



McTigue, 'The challenge of HIV – Social stigma or disability?', [2010] 5 *Web JCLI*
<http://webjcli.ncl.ac.uk/2010/issue5/mctigue5.html>

The challenge of HIV – Social stigma or disability?

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First published in Web Journal of Current Legal Issues.

Summary

The nature of discrimination against people living with HIV and with AIDS (“PLHA”) is rooted in deeper stigmatisation than discrimination against other groups. Reasons for this include the association of HIV/AIDS with behaviours that may be considered socially unacceptable by many people. To combat such discrimination, HIV is deemed to be a “disability” under the Equality Act 2010. Whilst this protection has been welcomed by various activists and policy groups within the field, it will be argued that the decision to classify HIV as a disability is an inadequate response to the unique and multi-faceted discrimination faced by PLHA.

To achieve this this article will examine the history of the virus; current epidemiology within the UK; the extent to which HIV accords with traditional models of disability and the definition employed by the Equality Act 2010; and finally, the manner in which HIV is socially constructed and how this has compounded discrimination against PLHA.

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The 5 June 1981 issue of *Morbidity and Mortality Weekly Report* (CDC 1981) which reported the deaths of five homosexual men in Los Angeles from *Pneumocystis* pneumonia is generally acknowledged as the first clinical mention of AIDS see further Treichler 1999). This account published by the Centers for Disease Control, an agency of the United States Department of Health and Human Services, reported that two of the deceased men had histories of “frequent homosexual contacts with various partners” which led to an editorial note alongside the report to note that, “The fact that these patients were all homosexuals suggests an association between some aspect of a homosexual lifestyle or disease acquired through sexual contact and *Pneumocystis* pneumonia in this population” (CDC 1981, p251). This generalisation about the “homosexual lifestyle” being linked to this unexplained syndrome was remarkable given the fact that it was only based on five reported cases. Nevertheless the association stuck and the syndrome popularly became known as gay pneumonia and gay cancer.

The syndrome was informally described by some professionals as *GRID* or Gay-Related Immune Deficiency. This early terminology, although never formally adopted, has proven surprisingly pertinent and the cultural association between HIV/AIDS and Men who have sex with Men (“MSM”) persists to this day to such an extent that many members of the general population solely perceive HIV as a “gay disease”.

By mid-1982 the syndrome had been identified in various other groups, notably drug users who shared needles, Haitians living in the United States, haemophiliacs and blood transfusion recipients. Towards the end of 1982 enough non-MSM cases had now been identified to render Gay-Related Immune Deficiency an unsuitable acronym for the syndrome and consequently at a conference in Washington D.C. the CDC accepted a recommendation to term *AIDS*, shorthand for Acquired Immune Deficiency Syndrome.

Epidemiology

Information on prevalence of the virus within the UK may be gleaned from the Health Protection Agency’s Survey of Prevalent HIV Infections Diagnosed (SOPHID). SOPHID commenced monitoring in 1995 and is a cross-sectional survey of all individuals with diagnosed HIV infection who attend for HIV-related care within the UK within a calendar year. It gives a profile of the geographical distribution, gender, age and ethnicity of people with HIV, as well as the most advanced stage of HIV disease they have experienced and their current use of HIV anti-retroviral therapy.

According to SOPHID in 2008, there were an estimated 83,000 people living with HIV (both diagnosed and undiagnosed), equivalent to 130 people per 100,000 population in the UK (Health Protection Agency 2009). Of concern is the fact that over a quarter were

unaware of their HIV status, thus having potentially negative impacts upon the health of both them and others. Thus, as a consequence of this only 61,213 PLHA were seen for the purposes of clinical care in the UK in 2008.

Overall, half of HIV-diagnosed individuals accessing HIV care in 2008 were infected via heterosexual sex and where ethnicity was reported, 67 per cent were black African and 20 per cent were white. MSM made up 42 per cent of HIV-diagnosed individuals attending care; of these 87 per cent were white.

