communities should be supported and reinforced.
- B. Sex education and health promotion in schools must include HIV prevention messages relevant to young gay and bisexual men. Section 28 of the Local Government Act should be abolished in England and Wales in order to combat the social exclusion which many young gay men feel at school.
- C. People undertaking HIV prevention and information work should ensure that materials and methods are culturally appropriate to the groups they are to be used with, and that all groups at particular risk in their catchment area are targeted.
- D. The Prison Service and Home Office should recognise the prevalence of risk activities within prisons and take steps to prevent transmission, including access to condoms and cleaning materials for injecting equipment.
- E. The Home Office should reform the current asylum arrangements to take account of the needs of people with long term or specialist health conditions, including HIV. These reforms should include the abolition of the current voucher system.
- F. The NHS should ensure that health authorities and practitioners throughout the United Kingdom are reminded that asylum seekers and other socially excluded groups are entitled to their services on an equal basis with others.
- G. NASS should cease to disperse asylum seekers with HIV to areas where there is little or no appropriate support available to them and should provide training for their staff in understanding the needs of people with HIV and other long term medical conditions.
- H. Health and social care professionals should receive information and training to ensure that they understand the current reality of living with HIV and are able to respond appropriately to people with HIV who need their services.
- I. The Department of Work and Pensions should review benefit regulations to make them more flexible for people with long term chronic medical conditions and the Department of Education and Skills consider ways of supporting those people with HIV who are able to work to do so.
- J. The Government should establish a cross-departmental coordinating mechanism to oversee the legislative and other changes needed to combat social exclusion through HIV
- K. The Government should fund and endorse a national public information campaign to reduce stigma and prejudice about HIV, which should involve people with HIV and those who support them

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