

European (Legal) Studies on-line papers

Queen's University Belfast - School of Law – Jean Monnet ad personam Chair Professor D Schiek

<http://go.qub.ac.uk/law-cetls>



PETER MCTIGUE

THE DISORGANISED NATURE OF EUROPEAN DISABILITY LAW; RETHINKING PROTECTION FOR HIV POSITIVE INDIVIDUALS

VOLUME 3 (2014), ISSUE 4

These on-line papers are part of the programme provided under the Jean Monnet ad Personam Chair held by Dagmar Schiek, which was part-funded by the EU Commission from September 2011 to August 2014, when they were published from the Centre of European Law and Legal Studies (CELLS) at the University of Leeds. The support of the EU Commission is acknowledged with gratitude.

The disorganised nature of European Disability: Rethinking protection for HIV positive individuals

Peter McTigue

Despite the fact that there are approximately 80 million individuals with disabilities within the EU¹, there is no coherent definition of disability. There is also no clear consensus amongst Member States as to the question of whether People Living with HIV/AIDS (“PLHA”) should be defined as “disabled” and thus acquire the various legal protections associated with such a designation. This paper will argue that in order to adequately protect PLHA within the EU, the European Court of Justice (“CJEU”) need to ensure that a coherent EU wide definition of disability based upon the social model of disability is adopted. Such a definition is necessary in order to ensure adequate protection not only for PLHA but for all individuals from disability discrimination throughout the EU. In addition to this central argument, this paper will also argue that the lack of a coherent definition of disability grounded in the social model fragments protection for PLHA across the EU leading to a number of possible unintended consequences.

PLHA may seem a strange choice of focus but, in some ways, PLHA represent the “front line” in the ideological battle concerning the definition of disability at an EU level and the question concerning the relationship between sickness and disability as will be seen by the Advocate General’s opinion in the recent *HK Danmark (Ring and Skouboe Werge)*² case concerning unlawful discrimination within employment.

HIV and AIDS

HIV represents a major public health problem for Europe. It has been estimated that there are approximately 2.2 million people living with the virus in the WHO European Region; approaching 1 million in the European Union³ and 1.4 million in Eastern Europe and central Asia⁴. However, due to the fact that HIV does not generally produce symptoms which lead to diagnosis around the time of infection, these figures are mere estimates. There are many PLHA who are unaware of their HIV and who have not been diagnosed. It is estimated that as many as one-third of PLHA in the European Union are unaware of their HIV status and in some eastern European countries up to 60% of PLHA are undiagnosed⁵.

¹ European Commission, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, SEC(2010) 1324 final, Brussels, 15 November 2010, <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=SEC:2010:1324:FIN:EN:PDF>. Accessed 15th May 2014

² Joined Cases C-335/11 and C-337/11 11 April 2013 *HK Danmark*, acting on behalf of Jette Ring v Dansk Almenyttigt Boligselskab DAB and *HK Danmark*, acting on behalf of Lone Skouboe Werge v Pro Display A/S in liquidation [2013] 3 CMLR 21

³ UNAIDS, Global report: UNAIDS report on the global AIDS epidemic (UNAIDS 2010)

⁴ Hamers F & Phillips A, Diagnosed and undiagnosed HIV infected populations in Europe. (2008) *HIV Medicine* 9:6.

⁵ Hamers F & Phillips A (n 4)

HIV damages the immune system, leaving the infected person vulnerable to a variety of infections (called "opportunistic" infections to indicate that they arise in the setting of immune impairment). The effect of HIV on the immune system is monitored by measuring the CD4 count in the blood. A normal CD4 count (between approximately 600 and 1,200 cells per cubic millimetre of blood) indicates that the immune system has not undergone sufficient damage to put the individual at risk for opportunistic illness.⁶ Having HIV does not mean that an individual has AIDS. According to the United States Center for Disease Control and Prevention, AIDS is diagnosed when the immune system of a person infected with HIV becomes severely compromised (measured, inter alia, by CD4 cell count of less than 200 cells per cubic millimetre of blood) and/or the person becomes ill with an opportunistic infection⁷. However, with early HIV diagnosis and access to effective treatment, evidence now indicates that PLHA can be expected to live into their early seventies, a life expectancy approaching that of the general population⁸.

