

# **Prejudice, Discrimination and HIV**

**A Report**

Terrence Higgins Trust  
Policy Campaigns and Research Division  
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## Foreword

Prejudice and discrimination have gone hand in hand with HIV and AIDS since the syndrome was first described some 20 years ago. Their continued existence is unacceptable.

Many people with HIV experience problems in their everyday lives purely because of the virus. People fear – and can face – rejection from friends and family and difficulties at work. They may get worse treatment from health and social care services. Sometimes their own communities appear to turn their backs on them.

As a result, as this report shows, many people choose to conceal their HIV diagnosis for fear of the possible consequences. This can result in other problems; increased anxiety; difficulty in making relationships; lack of access to information or services; unexplained absences from work; misdiagnosis of health problems. Some people choose not to get tested at all because they fear the difficulties a positive diagnosis could bring, thus risking long term damage to their health and possibly even death. This understandable concealment also means that the real extent of discrimination remains hidden.

In examining the research evidence available, we expected to find a catalogue of stories about prejudice and discrimination. What surprised us was the evidence that the fear of discrimination is, if anything, the more disabling problem currently for many people. Whereas prejudice and discrimination undoubtedly do occur, the fear of them appears to be having at least as much, and possibly more of, a detrimental effect on the health and well being of people with HIV in the U.K.

Currently, the majority of people with HIV in the UK do not experience direct discrimination; but they fear it, and will try to avoid it. It is vital that people with HIV be given information, not only on the levels of genuine prejudice but also on how to combat it when it does occur, and space to support each other in doing so. It is also important that Government and HIV agencies act to fully protect the right of people with HIV to live lives free from fear of abuse or attack.

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

## Acknowledgements

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## 1. HIV in the UK – the facts

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.<sup>1</sup> Currently, there are around 33,200 people in the UK infected with HIV but around a third are untested and do not yet know that they have the virus.<sup>2</sup>

Within this growing population living with HIV, the largest group are gay men. There are now more new diagnoses amongst heterosexuals (48% of all diagnoses in 2000), but much of this transmission took 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. Currently there are less than 500 deaths a year in the UK directly from HIV infection. The two main causes of these deaths are being diagnosed too late for effective treatment, or treatments failing or being ineffective for some people. The most likely way to bring down this death rate is 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. 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 drop, as the incidence of unprotected sex rises. There is also evidence that the level of awareness of HIV amongst young people is declining.<sup>3</sup>

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.<sup>4</sup> This, coupled with an increase in the number of hepatitis C diagnoses among drug users, suggests a level of undiagnosed HIV infection may be present within this community.

## 2. HIV related prejudice and discrimination

Prejudice and discrimination against people infected, or presumed to be infected, with HIV has occurred since the disease was first identified in the early 1980s. More recently, the impact of effective long term treatment has meant that more people with HIV have been able to lead apparently ordinary lives, including staying in work, as HIV related illnesses have declined. The visibility of HIV infection has also decreased, as conditions such as wasting and skin diseases have become less common. Despite this lowered visibility of the results of HIV disease, for a substantial proportion of the growing numbers of people with HIV, prejudice and discrimination remain a reality.

A study conducted by Sigma Research in 2001 into the experiences and needs of people living with HIV suggested that up to 20% had experienced some form of discrimination in the last 12 months.<sup>5</sup> Although these findings are preliminary they suggest that discrimination is experienced in a range of places and continues to be a real concern for many people living with the virus.

Recent research into stigma and discrimination against people with HIV in the United Kingdom has been minimal and low key, often being one or two questions in a general survey. In conducting a major literature search and contacting over 20 key organisations, relatively few pieces of recent research relating to discrimination based on HIV were found.<sup>6</sup> Evidence was primarily anecdotal, and there was also no systematic collection of case studies of discrimination.