Thus in the UK today prevalence is concentrated amongst two main groups: MSM, who are predominately white and black Africans, whose route of infection is primarily through heterosexual sex. With these issues in mind, I now wish to turn to how Parliament has sought to protect PLHA from discrimination.

Legislation

Whilst legislation to protect individuals against discrimination on the basis of gender or race was introduced in the 1970s, disabled individuals were not protected until the introduction of the Disability Discrimination Act 1995. In the original legislation, PLHA were only protected if they were symptomatic. However, in an attempt to increase the scope of protection and overcome discrimination against PLHA, Parliament took the step of classifying HIV as a “disability” from the point of diagnosis, by the Disability Discrimination Act 2005, and therefore afforded PLHA with protection under the Disability Discrimination Act 1995.

The employment provisions were to be found in Part II of the Disability Discrimination Act 1995 and from 6 December 2005, persons diagnosed with cancer, HIV, and multiple sclerosis were deemed to suffer from a disability and hence be a disabled person, irrespective of whether they exhibited symptoms of their disease (Disability Discrimination Act 1995 Sch 1 para 6A).

In an attempt to consolidate and harmonise the numerous pieces of anti-discrimination legislation (concerning disability, race, sex, age, religion, sexual orientation, gender reassignment, marriage, civil partnership, pregnancy, maternity, religion and belief), the Equality Act was passed in 2010. This legislation supersedes the Disability Discrimination Act, yet PLHA receive similar protection. Thus, paragraph 6 to Schedule 1 of the Equality Act states:

- (1) Cancer, HIV infection and multiple sclerosis are each a disability.
- (2) HIV infection is infection by a virus capable of causing the Acquired Immune Deficiency Syndrome.

Whilst this protection for PLHA is to be welcomed, I argue that portraying HIV as a disability is an inadequate response to the unique multi-faceted discrimination faced by PLHA. In what respects then can HIV be said to accord or be at variance from the concepts and models of “disability” employed by the Equality Act 2010 and society as a whole?

The definition of disability is found at s 6 of the Equality Act 2010. It states:

- (1) A person (P) has a disability if—
 - (a) P has a physical or mental impairment, and
 - (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.

This mirrors the near identical provision contained at s 1(1) of the Disability Discrimination Act 1995:

Subject to the provisions of Schedule 1, a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.

How then does the definition employed by the Equality Act 2010 accord with traditional models of disability?

Impairment and models of disability

It is generally accepted that there are two dominant models of disability – the medical model of disability and the social model of disability.¹ In addition, one can also note the moral model of disability which serves as a reminder of the stigma that disabled individuals were, and indeed are, subjected to.

The moral model of disability is historically the oldest of the models, although its current influence is negligible (Kaplan 1999). The model is simplistic and two distinct strands can be identified. First, it views disability as the direct consequence of sin. Second, it opines that disability is divinely inflicted and arises due to some inadequacy within the individual (Drimmer 1992). When these elements of “sin” and “inadequacy” are combined, the model regards disabled individuals as spiritually and religiously inferior. For the individual with a disability this model is deeply offensive and has resulted in self hatred; whilst families with a disabled family member have removed them from education and society and prohibited them from having any active involvement with society as a whole (Beaumont 1996).

The medical model of disability locates disability within the individual. Disability is a medical condition and consequently, like all other conditions it can be treated by doctors to ensure that its symptoms are, ultimately, alleviated or eradicated (see further Drimmer, 1992, Oliver 1996 and Beaumont 1996). The nature of the model is that, from a social perspective, the disabled individual is placed in the sick role (Parsons 1958), with this role containing four key elements (Drimmer 1992). Firstly, the sick person is not held responsible for their illness – it is due to biological factors over which they have no control. Following on from this primary tenet, it is advanced that (2) the sick person is

¹ Academics are not however consistent in their use of terminology. The social model is also frequently referred to as the disability model, whilst the medical model is often referred to as the individual model.

exempted from normal social obligations and (3) is in a socially legitimate position if (4) they co-operate with medical professionals in order to work towards recovery.