Legal Protection for PLHA

The marginalised nature of the vast majority of PLHA, for example their status as men who have sex with men, and the need to protect such individuals from discrimination has led to a plethora of legislation. This emanates from a variety of sources: international, European and domestic. Whilst each has at its heart the objective of protecting PLHA from discrimination the collective result is a multi-faceted collection of various pieces of legislation, often overlapping and sometimes contradictory.

From a specifically legal perspective, HIV and AIDS have provoked a range of interventions. In some countries, PLHA benefit from general anti-discrimination legislation. By way of example, in the Netherlands and Latvia, PLHA benefit from the general constitutional prohibition of discrimination. In others anti-discrimination provisions expressly refer to HIV/AIDS as a separate protected status or are included in special laws dealing with the prevention and control of HIV. In others still, PLHA are protected under disability laws which either expressly include HIV in the definition of a disability or have been interpreted to that effect.

As such, the EU, its institutions and Member States are faced with a quandary as to the exact definition, description and classification of HIV. This paper will now identify and analyse the overlapping legal frameworks and definitions facing the CJEU when asked to decide cases involving unlawful discrimination directed towards individuals with disabilities and in particular PLHA. It will then proceed to examine the possible implications of the *HK Danmark (Ring and Skouboe Werge)* in relation to PLHA before, briefly, identifying possible unintended consequences of the law in relation to PLHA.

⁶ Bradley Hare, C, "Clinical Overview of HIV Disease" (HIV InSite Knowledge Base) <<http://hivinsite.ucsf.edu/InSite?page=kb-00&doc=kb-03-01-01>> accessed 15th May 2014

⁷ Schneider E, Whitmore S, Glynn KM, Dominguez K, Mitsch A, McKenna MT, "Revised surveillance case definitions for HIV infection among adults, adolescents, and children aged <18 months and for HIV infection and AIDS among children aged 18 months to <13 years--United States, 2008" (2008) *MMWR Recomm Rep* 57

⁸ Samji H, Cescon A, Hogg RS, Modur SP, Althoff KN, et al., "Closing the Gap: Increases in Life Expectancy among Treated HIV-Positive Individuals in the United States and Canada" (2013) *PLoS ONE* 8(12):

The European Union

The starting point in relation to a consideration of the legal framework prohibiting discrimination within the European Union is Article 19 TFEU⁹. This provides:

“Without prejudice to the other provisions of the Treaties and within the limits of the powers conferred by them upon the Union, the Council, acting unanimously in accordance with a special legislative procedure and after obtaining the consent of the European Parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.”

There is no explicit mention of an individual’s HIV status in Article 19 TFEU nor any opportunity to expand the closed list of prohibited grounds. Yet despite this the European Union has committed itself to combating discrimination against PLHA. The Dublin Declaration¹⁰ commits Member States to:

“combat stigma and discrimination of people living with HIV/AIDS in Europe and Central Asia, including through a critical review and monitoring of existing legislation, policies and practices with the objective of promoting the effective enjoyment of all rights for people living with HIV/AIDS and members of affected communities.” (at para. 20)

This is reaffirmed in the Vilnius Declaration¹¹ where there is a commitment on the part of Member States to “continue to develop and implement relevant legislation, in particular with a view to prohibiting discrimination, inter alia in employment, on the grounds of HIV status”. Despite these commitments discrimination provisions in EU law fail to explicitly include HIV status. The consequence of this is that Member States are free to choose either to protect or not to protect PLHA from discrimination, and that PLHA must therefore seek protection from discrimination on the grounds that their condition constitutes a disability.

