

2006

HIV AND YOUR DISABILITY EQUALITY SCHEME



**A Practical Guide for Chief
Executives, Board Members
and Senior Managers**





INTRODUCTION

A Practical Guide for Chief Executives, Board Members and Senior Managers

The Disability Discrimination Act 2005 [DDA 2005] defines all those living with HIV as disabled for the purposes of the Act. This means that people living with HIV are protected from discrimination in employment, trade union membership, education and the provision of goods, services and facilities, including the letting and selling of property.

The DDA 2005 has also established a **Disability Equality Duty** for public bodies.¹ The inclusion of all those living with HIV within the definition of disability means that the duty requires due regard to be had to those living with HIV in promoting equality of opportunity and all other aspects of the duty. This is a proactive duty which aims to tackle institutional discrimination, promote disability equality and address issues such as harassment whilst also ensuring public bodies promote positive attitudes towards disabled people, including people living with HIV. There is additionally a specific duty on particular public bodies to publish a **disability equality scheme** by 4 December 2006.

Detailed guidance on the disability equality duty and on the development and contents of the disability equality scheme is available from the Disability Rights Commission (DRC) website at <http://www.dotheduty.org>. This brief guide does not aim to repeat the legislative information and guidance which apply to all disabilities including HIV. It is intended simply to provide some initial and additional pointers to how the HIV-related aspects of the duty could appropriately be addressed in the initial information gathering and action planning stages.

We have designed this document as 'A Practical Guide for Chief Executives, Board Members and Senior Managers' to emphasise the need for leadership in tackling HIV-related equality and discrimination issues in both employment and service delivery. For the disability equality scheme to be effective in changing organisational culture it has to be owned and promoted from the very top of the organisation.

This guide also provides important HIV-related information for all public bodies to assist in meeting their general duty to promote disability equality under the DDA 2005.

¹ For a list of all public bodies subject to the specific duty see Disability Rights Commission 'The Duty to Promote Disability Equality Statutory Code of Practice England and Wales' and 'The Duty to Promote Disability Equality Statutory Code of Practice Scotland' DRC 2005. There are some variations in required publication dates for the disability equality schemes of some schools and educational establishments (see Statutory Code of Practice England & Wales para.3.5.).

The most important message is:

Meeting the needs of people living with HIV, and ensuring services do not discriminate against them, are essential elements in the design of an effective Disability Equality Scheme.



INVOLVING PEOPLE LIVING WITH HIV

Public bodies are required to involve disabled people, including people living with HIV, in developing their disability equality schemes and action plans.

HIV AND YOUR COMMUNITY

There are over 42,000 people living in the UK diagnosed with HIV (it is estimated that there are an additional 20,000 undiagnosed).² About half of all people with HIV live and are seen for care in London. Numbers living with HIV elsewhere in the country have risen in recent years, in some areas quite significantly, in particular those areas which are dispersal locations for asylum seekers.

52% of those diagnosed with HIV are ethnically white and 38% black African. Just over 3% are black Caribbean.

43% of those diagnosed with HIV are gay or bisexual men; 47% were infected through heterosexual sex; just over 3% were infected through injecting drug use.

There are just under 1,200 under 18s being seen by paediatric HIV services across the UK. It is estimated that there are between

15,000 and 20,000 children affected by HIV across the UK, where one or more family members is living with HIV.

A significant number of those living with HIV from African and other BME communities are at some stage within the immigration process. This will have an impact on their resources, accommodation, employment, legal rights and social engagement. They will both be amongst the most difficult to involve but also those most affected by the service delivery of a wide range of public bodies.

Whilst there are two communities most seriously affected by HIV (gay men and Africans), there are also people living with HIV who do not come within either of these two groups and who nevertheless have a right to involvement and to equality of opportunity. They are sometimes left out of involvement processes, with their specific concerns ignored as a result. Targeted work with gay or African groups, whilst very

² Statistics are from 2004 as found in 'Mapping the Issues: HIV and other Sexually Transmitted Infections in the United Kingdom: 2005' Health Protection Agency 2005

important, cannot substitute for efforts to reach and hear from all people living with HIV.