The medical model has been the dominant model of disability and indeed it is the model generally employed by the Disability Discrimination Act 1995. However the prominent disability academic, Michael Oliver, has been highly critical of this model of disability. He contends that there are two fundamental aspects to the medical model of disability. Firstly, it locates the “problem” of disability within the individual and secondly, it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability (Oliver 1996). Oliver consequently advocates the use of the term “Individual model” as opposed to “Medical model”.

In general the Equality Act 2010 adopts a medical model of disability. This decision is controversial as the model has been subject to substantial criticism by disabled individuals. They contend that it is, in fact, society which disables physically impaired people as “Disability is something imposed on top of our impairments by the way which we are unnecessarily isolated and excluded from full participation in society” (UPIAS, 1976, p 14). Further criticism derives from that fact that a cure for many disabilities may never be found; and in any event, persons with disabilities are quite capable of participating in society and the practices of confinement that accompany the sick role are unacceptable (Kaplan 1999). To combat these inadequacies, the use of a social model of disability has been advocated.

According to the social model, disability is any societal factor which imposes restrictions on disabled people. These can range from individual prejudice to institutional discrimination and from inaccessible public buildings to inaccessible transport systems (Oliver 1996). As Wendell (1996, p 46) notes:

The cultural habit of regarding the condition of the person, not the built environment or the social organization of activities, as the source of the problem, runs deep. For example, it took me several years of struggling with the heavy door to my building, sometimes having to wait until a person came along, to realize that the door was an accessibility problem, not only for me, but for others as well. And I did not notice, until one of my students pointed it out, that the lack of signs that could be read from a distance at my university forced people with mobility impairments to expend a lot of energy unnecessarily, searching for rooms and offices. I interpreted it, automatically, as a problem arising from my illness (as I did with the door), rather than as a problem arising from the built environment that has been created for too narrow a range of people and situations.

Curiously in certain limited circumstances the Equality Act, in common with the earlier Disability Discrimination Act 1995, favours the adoption of the social model of disability. So, where an impairment consists of a severe disfigurement, it is deemed to have a substantial adverse effect on the person's ability to carry out normal day-to-day activities (Sch 1 para 3). Again with HIV, there appears to be use of the social model – thus, at the point of diagnosis for the majority of PLHA – can it really be said that they

accord with the Disability Discrimination Act's traditional definition of disability? Does their impairment have a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities? No, at this point PLHA are fit and healthy. It is only when their health deteriorates or when they acquire a diagnosis of AIDS, that they will meet the definition.

However, at this early stage of infection, it is not the virus which is disabling but rather the interaction and reaction of members of society to the virus that is disabling. Thus, stigma rather than the virus disables the person living with HIV.

Indeed as treatments and therapies for PLHA develop and improve, life expectancy is enhanced and the anomaly that the virus itself is not a disability is accentuated. Thus, HIV has started to be perceived by some as a long term chronic condition rather than an acute life threatening illness (Yallop 1999). This opinion gains credence from research undertaken in the United States which discovered that PLHA who were working were more likely to remain employed due to increasingly superior methods of treatment (Goldman and Bao 2004). Unquestionably, the greatest advance in treatment for PLHA has been the introduction of antiretroviral therapy ("ART") which is also known as "Highly Active Antiretroviral Therapy ("HAART"), which consists of the use of at least three antiretroviral drugs to suppress the virus and slow the progression of disease. Within the employment sphere, studies by Nancy Kass and others have revealed that the likelihood of PLHA working decreases with disease progression (Kass *et al.* 1994; Leigh *et al.* 1995), however by slowing such progression the advent of ART has been especially effective in helping PLHA remain employed (Goldman and Bao 2004). In addition, decreases in workplace absenteeism have been observed by J. Paul Leigh and others to such an extent that HIV positive individuals within an employment relationship in the United States are no more likely to be absent from work than any other employed person (Leigh *et al.* 1997).