Due to the scope of Directives adopted in order to combat discrimination within the EU, protection from discrimination on the grounds of disability is less far reaching than protection from discrimination in relation to other grounds. By way of example, the Racial Equality Directive¹² protects individuals from discrimination upon the ground of racial and ethnic origin in a number of fields including employment, social protection, social advantages, education and access to and supply of goods and services. In addition, the Gender Goods and Services Directive¹³ was introduced in order to expand the scope of equality on the grounds of gender to goods and services. However protection from

⁹ Consolidated Version of the Treaty on the Functioning of the European Union [2010] OJ C83/47

¹⁰ Representatives of governments from Europe and central Asia met at a conference ‘Breaking the Barriers – Partnership to fight HIV/AIDS in Europe and central Asia’ in Dublin on 23-24 February 2004. The outcome of that conference, the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia, embodied countries’ commitments in a set of 33 objectives.

¹¹ Vilnius Declaration on Measures to Strengthen Responses to HIV/AIDS in the European Union and in Neighbouring Countries, adopted at the International Inter-ministerial Meeting on Combating HIV/AIDS (Vilnius, 16-17 September 2004)

¹² Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin [2000] OJ L 180

¹³ Council Directive 2004/113/EC of 13 December 2004 implementing the principle of equal treatment between men and women in the access to and supply of goods and services [2004] OJ L 373

discrimination on the grounds of disability is more restricted in scope due to the fact that the relevant Directive, the Employment Equality Directive (“the Framework Directive”)¹⁴, only provides protection against discrimination in the fields of employment, occupation and vocational training¹⁵.

Article 2(1) of the Framework Directive provides:

“For the purposes of this Directive, the principle of equal treatment shall mean that there shall be no direct or indirect discrimination whatsoever on any of the grounds referred to in Article 1.”

The grounds referred to in Article 1 are religion or belief, disability, age and sexual orientation. Rather unsatisfactorily, the Framework Directive provides no definition of disability. This has the potential to permit multiple varying definitions of disability to be adopted across the EU and for different domestic courts to adopt differing approaches as to whether a particular impairment constitutes a “disability”. For example, in relation to PLHA, there is no guarantee that they will be afforded uniform protection across the EU.

In the seminal 2006 case of *Chacon Navas v Eures Colectividades SA*¹⁶ the CJEU offered guidance on the issue stating at para 43 that:

“[The Framework Directive] aims to combat certain types of discrimination as regards employment and occupation. In that context, the concept of ‘disability’ must be understood as referring to a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life.”

Importantly in *Chacón Navas*, the CJEU held that workers do not fall within the scope of the protection afforded by the Framework Directive as soon as they develop any type of sickness and so made an important distinction between sickness and disability. In addition, it was strongly stated that sickness cannot be regarded as a separate prohibited ground of discrimination for the purposes of the Framework Directive.

It was against this backdrop that judgment in the case of *HK Danmark (Ring and Skouboe Werge)* was delivered by the CJEU in April of this year. In *HK Danmark (Ring and Skouboe Werge)*, Danish legislation permitted businesses to dismiss those who had been off ill for a certain number of days with only one month's notice, shorter than the notice normally required under Danish employment law. The case was brought by two applicants one of whom, Ms Ring, had developed back pain. The second applicant, Ms Werge, had whiplash following a road accident. Crucially, both applicants were still able to work but were unable to work on a full-time basis.

The applicants argued that they had a disability, and that this reduced notice period was unlawful disability discrimination, in breach of the EU Framework Directive. A question of fundamental importance was whether or not they fell within the definition of disability as expounded by the *Chacon Navas* case.

¹⁴ Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ L 303

¹⁵ Discrimination upon the grounds of religion or belief, age and sexual orientation are also prohibited by the Framework Directive.