Don't assume all people living with HIV have identical needs or concerns. Take account of differences amongst those living with HIV, for example sexual orientation, gender, ethnic group, residency status and age.

OPPORTUNITIES AND CHALLENGES IN INVOLVING PEOPLE LIVING WITH HIV

Since the beginning of the epidemic in the UK, there has been a strong tradition of activism, involvement and voluntary sector mobilisation around HIV. There will almost certainly be both individuals and organisations in your locality or region with whom you can initially engage as you start thinking about HIV and your disability equality scheme.

Many people living with HIV are concerned to protect their privacy and the confidentiality of information on their HIV status. This is in part a result of the significant levels of HIV-related stigma and discrimination which still exist in society.

Many people living with HIV would not describe themselves as disabled, even in cases where they are aware of the new definition and protections under the DDA 2005. It is also unusual for people living with HIV to involve themselves in wider disability groups.

The majority of people living with HIV in the UK are either gay or bisexual men, or from African communities. Discrimination on grounds of sexual orientation or race may have an impact on visibility, and on willingness or capacity to be involved or provide information.

Furthermore, there are particular vulnerabilities for people in the immigration process (including those who have failed in asylum claims or in requests for leave to remain). Poverty, language barriers, accommodation problems, social isolation, fear of authorities and mental stress may all have a bearing on how easy it is to reach these disabled people and how ready and confident they are to respond.

HOW TO INVOLVE PEOPLE LIVING WITH HIV

Involving people living with HIV is vitally important in order to inform the priorities and direction of your Disability Equality Scheme.

When considering how to involve people living with HIV for your Disability Equality Scheme, contact your local HIV organisations – most will provide services for people living with HIV and some will represent people living with HIV. They will be important routes to involve people either directly, contacting individuals and focus groups, or indirectly through discussions with organisation representatives. There may be local publications for people living with HIV, for example published or emailed newsletters, which you can use. A national directory of HIV organisations around the country can be downloaded from

<http://www.nam.org.uk/en/orgs/ux/default.asp>. The organisation may well have good advice on how best to gather information from people living with HIV in a way which can reassure with regard to confidentiality and inspire trust that the process can deliver real improvements.

There may also be important contacts through gay and lesbian organisations (go to <http://www.queery.org.uk>) and refugee/asylum seeker support groups (contact the Refugee Council

<http://www.refugeecouncil.org.uk> or Refugee Action <http://www.refugee-action.org.uk> for advice on local groups).

There may be people living with HIV active in local Patient and Public Forums and in other parts of the NHS Patient and Public Involvement (PPI) processes. People living with HIV will have important things to say not just about HIV-specialist services but about all aspects of NHS and social care.

One key route to contacting people living with HIV is the local HIV clinic (for a list of HIV and GUM clinics go to <http://www.fpa.org.uk/helpnow/>) – all those diagnosed with HIV will be attending for routine monitoring every three or four months. A poster or leaflet inviting contact or views could be effective. But you might wish to consider joining with other key public bodies in your area to inform about involvement processes and the disability equality duty. Clinics will be more likely to display a single leaflet, for example, rather than a large number from a host of different organisations.

In addition to such direct approaches to people living with HIV and specific communities, you will need to involve your service-users, and those affected by your services, who are living with HIV. As you work to gather disability-related information from your service-users, it will be important to make clear that HIV infection is defined as a disability and that you wish to hear from people living with HIV – again, this will need to be accompanied by assurance of confidentiality for respondents. Think about *how* you gather information. For example, for people with concerns around disclosure of their status and identity, the internet could be an important resource for involvement, or a focus group exclusively for people living with HIV.