However, it is clear that the stigma is still disabling, thus for those PLHA within an employment relationship the issue of disclosure often presents challenging questions and decisions. Fesko (2001) reviewed the workplace experiences and disclosure decisions of 18 PLHA. She discovered that individuals identified the stigma associated with HIV as being a factor in their decision to disclose and some felt that they might disclose in future if the stigma associated with the disease were reduced. In addition, participants also described multiple levels of stigma associated with homosexual orientation or membership of an ethnic minority group. By way of example, one African-American woman described her work environment in the following terms:

With my boss, he was a joker – jokes around and stuff like that – but they had a lot of semi-gay bashing and they raised some very nasty little jokes that I didn't care for, and people were joking around and by me being black and it was an all white company I was working for, I decided not to tell. (Fesko 2001, p 239)

Douglas (2009) conducted research into the employment experiences of MSM and black African men and women living with HIV in the UK and also found the issues of

intersectional discrimination facing PLHA. In essence, intersectional discrimination is the recognition that some people can experience particular disadvantage because of a combination of protected characteristics. A simple contemporary example is the treatment of young Muslim men post September 11th. Due to adverse media coverage, young Muslim men have been subjected to high levels of stigma which has resulted in certain sections of society incorrectly perceiving them as terrorists. Crucially however the manifestation of this stigma which portrays young Muslim men as terrorists has not been directed towards young Muslim women or older Muslim men. Thus with regard to HIV, one respondent noted to Douglas that it added an extra layer of disadvantage to her life:

Being from an ethnic background, being black, is one thing; to being from [an] ethnic background and can't communicate, that's another thing. Being from an ethnic minority and being black and having HIV, that's another problem.
(Douglas 2009, p 31)

This stigma and discrimination has its roots in the manner in which HIV, and other contagious diseases, have been conceptualised by society.

Susan Sontag has conceptualised AIDS metaphorically as a plague (Sontag 1988). She asserts that AIDS belongs to that most feared group of diseases, those that are not simply fatal but that transform the body into something alienating like syphilis, cholera and cancer. Yet whilst the fear associated with HIV and AIDS undoubtedly have similarities to each of the illnesses Sontag cites, collectively the fear is significantly greater because of its interaction with three distinct phenomena; namely HIV/AIDS's association with unacceptable practices, the complete lack of any successful treatment to completely eradicate the virus from the human body and the issue of self-infliction. Hence it is apparent that unlike cancer and cholera, HIV/AIDS is associated with unacceptable social practices. Instead and in common with syphilis it is associated with sex, which has led to it being regarded by many as associated with excess.

In addition and unfortunately for PWH the idea that they are being punished for their behaviour is deeply ingrained into society's construction of HIV. Whilst getting cancer is sometimes understood as the fault of an individual who has engaged in unsafe behaviour, for example the alcoholic with cancer of the oesophagus or the smoker with lung cancer, the acquisition of cancer is always associated with one identifiable risk factor or weakness. Within the popular imagination the unsafe behaviour associated with HIV is various - injecting drug use, sex amongst MSM and/or promiscuity. These unsafe behaviours are viewed by society as indulgent, deviant and sometimes delinquent.

Following on from the concept of promiscuity noted earlier is the idea that, through their unacceptable practices and behaviours, some PLHA are responsible for their acquisition of the disease. Indeed by participating in promiscuous, deviant or delinquent activities PLHA are perceived by some as having self-inflicted the disease upon their bodies. Sontag notes, "Getting the disease through a sexual practice is thought to be more wilful, therefore deserves more blame" whilst, "Addicts who get the illness by sharing contaminated needles are seen as committing (or completing) a form of inadvertent

suicide (Sontag 1988, p 26). This idea is supported by interviews with individuals living with both cancer and HIV undertaken by Dawson. One interviewee commented, "I've told everyone about (my cancer diagnosis) because you get sympathy for having cancer don't you... people just think you deserve to get HIV, like you're a guilty victim, whereas with cancer you're an innocent victim." (Dawson 2007, p 3).