¹⁶ Case C-13/05 [2006] ECR I-6467

The employers disputed that the applicants' state of health was covered by the concept of 'disability' within the meaning of the Framework Directive, since the only incapacity that affected them was that they were now not able to work full-time. As such it was argued by the employers that as they could work part-time they were not excluded completely from participating in professional life and so fell outside the *Chacon Navas* definition. The employer's central argument was that disability, as constructed by the decision in *Chacon Navas*, implies a complete exclusion from work or professional life as opposed to a partial exclusion here.

The CJEU disagreed and placed strong emphasis on the United Nations Convention on the Rights of Persons with Disabilities ("the UN Convention"). The UN Convention was adopted by the UN General Assembly in December 2006, following prolonged lobbying by disability rights activists. It entered into force in May 2008 and was ratified by the European Union in 2010. The ratification of the UN Convention by the European Union thus followed the *Chacon Navas* decision and accordingly it clearly follows from Article 216(2) TFEU that international agreements concluded by the European Union are binding upon the institutions of the European Union and on its Member States. Thus, the concept of disability within the meaning of the Framework Directive should not fall short of the scope of the protection afforded by the UN Convention.

The UN Convention itself does not include a definition of "disability" or "persons with disabilities". However the convention's preamble recognises (at point (e)) that "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

Article 1 of the UN Convention further states: "Persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

At this point in order to adequately understand the social construction of the relevant legal framework, it is important to consider how disability itself has been socially constructed. It is generally accepted that there are two dominant models of disability – the medical model of disability and the social model of disability.

This medical model 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. The nature of the model is that, from a social perspective, the disabled individual is placed in the sick role¹⁷.

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

¹⁷ Parsons, T (1958), Definitions of Health and Illness in Light of American Values and Social Structure in *Patients, Physicians and Illnesses* 165

from disability¹⁸. The medical model has also 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”¹⁹. 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 unacceptable²⁰. 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 systems²¹. As Wendell 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.”²²

HIV clearly fits more comfortably within the social model due to high levels of stigma faced by PLHA. At its most basic stigma can be characterised as the negative perceptions of so-called normal people to all individuals who are different from themselves²³. However academic and policy discussions of stigma, particularly in relation to HIV and AIDS, concentrate on Goffman’s seminal work²⁴. Goffman’s research draws upon the experience of people suffering from mental illness, possessing physical deformities, or practicing what were perceived to be socially deviant behaviours such as homosexuality or criminal behaviour and defines stigma as “an attribute that is significantly discrediting” and which serves to reduce social standing of the person who possesses it. He identifies three bases of stigma. First, abominations of the body. Second, blemishes of individual character and third tribal stigma, due to an individual’s membership of a despised group in society. Watt²⁵ advances that stigmatisation of individuals with HIV rests upon all three of Goffman’s bases and consequently stigma

¹⁸ Oliver, M, *Understanding Disability: From Theory to Practice* (Palgrave 1996)

¹⁹ Union of the Physically Impaired against Segregation, *Fundamental Principles of Disability* (UPIAS 1976), 14

²⁰ Kaplan, J, “The Definition of Disability: Perspective of the Disability Community” (1999) *Journal of Health Care, Law & Policy* 352

²¹ Oliver (n 9)

²² Wendell, S, *The Rejected Body: Feminist Philosophical Reflections on Disability* (Routledge 1996), 46

²³ English, R (1977), in *Correlates of stigma towards physically disabled person*, Marinelli and Dell Orto (eds), New York: Springer

²⁴ Goffman, E (1963), *Stigma notes on the management of spoiled identity*, Harmondsworth: Penguin

²⁵ Watt, B, *Discrimination Law: Concepts, Limitations and Justifications*, (Longman 1996)

is more pronounced. Building on this theory Conyers, Boomer and McMahon²⁶ assert that two main theories assist us in explaining the unique level of discrimination and stigma directed at PLHA. 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. The second relates to the marginalised nature of the vast majority of PLHA, e.g. their status as intravenous drug users, men who have sex with men or members of ethnic minorities. Thus, a number of commentators²⁷ advance that discrimination against PLHA is often related to pre-existing stigma which makes PLHA particularly vulnerable to discrimination. The virus is thus socially disabling and the fear of stigma often prevents PLHA from accessing full legal protection by for example failing to disclose their condition to their employer.