### **Recommendation A**

**Research should be undertaken to map the current prevalence of HIV prejudice and types of HIV discrimination experienced in the UK, and Terrence Higgins Trust should establish a database of case studies.**

The evidence that does exist, however, is enough to show that prejudice, and fear of discrimination, do play a significant role in both the transmission of HIV and the progress of any subsequent illness. In its recent National Strategy for Sexual Health and HIV, the Department of Health make clear the need to reduce stigma and the relationship between illness and social exclusion. They call for strategies to deliver this target.

### **Recommendation B**

**The Department of Health should ensure that their concerns about the role of stigma in HIV transmission and illness be met by, amongst other strategies suggested here, supporting projects to aid people with HIV in challenging prejudice and discrimination through positive role models, speaker and media work and support networks.**

## 2.1 Employment

Many people with HIV have managed to remain in employment since their diagnosis. For others, the effective use of HIV treatment has meant that they have become well enough to contemplate a return to work or study.<sup>7</sup> Programmes such as *Positive Futures* in London have been developed to provide training and support in helping people with HIV to make decisions about their future career or study options and Terrence Higgins Trust is a partner in providing these services. However, despite the growing number of people with HIV who are in employment, discrimination remains a problem.<sup>8 9</sup>

*When Ben found out he had HIV, he only told a couple of close friends – but one of them was the partner of his union representative at his workplace in a major national charity. The union rep began to maliciously tell others at work and refused to let Ben use kitchen equipment. Despite taking out a complaint, Ben was made to work alone with the rep on several shifts. Ben felt that management were more interested in his HIV status than the complaint and the union failed to give him legal or moral support. Eventually he felt forced to quit both the union and the job. "...life is great now. But I learnt that even the most liberal organisations with good track records of equality are shit scared of HIV and think nothing of those of us living with it. My union had a large handbook on HIV... and broke nearly every single promise of equality and respect for people living with HIV."*

The Disability Discrimination Act 1995 (DDA) has made discrimination in the workplace against a person illegal where they are unwell through HIV, but this does not cover the stigma and prejudice which they often face from their colleagues even when well. Although the Government have signalled that the DDA will be amended to protect people with HIV from discrimination from the point of diagnosis, this has still to be enacted. Both Terrence Higgins Trust and the Disability Rights Commission have called for this to happen as soon as possible. In addition, the DDA only requires employers with over 15 employees to comply with the legislation. Clearly this is unacceptable as it means that over 12 million employees are not protected from discrimination in the workplace.

Prejudice and discrimination within the workplace can take a variety of forms and at their worst can result in people being sacked from their job.<sup>10</sup> However, subtle discrimination is far more common and can often feel worse than open discrimination as it is much more difficult to tackle. In some instances, whispering campaigns have occurred while in other cases people have found their job changed to such an extent that it was too difficult to continue in their employment. This is particularly true for those people who are also on complex HIV treatment.

*Terry had been working shifts for some time in a fast food restaurant when he began his HIV treatment. He decided that it would be best to tell his employers what treatments he was taking several times a day and why, rather than just be seen taking pills. Although there was no overt discrimination, he noticed soon after this that his shift patterns were changing and becoming ever harder to manage, especially with the treatments. Before long, the job became impossible to do. Because he had kept a record of his shift pattern, Terry was able to prove constructive dismissal.*

As a result of the fear of prejudice and discrimination, many people with HIV choose to remain silent about their status and/or other factors. Three types of silence are often used to protect themselves; silence about having HIV, silence about being on HIV treatment (possibly for fear of it reinforcing the notion that the person is sick and therefore likely to need extra time off work), and in some cases silence around their sexual orientation.<sup>11</sup>

For many Black Africans, their HIV status is just another hurdle to overcome in trying to find or maintain employment.<sup>12</sup> Research has consistently shown that despite having broadly similar educational qualifications, Black people were more than twice as likely to be unemployed than White people were.<sup>13</sup> This double discrimination is discussed later in this report. Further evidence on employment discrimination and HIV can be found in the Terrence Higgins Trust report "Give Us A Job" (2000).