Society's failure to accept that "normal" individuals may also be HIV positive leads to Douglas Crimp constructing HIV and AIDS as foreign concepts (Schiller 1994, Crimp 1988). Ever since the first cases of HIV were reported in the early 1980s, society viewed the virus as originating from "outside". Where "outside" was varied dependent upon the cultural setting of the discussion in question. So, at first in places such as France and Germany Sander Gilman notes that HIV was said to be imported - together with poppers, tight jeans and rock music - by MSM from the United States of America (Gilman 1988).

However, it was not long before HIV became to be perceived as emanating from peoples who were not only culturally different but also racially different. Western researchers soon began searching ethnographies for descriptions of unusual African sexual practices, seeking to identify that the virus originated in remote populations and to identify behaviour as culturally different from heterosexual vaginal intercourse as the mode of transmission (Schiller 1994). Although confusion still surrounds the origin of the virus Sontag notes that, illustrating the classic script previously taken by diseases such as syphilis, it is believed to have started in the "dark continent", then spread to Haiti, then to the United States and Europe. She argues:

Africans who detect racist stereotypes in much of the speculation about the geographical origin of AIDS are not wrong (Nor are they wrong in thinking that depictions of Africa as the cradle of AIDS must feed anti-African prejudices in Europe and Asia.) (Sontag 1988, p 52)

This idea of certain marginalised racial or cultural groups being in some way responsible for HIV invariably leads to greater levels of stigma and discrimination against the members of such groups.

Conclusion

From the above it is apparent that, in essence two main theories assist in explaining the unique levels of discrimination and stigma directed at PLHA (Conyers *et al* 2005). The first centres upon the characteristics of the virus itself, with significant focus placed upon the fact that it is currently a potentially fatal infectious disease with no cure. To some extent, although not entirely, this is the approach adopted by Sontag (1988) who illustrates how throughout history misapprehension and misunderstanding about disease and the possibility of its spread has led to the exclusion and isolation of those affected. The second relates to the marginalised nature of the vast majority of PLHA, e.g. their status as intravenous drug users, MSM or members of ethnic minorities. Thus, a number of commentators advance that discrimination against PLHA is often related to pre-existing stigma which makes PLHA particularly vulnerable to discrimination (Herek *et al.* 2002, Studdert 2002).

HIV can no longer be analysed in terms of binary approaches; that is we must no longer solely examine the discrimination and disadvantage that individuals face using one prohibited ground in isolation to all others. Instead, we must draw upon the second approach cited above that recognises that discrimination against PLHA is often related to pre-existing stigma. For academics or commentators to merely examine HIV using the individual concepts of race, sex, sexuality or indeed, like the Disability Discrimination Act 1995, disability would be to close our eyes to the unique and subtle nature of the virus. Thus by analysing HIV from only one perspective, the approach initially employed by the Equality Act 2010 is flawed. HIV transcends barriers, be they social, cultural, racial or national. Whilst to be HIV positive is to experience discrimination, the same can not be said of the virus. Whilst acknowledging that rates of HIV infection are higher amongst some sectors of society than others, the virus itself does not discriminate – it will happily infect people be they queer or straight, black or white, male or female, African or English. The use of a binary approach to understand or combat HIV is further compromised by the fact that individuals invariably have more than one identity, for example within MSM a homosexual will not just perceive himself, or indeed be perceived by others, as homosexual, he may also be young, poorly educated, black and African. These identities coexist and interrelate with one another. The use of a binary approach also fails to recognise that identities are not static concepts and may alter both with time and the social setting or context which the individual finds themselves in (Goffman 1959, Zappone 2003).