There are written resources available which can provide further information on the needs and experiences of people living with HIV. These resources are in no sense a substitute for the duties of involvement and information gathering. They can usefully suggest issues to be aware of as the public body considers how to hear from and involve people living with HIV in their disability equality scheme. A good place to start are *'What do you need? Findings from a national survey of people living with HIV'* Sigma Research 2002 and *'The needs of people living with HIV in the UK: a guide'* National AIDS Trust 2004. Further information can be found at <http://www.nat.org.uk>, <http://www.sigmaresearch.org.uk>, and <http://www.tht.org.uk>.



KEY POINTS FOR YOUR

Employment practice and service delivery can have an impact on:

- **the health of people living with HIV**
- **their confidentiality and privacy with regard to their HIV positive status**
- **their ability to maintain uninterrupted their course of anti-retroviral therapy, and more generally to access both regular and emergency healthcare.**

The vast majority of people living with HIV need only minor flexibilities in the workplace as reasonable adjustments, but organisations need to have a clear and efficient system in place to deliver these reasonable adjustments.

Case Study – Employment:

A government department in developing its disability equality scheme decides at this stage to monitor disability by very broad impairment groups. In considering HIV, however, it wants to ensure that workplace procedures encourage the recruitment and retention of people living with HIV. A workplace policy on HIV is developed and published on its website. Health-related questions in the recruitment process are no longer sent out with application packs but rather with a conditional job offer to dispel fears that HIV status could in any way affect the recruitment process and remove a possible obstacle to applications from people living with HIV.

The specific nature of HIV-related stigma and discrimination requires particular consideration and explicit mention of HIV:

- **in policies around harassment and disability-related hate crime**
- **in workplace policy (whether in a distinct HIV policy or within a disabilities and/or equalities policy)**
- **in disabilities- and equalities-related training in the workplace.**

Case Study – Service delivery:

The police and local authority housing officials have agreed a strategy to respond promptly and sensitively to the accommodation needs of people experiencing hate crime. In considering their duties under the DDA 2005 someone in the local authority notices that the strategy makes no mention of HIV-related hate crime. Discussions are then held with local HIV support organisations and individuals living with HIV who reveal that there have been instances of such hate crime and difficulties in getting necessary action. The strategy is amended to provide training on HIV and HIV-related hate crime to officers, monitoring of incidents related to HIV, and guidance on particular accommodation needs of those living with HIV.

DISABILITY EQUALITY SCHEME



The prevalence, impact and complexity of HIV-related stigma and discrimination require consideration for employment and service delivery of:

- **how your public body can promote positive attitudes towards people living with HIV**
- **actions needed to respond to the impacts of discrimination, such as hate crime or social isolation**
- **related impacts of homophobia, racism and xenophobia**
- **whether your employment or service delivery in any way perpetuates or entrenches HIV-related stigma and discrimination.**

Case Study – Service delivery:

A secondary school has a large number of children from African communities. Information on the epidemiology of HIV in the area suggests a number of the parents could be living with HIV. In considering its disability equality scheme, the school discusses how its functions might contribute to ending discrimination and promoting positive attitudes towards members of this community with HIV, encouraging their participation in public life. The curriculum is changed to go beyond just a biological discussion of HIV and sex, and address what it is like to live with HIV in the UK, dispelling myths and misconceptions, and confronting stigma and discrimination. There is a discernible impact on attitudes towards HIV amongst young people in the area as a result.

In developing and implementing the disability equality scheme, there will need to be consideration of:

- **the way HIV can deepen and further complicate already existing disadvantage (for example additional travel, dietary or accommodation needs for those on limited benefits)**
- **the implications of HIV for public bodies which provide support services for those with limited resources and significant social need.**

Case Study – Service delivery:

The National Asylum Support Service (NASS) was considering health-related issues relating to the dispersal of asylum seekers (many of whom are from countries with high HIV prevalence rates). NASS worked with the National AIDS Trust and the British HIV Association to gather information of the impact of dispersal on those living with HIV and found that the short notice period before dispersal took place meant that in certain cases anti-retroviral therapy was interrupted, with potentially dangerous consequences. As a result of its information gathering and impact assessment, the notice period was changed for people living with HIV to ensure effective clinical hand-over.