#### **Recommendation C**

**The Government should enact agreed proposals to extend the Disability Discrimination Act to cover medical conditions from the point of diagnosis, rather than the onset of illness, in the next legislative session.**

## **2.2 Healthcare**

Stigmatisation of people with HIV in healthcare settings was a well-established, if disturbing phenomenon in the earlier years of the epidemic in the UK, and in the late 1980s and early 1990s many studies identified substantial, widespread and persistent hostile or discriminatory attitudes among various categories of health and social care professionals.<sup>14 15</sup>

In recent years evidence suggested that for most people with HIV, their experience, in terms of their HIV related treatment at least, is generally good.<sup>16</sup> Research amongst gay men showed 93% being satisfied with the service provided.<sup>17</sup> However, gay men tend to use a small number of HIV clinics where they know that they are unlikely to encounter prejudice. With both the spread of HIV amongst other population groups and the increasing "mainstreaming" of HIV services, however, many people with HIV fear that they may encounter substantial discrimination again in the future from non-specialist healthcare workers.

*Elizabeth and her partner were trying to conceive and were referred to a local general hospital service. Once they found she was HIV positive, the gynaecologist refused to do any further tests for fear of endangering themselves and their staff.*

Gay men are encouraged to attend sexual health clinics at regular intervals, which gives greater opportunity for HIV to be detected and subsequent HIV treatment more effective. Black Africans in the UK are less likely to regularly attend such clinics, preferring to visit a GP where their symptoms are less likely to be recognised for what they are. Consequently, by the time some Black Africans are diagnosed with HIV their immune system has been so damaged that HIV treatment is ineffective.<sup>18</sup>

Research about to be published shows that thirty five per cent of Africans had an AIDS-defining illness within one month of their HIV diagnosis. This compares with 13% for non-Africans.<sup>19</sup> This shows that many Africans are being diagnosed with HIV much later than White people although reasons for this remain unclear. However, lack of perceived risk as a result of viewing HIV as a disease associated with 'deviant lifestyles' may play a part in this.

The failure to diagnose some HIV at an earlier stage is also partly due to generalist healthcare professionals failing to spot signs of possible HIV infection. However, this in itself is possibly a result of a lack of cultural understanding and in some cases the patient themselves holding things back for fear of the consequences (including a possible HIV diagnosis). Much of this fear is due to ignorance of the treatment options available to people with HIV<sup>20</sup> and also because of the prejudice and discrimination that exists within some Black African communities and discussed below.

Black Africans with HIV are also less likely to be referred to specialist mental health services than White people and more likely to have progressed to AIDS when they were referred.<sup>21</sup> Although it is unclear whether the failure to refer Black Africans is because of a failure to recognise psychological need on the part of health care staff or a reluctance and fear on the part of patients to be referred, both are problems influenced by prejudice.

Experience of other health care professionals by people with HIV varies widely. Incidents involving dentists either refusing to treat HIV positive people or insisting that they are treated at the end of the day to ensure that surgical instruments can be 'properly sterilised afterwards' continue to be related to Terrence Higgins Trust and remain unacceptable.

Those providing services for people who have tested positive for HIV have tended to assume that people living with HIV no longer have a sex life and therefore do not have wider sexual health needs.<sup>22</sup> However, the reality is that most people with HIV continue to have an active sex life and may have cause to receive treatment for sexually transmitted infections or advice around their sexual health generally. It is therefore important that sexual health services remain accessible to people after they have been diagnosed with HIV.

The National Sexual Health and HIV Strategy<sup>23</sup> proposes that sexual health and HIV services should be organised into three levels. As part of the first level, it suggests that GPs should provide more sexual health services, including a much greater role in HIV testing and counselling. Many Black Africans feel that the GP surgery is the best place to receive information and/or services around HIV,<sup>24</sup> but as many as one in five gay men have had bad experiences with their GPs because of their sexuality.<sup>25</sup>

*A woman living in the Home Counties found her GP on her doorstep when she arrived home one day. The GP, who had received information that the woman was HIV positive, accused her loudly within earshot of the neighbours of putting the GP in danger by not disclosing her status.*