Intersectionality, a concept which has its roots in the feminist movement, means “paying attention to how multiple social forces, such as race, class, gender, age, sexuality, and culture, shape our experiences” (Deckha 2004, p 16). It is clearly highly relevant to this area and could prove to be an effective tool in combating discrimination, yet the Equality Act only has limited provision for this concept at section 14 which states:

- (1) A person (A) discriminates against another (B) if, because of a combination of two relevant protected characteristics, A treats B less favourably than A treats or would treat a person who does not share either of those characteristics.
- (2) The relevant protected characteristics are—
 - (a) age;
 - (b) disability;
 - (c) gender reassignment;
 - (d) race
 - (e) religion or belief;
 - (f) sex;
 - (g) sexual orientation.

One of the intentions of this section is for it to tackle situations where discrimination arises out prejudice or assumptions specific to a combination of factors. By way of example, the Equalities and Human Rights Commission’s draft Code of Practice provides the following example of combined discrimination:

A hotel rejects an application from a black man for a job as a room cleaner. The hotel employs black women and white men as room cleaners. However, the black male applicant is rejected because of a presumption that he is more likely to steal from guests or from the hotel. The reason for the less favourable treatment is not the applicant's race or sex, but rather a presumption based on the combined characteristics of his sex and race. (EHRC, para. 3.34)²

Unfortunately however there are significant weaknesses with the approach that the section adopts to tackling discrimination. Perhaps the greatest is the fact that only discrimination with regard to a combination of two relevant protected characteristics can be taken into account. This highly restricts the application of section 14 to many PLHA. By way of example, gay men who are HIV positive tend to be subjected to a particular and aggressive form of stigma. Indeed they are incorrectly perceived as promiscuous and responsible for the spread of the virus in a manner in which lesbians who are HIV positive are not. Thus it is apparent that there are two distinct characteristics at play that both contribute to, and cause, this unique form of discrimination. First their sexuality and second their HIV status. If such an individual were also a member of an ethnic minority and were, for example, told that they should go home to prevent the spread of AIDS then a third factor comes into play, their race. Yet, section 14 only allows two protected characteristics to be taken into account. How is such an individual to bring their claim? Using the traditional separate provisions of sex, race and disability or by using section 14? If they are use section 14, which of the three characteristics should they not refer to in their claim? Would they still be adequately able to explain the nature of the discrimination they have suffered were they only able to refer to two protected characteristics? These are clearly difficult questions that are going to have to be faced in the near future. However, it is apparent that the greater the number of grounds an individual seeks to claim protection under, the further they stray from the "norm". Society is still unable to fully accept such individuals and thus, even after the passage of the Equality Act, Fredman's (2001) comment that the dominant white, male cultural model is the norm still rings true.

Of concern also is the fact that at the time of writing, whilst the majority of the Equality Act has been brought into force, section 14 has not. Indeed, the only information available via the Government's Equalities office states that, "Ministers are currently considering how certain provisions of the Act, including the dual discrimination provisions, can be implemented in the best way for business and for others with rights and responsibilities under the Act."³ Thus, it remains to be seen both the extent of the

² Equalities and Human Rights Commission (2009), *Employment Statutory Code of Practice: draft for consultation*, 2010. Available via: <http://www.equalityhumanrights.com/legislative-framework/equality-bill/equality-bill-codes-of-practice-consultation/#1> (Accessed: 14th July 2010)

³ Available via:

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current coalition Government's commitment to this provision and also how effectively this vaguely drafted section might operate in practice. With considerate and well intentioned interpretation by the judiciary, it could prove to be a useful tool in combating stigma and discrimination against PLHA. However, what is certain is that as treatments for HIV advance and life expectancy increases, the challenge of how to combat discrimination against PLHA within both employment and wider society will only intensify.

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