GATHERING INFORMATION

It will be necessary to gather and analyse evidence to inform your Disability Equality Scheme and its action plan.

The DRC has published guidance on this.³ When following this guidance and gathering information, public bodies should bear in mind some key issues in relation to HIV.

STATISTICS

Find out about the numbers and demographic profile of people living with HIV in your area by talking to organisations and individuals who have this information (don't make assumptions).

HIV has only been defined as a disability from the point of diagnosis since the DDA 2005 came into force in December 2005. The result is that information sources on disability may not as yet include information, or have only limited information, on HIV.

You will wish to find out how many people diagnosed with HIV are living in your area, and something about the breakdown by gender, age, ethnicity and sexuality. National, regional and Strategic Health Authority statistics are available from the Health Protection Agency website at <http://www.hpa.org.uk>, and from Health Protection Scotland at <http://www.hps.scot.nhs.uk>. The Primary Care Trust sexual health lead or the local Consultant in Communicable Disease Control (CCDC) will have important information relevant to your disability equality scheme at the local level (for CCDC contacts go to http://www.hpa.org.uk/lars_hpus.htm). In Scotland, Health Protection Scotland or the relevant Consultant in Public Health Medicine (CPHM) at the Local Health Board should be

contacted. In Wales contact the National Public Health Service and your Local Health Board (see <http://www.wales.nhs.uk>).

IN THE WORKPLACE

Workplace disability monitoring should be confidential at all stages, and this has to be stressed very clearly in all forms and monitoring processes to allay concerns amongst stigmatised groups such as those living with HIV (perhaps explain how this confidentiality is safeguarded in your processes). Wherever possible, monitoring should also be anonymous.

The DRC gives guidance to help you decide whether to monitor disability in general or gather information on specific conditions/impairments. It recommends that gathering information from disabled respondents should be based on self-disclosure – 'disabled persons themselves should be asked whether they are disabled'. Particularly where there is no monitoring by impairment/condition, it can be helpful to make clear, whilst affirming the principle of self-disclosure, that the law defines those living with HIV as disabled from the point of diagnosis and entitled to all its disability-related rights and protections (similar clarification might also be useful for other 'hidden disabilities').

IN SERVICE DELIVERY

There may be few data and statistics available on the experiences and usage of people living with HIV of your services and functions. Involving people living with HIV

³ 'Guidance on Gathering and Analysing Evidence to Inform Action'. DRC <http://www.drc-gb.org>

effectively and accessing some of the available literature from HIV organisations will provide pointers as to what HIV-related data might usefully and appropriately be gathered for the future. Your action plan can contain targets and indicators in relation to people living with HIV, devised to measure change and encourage commitment. The

DRC's 'Guidance on Gathering and Analysing Evidence to Inform Action' provides useful suggestions on the range of approaches that can be planned to collect both quantitative and qualitative data over the lifespan of your Disability Equality Scheme and action plan.



THE DISABILITY EQUALITY SCHEME AND ACTION PLAN

Reasonable adjustments and discrimination issues for people living with HIV.

With the introduction of potent anti-retroviral therapy (ART), most people living with HIV are able to remain well and lead active lives. However, their health must be monitored on a regular basis and on occasion, for those on ART, it may be necessary to change drug regimes which might require a period of physical readjustment. Anti-retroviral drugs can lead to side effects, including fatigue, nausea, sleep disturbances and diarrhoea

At any time about one third of people diagnosed with HIV are not as yet on treatment because they continue to be well enough not to need it.

It is extremely important that HIV drugs are taken consistently and at the specified times (not to do so can result in the development of drug resistance). It will be important that they can be taken without compromising the individual's privacy. Some ART drugs require refrigeration in hot weather and/or to be taken with a meal. In addition, ART may also require a change in diet (e.g. low fat/low sugar). Changes in personal circumstances or place of residence can pose particular challenges for continuity of clinical care and adherence to HIV medication.