Clearly such experiences are a matter of concern when there is an increasing momentum towards replacing the "exceptionalism" of HIV/AIDS services with "mainstream" provision.<sup>26</sup> Although the provision of some health services can be effectively provided at a primary care level, there are a number of concerns that remain. These are particularly about ensuring the confidentiality of patients, particularly in light of the fear of prejudice and discrimination that many people with HIV have. In addition, prejudice and discrimination from General Practice staff need to be tackled, not only around HIV but also along the lines of race and sexuality.<sup>27</sup>

**Recommendation D**

**In the light of increasing prevalence of HIV and mainstreaming of healthcare services to people with HIV, the Department of Health and the Health Service should provide information and training on HIV to all relevant staff, and provide for consultancy to healthcare services needing support to manage the healthcare needs of people with HIV.**

## 2.3 Family and friends

For many people living with HIV, the most hurtful prejudice they may face comes from those to whom they would normally turn for support. Close family, friends and partners have been known to turn their back on people diagnosed with HIV. In addition, the sense of belonging that being part of a community provides can quickly disappear when that community appears to discriminate against you simply because of its own prejudice against HIV.

*Mary, who shared a house with three women friends, came home one day to find every cup and plate in the house broken and put in the bin. One of the women had found out that Mary had HIV and this had been her reaction.*

Africans living with HIV in the United Kingdom can face particularly harsh discrimination, even from their own families. There is evidence to suggest that African women in particular are sometimes judged as having brought shame on their family and run the risk of abandonment as their husbands feel unable to accept them.<sup>28</sup> This often leads to financial and further social difficulties.

Research commissioned by Terrence Higgins Trust in 1999 also found that more than 1 in 10 people with HIV had experienced prejudice and discrimination from neighbours. Possibly because of links with racial prejudice, for Africans with HIV this figure was higher.<sup>29</sup>

*Two African men living in shared housing were asked to use a bucket instead of the communal toilets after the landlord informed the other tenants that one of the two men had HIV; the men refused to tell the other tenants which of them it was, for fear of further persecution of the identified individual.*

As a result of having already witnessed discrimination about HIV, many Africans who are recently diagnosed choose to keep that diagnosis secret from their family, friends and community. Although this means that they do not have to live with the day to day fear of discrimination, it has the negative impact that they have few people, if anyone, to talk to about their concerns for the future,

to lean on for emotional support or to confide in about problems they may be facing. This appears to be directly related to the climate of secrecy and shame around HIV that prevails within many African communities.<sup>30</sup>

**Recommendation E**

**HIV social care organisations should give support to people wanting to set up local support groups and systems to help people combat incidents of discrimination.**

For gay men, rejection from their family remains a real concern following an HIV diagnosis, particularly where their families were unaware that they were gay. Even where their family was previously aware that they were gay, finding they have HIV can often lead to further prejudice and discrimination, sometimes as a result of their parents' fear of stigma from their own friends and neighbours.<sup>31</sup>

Although there is little evidence to suggest that the gay community as a whole discriminates against gay men with HIV, there are a number of examples where gay men have lost friends or partners once their HIV status became known.

**Recommendation F**

**Health promotion agencies producing information on sexual health and HIV should include, as appropriate, messages countering prejudice and discrimination both in the general population and within targeted communities.**

## 2.4 Prejudice and discrimination from the wider community

Historically, there has been consistent evidence of hostility expressed against people with HIV, and this has always been very closely linked to underlying hostility to gay men.<sup>32</sup> Drug users were also demonised, particularly in Scotland and other areas of high IV-drugs related HIV prevalence. Although there is little previously published evidence of Africans having been singled out for discrimination because of their known or assumed HIV status, Terrence Higgins Trust has a number of clients who have been harassed and/or victimised by strangers because they were assumed to be HIV positive.<sup>33</sup>

Much of the discrimination which people with HIV face has been fuelled by parts of the UK media which have historically been homophobic and racist in the tone in which they have alluded to HIV.<sup>34</sup> Recent media reports have done nothing to repair the damage done to those communities primarily affected by HIV.