Employers should already be providing reasonable adjustments for anyone who meets the DDA 2005 definition of disability. Reasonable adjustments for people living with HIV in the workplace may involve flexibilities to allow necessary health monitoring and the opportunity to take medication whilst maintaining privacy and confidentiality. It may also be necessary to respond on occasion to health-related needs relating to the impact of HIV or its treatment. The production of a disability equality scheme gives employers the opportunity to look at the systems they have in place to ensure that all disabled employees, including people living with HIV, have access to appropriate reasonable adjustments.

HIV-related discrimination relates most profoundly to the stigma associated with the disease. As a transmissible (usually through sexual contact or needle sharing) and incurable condition, and as a global pandemic with significant legal, social and political implications, HIV-related discrimination has a number of distinct aspects. Stigma and discrimination are reflected in unfounded and excessive fears of HIV transmission (for example, refusing to use cutlery previously used by someone living

with HIV) and in an out-of-date perception of the health prospects of HIV positive people (for example, a belief, despite treatment, that someone living with HIV will take excessive sick leave, or die in the near future).

Stigma also arises from judgemental or discriminatory views of certain groups or behaviours. Whether it is homophobia, racism, xenophobia or discriminatory attitudes to injecting drug users, these views are both additional discriminatory barriers faced by many people living with HIV and also prejudices which fuel negative opinions about the disease itself. Such stigma can result in verbal and/or physical harassment, social ostracism and abandonment, and in hate crime.

Significant numbers living with HIV experience poverty, low incomes and difficult and stressful social circumstances, sometimes related to their HIV status but more frequently to issues such as immigration status.

Some of the aspects of HIV-related discrimination identified above are specific to HIV, for example the link with homophobia and racism. Other aspects, such as confidentiality concerns and stigma, are also experienced by other people living with a disability or long-term medical condition, such as those with mental health problems.

In developing a disability equality scheme there will be decisions to be made on the extent to which disability is considered in the round and the extent to which it is addressed by impairment or condition. But NAT considers that **some specific reference to HIV will be necessary –**

- **because many are unaware that HIV is a disability under the DDA 2005;**
- **because most people affected in the UK are from two already marginalised and disadvantaged groups; and**

- **because HIV-related discrimination has such a distinct and complex nature.**

The specific aspects of HIV-related stigma and discrimination outlined above mean that NAT recommends all public bodies should have either a distinct policy on HIV in the workplace, or make specific and substantive reference to HIV in any disability and/or equalities policies. Even if there is no HIV-specific workplace monitoring, the public body should be able to assure itself that there is a clearly disseminated commitment to equality of opportunity for people living with HIV. This will be an important contribution to the recruitment, retention and appropriate support of people living with HIV in the workforce. For more information on what a workplace HIV policy might look like see NAT's HIV@work pack available at <http://www.employment.nat.org.uk>.

Training of staff around disability equality should also include explicit reference to HIV. Without such explicit training it is likely many will not appreciate the protections afforded to people living with HIV under the DDA 2005, nor specific issues around stigma, understanding of risks of transmission, and linkages with racism and homophobia. For further information on workplace HIV training go to the Ensuring Positive Futures (EPF) website at <http://www.e-pf.org.uk>.

HIV-related disability training is relevant not just for the experience of people living with HIV in the workforce but also in ensuring non-discriminatory and supportive service delivery. It does not, of course, substitute for more detailed training where service delivery raises more specific HIV-related issues (for example, accommodation provision, policing or health and social care). Remember the disability equality scheme must cover service delivery just as much as internal employment practice.




MEASURING YOUR SUCCESS

Key Questions

The two key questions to ask as you finalise your Disability Equality Scheme:

 **What will success look like in relation to HIV?**

 **What difference will you be able to claim your Disability Equality Scheme and action plan can make to people living with HIV?**

CONCLUSION

The Disability Equality Duty has the potential to transform the lives of people living with HIV. But it requires determination, hard work and vision from those in positions of leadership if such potential is to be realised. We hope that this document is useful to you as you frame your Disability Equality Scheme and action plan so as to take account of people living with HIV. We are also happy to discuss matters further – please email us at policyandcampaigns@nat.org.uk.



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