**'NURSES WITH HIV RECRUITED!**

**Up to ten infected trainees from Africa can work on in NHS'**

*(Daily Mail, 12/01/01)*

### **'WHY DO WE TREAT GAYS AS HEROES?**

**If homosexual acts were as common as smoking, we would have to bury the victims in mass graves...'**

*(Mail on Sunday, 17/12/00)*

Perhaps one of the most high profile ways in which people with HIV have faced discrimination is in insurance. In the late 1980s the Institute of Actuaries advised that certain life policies should only be issued if applicants agreed to a blood test and in 1990 the Prudential Assurance Company announced that it would cancel benefits if an individual policyholder subsequently became infected with HIV.<sup>35</sup> Even today single men are often refused life insurance or face increased premiums if they refuse to answer or answer affirmatively questions which ask whether or not they are gay or bisexual.

*John, a single man, obtained a mortgage from a major building society and applied for illness cover with a well known insurer. Asked, on the form, if he was gay, he answered yes and was asked to take a full medical and HIV test. Despite the test being negative, and John being in a long term monogamous relationship (which was never asked about) he was told that his monthly premium would be more than doubled.*

In the past year, Terrence Higgins Trust has seen over 70 cases where HIV or perceived risk of HIV has been used to actively discriminate through refusing insurance policies or massively increasing premiums.<sup>36</sup>

#### **Recommendation G**

**In addition to the Codes of Practice produced by the Disability Rights Commission offering guidance to the providers of goods and services about their legal obligations, the Government should legislate to tackle the discrimination encountered by people with HIV and other medical conditions when they access goods and services.**

Prejudice against people with HIV can also appear in less expected and less publicised ways than these. Some religious organisations have denied funeral rituals to people who have died with HIV, while others have placed restrictions on participating in certain religious activities. In other areas, educational establishments have in the past refused to teach children infected with HIV.<sup>37</sup> Recently even Universities have attempted to remove students from courses when their HIV status was revealed.

*Julius had obtained a place on a training course for psychiatric nursing, but when he disclosed his HIV positive status to the college medical officer, the offer of a place was withdrawn. On investigation, with the support of his local HIV organisation, it was found that the college were extremely confused about routes of transmission and whether there was any potential threat (which there was not). The denial of a place appeared to have been a panic reaction without proper investigation.*

Partly as a result of knowing people who have been harassed, and partly as a result of the ways in which they have been historically demonised within the media, many people with HIV experience a

greater impact on their lives from the fear of discrimination rather than the reality. Although the discrimination faced by many people with HIV is real, the fear of discrimination appears to be more debilitating for more people. Indeed, there is persuasive evidence to suggest that people with HIV perceive other people to be more prejudiced against HIV than they actually are.<sup>38</sup>

A recent MORI poll showed that the majority of people in the UK believed that there was a great deal of stigma surrounding HIV, although less than 15% felt they were likely to donate time or money to an HIV charity.<sup>39</sup> The same research also showed that most people felt that anyone who contracted HIV through sex or drug use only had themselves to blame. However, it also showed that almost three-quarters of people felt that people infected with HIV deserve the same level of support and respect as people with cancer.

### 3. Double discrimination; HIV, sexuality, race and gender

Much of the discrimination faced by people with HIV is only partly based on their being HIV positive. The discrimination they face may also be as a result of their being gay, black, drug users or female. In some instances, those expressing their prejudices may suspect that the person their prejudice is targeted at also has HIV, but this is unlikely to be the root cause of the prejudice. In this way, HIV discrimination can be used to 'legitimise' other prejudices that may have become less acceptable.

#### 3.1 Discrimination against gay men

Historically, HIV prejudice in the United Kingdom focused principally on gay men, and there is evidence to suggest that many people continue to equate HIV with homosexuality to a significant extent. However, discrimination against gay men occurred long before the advent of HIV and continues to be widespread, although this is now less socially acceptable than previously.

As Terrence Higgins Trust has previously noted, the discrimination and prejudice which many gay men encounter from an early age and throughout their lives can have a detrimental effect on their sexual health and increase the likelihood of HIV transmission.<sup>40</sup>

Within the education system, the sexual health needs of gay men, including HIV prevention, are generally ignored and homophobic school bullying often goes unpunished. Gay men continue to be turned away from bars and restaurants and many experience abuse and even violence from strangers. There is evidence to show that many GPs are uncomfortable in discussing the sexual health needs of their gay patients<sup>41</sup> and there is evidence to suggest that within hospitals, gay men are often assumed to be HIV positive.

*Marlon was taken to his local casualty department with an undiagnosed illness. He was asked general questions about smoking, drinking and countries he had travelled to, to try and diagnose what was wrong with him. Asked where he worked, he gave the name of an HIV charity. He was then asked if he was gay. Although tests showed him to have viral meningitis, he was pressured to have an HIV test and given the impression this would be the only way of confirming the meningitis.*

For those diagnosed with HIV, homophobic prejudice and discrimination continue but with the added burden of discrimination based on their HIV status where this becomes known or suspected. As a result of this, many people with HIV find it difficult to talk about being positive even with close friends, family and partners. This fear of discrimination can go on to have a negative impact on the health and well being of people living with HIV.<sup>42</sup>

#### **Recommendation H**

**Medical schools should provide training for all student doctors on discussing sexuality and sexual health issues, including HIV, with patients.**

### 3.2 Discrimination against Black and ethnic minority communities

Racial intolerance has been a feature of life in the United Kingdom for centuries and has most visibly affected Black and Asian people. Unemployment among Black people can be double the rate for White people and among Black Africans the rate is over three times as high.<sup>43 44</sup> This is despite the fact that there is likely to be little, if any difference in qualifications.<sup>45</sup>

Black people are also more likely to be victims of crime, particularly violent crime and are more likely to suspect that the crimes against them were racially motivated.<sup>46</sup> School pupils from some Black communities are five times more likely to be excluded from lessons than White pupils. Despite this, Black students are as likely to achieve qualifications as White people are although they are far more likely to work towards vocational qualifications rather than purely academic qualifications.<sup>47</sup>

Because of the manner in which people fleeing war and persecution have been vilified in both the British press and political life, asylum seekers too have now become prime targets for racial abuse and violence. People born in Africa are the second largest group of people in the UK with HIV and some – but not all, despite regular confusion of the two groups even within the HIV sector – are asylum seekers. Thus, someone who is Black, seeking asylum and living with HIV may have to contend with very complex – and very visible – prejudice and discrimination.

There is no doubt that fear of attracting further persecution has led to a reticence on the part of UK Africans and community health promoters to publicly target HIV messages.

*"We would never use billboards to inform African people about HIV risk and prevention, because it would initiate hatred and misinformation from the rest of the public and result in the rejection of the messages by the African communities themselves. The last thing we want to do is put messages somewhere that White people would see them and think that all Black people have HIV. That would just put those communities at greater risk of discrimination"*

Liz Kawonza, *Head of African Health Promotion, THT*

#### **Recommendation I**

**HIV prevention information targeting Africans, Black people and/or asylum seekers should be produced but their messages and formats need to take into account the concerns of these communities around potential prejudice.**

### 3.3 Discrimination against drug users

In some ways, the discrimination faced by drug users is more pronounced than that faced by gay men and Black Africans. This is undoubtedly because of the criminal activity associated with IV-drug use and the stereotype of drug users as worthless junkies. So long as the law on drug use continues to criminalise possession of drug paraphernalia, it is difficult to see how discrimination against this group of people can be realistically challenged.

However, it is unacceptable for drug users infected with HIV to receive a poor standard of medical care and support. Evidence shows that GPs, for example, were less tolerant of drug users than any other group of patients<sup>48</sup> and many hospital staff and clinicians are uncomfortable in dealing with them. Those drug users with HIV who are in prison also need to receive better care for both their drug use and their HIV infection. There is evidence to suggest that prison can be highly detrimental to both.<sup>49</sup>

## 4. Fear of discrimination

Most people with HIV are unlikely to encounter the kind of discrimination reported in the media, although their chances of encountering discrimination generally increase if they are part of the gay or black communities as these groups remain visible targets. As discussed earlier, preliminary findings from the Sigma Research survey *What Do You Need?*<sup>50</sup> suggested that around 17% of people with HIV had experienced some form of discrimination.

However, because of a combination of media reports, personal witnessing and anecdotal evidence of discrimination against others, many people with HIV fear discrimination and the prejudices they will encounter should their status become known. This fear can deter them from active involvement in everyday life, discouraging them from employment, from new activities and from finding a partner. For many people, this fear of discrimination may be causing more harm than the reality.<sup>51</sup>

### **Recommendation J**

**Government or other campaigns on HIV prejudice and discrimination should provide examples of how such prejudice can be, and has been, overcome and should ensure that support is available to people with HIV so that their fears are not exacerbated.**

### 4.1 Fear of discrimination can result in people not seeking support from friends and family

Many people with HIV are so concerned about the way others might react that they choose not to reveal their HIV status to anyone. Although such a decision should be respected, it must also be recognised that in many cases an HIV diagnosis can be extremely difficult to deal with, particularly in the early days. Being unable to talk to family or close friends through fear of their reaction can lead to further anxiety and isolation.<sup>52</sup>

Although gay men are more likely to reveal their HIV status to close friends or lovers, one of their main concerns is around their family finding out they have HIV.<sup>53</sup> This can be worse if their family were not aware that they were gay and, even where they were, finding that someone also has HIV can reawaken the hostile reactions encountered when they first came out as gay.<sup>54</sup>

For many Africans with HIV, the community stigma attached to the disease means that they often have nobody at all to whom they can talk about their fears. Research indicates that the feelings of isolation, stress and social exclusion that this causes can have a detrimental effect on the immune system of someone with HIV, even where drug treatment is being taken, leading to further illness.<sup>55</sup>

### 4.2 Fear of discrimination can result in people not taking up employment

As Terrence Higgins Trust has previously pointed out, discrimination against people with HIV in the workplace is a real concern for many people.<sup>56</sup> Almost a third of people with HIV fear the

discrimination they would face if their status became known.<sup>57</sup> This is despite the fact that evidence from the United States has shown that where people with HIV have revealed their status to their employer, in 88% of cases there was no change in the way in which they were treated.<sup>58</sup>

It is difficult to know whether there would be similar findings in the United Kingdom, as many people with HIV prefer not to tell employers their HIV status. Cases of workplace discrimination highlighted by the media, although very important in signifying to employers that such discrimination is unacceptable and will be fought, may also exacerbate the fear of discrimination in many people living with HIV.

**Recommendation K**

**The Department for Work and Pensions should work with initiatives such as Positive Futures and HIV organisations to ensure that people with HIV receive appropriate support in returning to or obtaining work, alongside legislative sanctions against discriminatory employers.**

### **4.3 Fear of discrimination can result in people not accessing HIV treatment and care**

In some cases, the fear of people finding out that they have HIV causes them to avoid using the HIV services they may need. Africans in particular have expressed great concerns around being recognised at an HIV clinic or support service.<sup>59</sup> This might explain why many Black Africans would prefer to access HIV support and information from their GP, whom they can visit without other people automatically identifying them as having HIV.<sup>60</sup> Similarly, some Black African women with HIV have said they are afraid to take treatment in case members of their family or friends discover the medication around their house.<sup>61</sup>

There is evidence to suggest that a number of people with HIV do not use certain care and support services because they fear discrimination from the organisations themselves, on the grounds of their race or sexuality, or on the grounds of their perception of those agencies' core audience.<sup>62</sup>

**Recommendation L**

**Resources produced by HIV services should make clear the service's intended target audience/s and make active efforts to ensure that all those who may need them know that they are welcome.**

### **4.4 Fear of discrimination can prevent people from testing for HIV**

For some people, the problems they fear they would face are such that they are afraid to even be tested for HIV in case the result is positive. The fact that many people continue to associate HIV with 'deviant' lifestyles means that some people may also not see a need to get tested because they do not identify with those lifestyles.

For Africans in particular, the fear of being recognised by someone while getting a test is particularly strong.<sup>63</sup> Research has also shown that some Africans fear that an HIV diagnosis may lead to having their children taken away from them, or even result in deportation (for those who are not UK citizens).<sup>64</sup> The same research concluded that profound worries about the practical, social and emotional consequences of testing may act as serious barriers to service uptake.

#### **4.5 Fear of discrimination is greater among Black Africans**

Research has shown that Black Africans are twice as likely to fear discrimination because they have HIV than White people.<sup>65</sup> They are also twice as likely to be worried about dying although this could be because Black Africans tend to be diagnosed with HIV later and are therefore more likely to be sick than White people. As a result, HIV is likely to be identified later within the black communities than elsewhere and consequently more likely to be a serious, debilitating illness.

Black Africans currently seeking asylum were also extremely worried that the immigration service would be informed if they were diagnosed with HIV and had real concerns as to what the Home Office would do to them.<sup>66</sup> There was also great concern as to whether or not they would be entitled to medical care.

**Recommendation M**

**HIV information providers to African people in the UK should produce materials which make clear their medical and legal rights if diagnosed with HIV.**

## 5. Recommendations

- A. Research should be undertaken to map the current prevalence of HIV prejudice and types of HIV discrimination experienced in the UK, and Terrence Higgins Trust should establish a database of case studies.
- B. The Department of Health should ensure that their concerns about the role of stigma in HIV transmission and illness be met by, amongst other strategies suggested here, supporting projects to aid people with HIV in challenging prejudice and discrimination through positive role models, speaker and media work and support networks.
- C. The Government should enact agreed proposals to extend the Disability Discrimination Act to cover medical conditions from the point of diagnosis, rather than the onset of illness, in the next legislative session.
- D. In the light of increasing prevalence of HIV and mainstreaming of healthcare services to people with HIV, the Department of Health and the Health Service should provide information and training on HIV to all relevant staff, and provide for consultancy to healthcare services needing support to manage the healthcare needs of people with HIV.
- E. HIV social care organisations should give support to people wanting to set up local support groups and systems to help people combat incidents of discrimination.
- F. Health promotion agencies producing information on sexual health and HIV should include, as appropriate, messages countering prejudice and discrimination both in the general population and within targeted communities.
- G. In addition to the Codes of Practice produced by the Disability Rights Commission offering guidance to the providers of goods and services about their legal obligations, the Government should legislate to tackle the discrimination encountered by people with HIV and other medical conditions when they access goods and services.
- H. Medical schools should provide training for all student doctors on discussing sexuality and sexual health issues, including HIV, with patients.
- I. HIV prevention information targeting Africans, Black people and/or asylum seekers should be produced but their messages and formats need to take into account the concerns of these communities around potential prejudice.
- J. Government or other campaigns on HIV prejudice and discrimination should provide examples of how such prejudice can be, and has been, overcome and should ensure that support is available to people with HIV so that their fears are not exacerbated.
- K. The Department for Work and Pensions should work with initiatives such as Positive Futures and HIV organisations to ensure that people with HIV receive appropriate support in returning to or obtaining work, alongside legislative sanctions against discriminatory employers.

- L. Resources produced by HIV services should make clear the service's intended target audience/s and make active efforts to ensure that all those who may need them know that they are welcome.
- M. HIV information providers to African people in the UK should produce materials which make clear their medical and legal rights if diagnosed with HIV.

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Copies of the literature review undertaken by Peter Scott as part of the research for this publication can be obtained from Terrence Higgins Trust.

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