Returning to the UN Convention, by the language employed in both the preamble and Article 1, it is clear that it adopts the social model. This use of the social model of disability, which shall be discussed later, is ground-breaking and has the potential to empower individuals with disabilities and PLHA on a global basis. Indeed it clearly influenced the thinking and decision of the CJEU in the *HK Danmark (Ring and Skouboe Werge)* case. Referring explicitly to the UN Convention, the CJEU felt that:

“the concept of ‘disability’ must be understood as referring to a limitation which results in particular from physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers.” (at para 38).

Unlike *Chacon Navas*, the impairment does not have to completely hinder, or rather exclude, an individual from participation in professional life but rather be one which *may* hinder full and effective participation in professional life.

Yet it may be argued that the CJEU in *HK Danmark (Ring and Skouboe Werge)* has set the bar relatively high. So, if we return to PLHA, due to the progressive nature of the disease it is questionable whether PLHA will fulfil the CJEU’s conceptual requirement of “disability” at the point of their diagnosis. If a purely functional approach to the question of “participation in professional life” is taken then the majority of PLHA face no functional or imitational barriers to participation in professional life. They can, to the naked eye, participate on exactly the same terms and meet the same functional requirements as fellow professionals without HIV. Unlike wheelchair users they are not disabled by any physical features of their employer’s premises, for example steps or heavy doors. However, at the point of diagnosis, stigma and the fear of discrimination combine to significantly hinder the full and effective participation of PLHA in professional life on an equal basis with their fellow workers. This is evidenced by research carried out by Fesko²⁸. Fesko reviewed the workplace experiences and

²⁶ Conyers, L, Boomer, K and McMahon, B, “Workplace discrimination and HIV/AIDS: The national EEOC ADA research project” (2005) *Work* 25(1), 37

²⁷ See for example Herek G, Capitanio J, Widaman K “HIV-related stigma and knowledge in the United States: prevalence and trends, 1991–1999” (2002) *American Journal of Public Health* 92(3), 371 and Studdert, D “Charges of Human Immunodeficiency Virus Discrimination in the Workplace: The Americans with Disabilities Act in Action” (2002) *American Journal of Epidemiology* 156, 219

²⁸ Fesko, S, Disclosure of HIV status in the workplace: considerations and strategies (2001) *Health & Social Work* 26(4) 235

disclosure decisions of eighteen PLHA in depth and discovered that six of the participants were completely open about their HIV status within the workplace. Seven individuals had revealed their status to selected people in the workplace and, at the point of doing so, requested that the information be kept confidential. Finally, five individuals reported that they did not tell anyone in their workplace. 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 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.”²⁹

This fear of stigma and the potential inability to disclose means across the EU numerous PLHA are unable to request that reasonable accommodations be made to their working environment because of the fact they have not disclosed their status to their employer. Such a fact could have detrimental effects on a PLHA’s health and their participation in professional life should they become ill. By way of example, in the absence of disclosure and reasonable accommodations being made PLHA may miss hospital appointments if such appointments fall during working hours or opt to not take doses of medication whilst at work for fear of possible awkward questioning by fellow workers.

HIV was mentioned by Advocate General Kokott in her opinion in *HK Danmark (Ring and Skouboe Werge)* when referring to the express distinction between sickness and disability that the CJEU had earlier drawn in *Chacon Navas*, she stated:

“33. A distinction must therefore be drawn between sickness as the possible cause of the impairment and the impairment resulting from sickness. A permanent limitation resulting from sickness which hinders participation in professional life is also covered by the protection of the directive.

34. The present cases concern physical impairments that manifest themselves inter alia in pain and lack of mobility. The distinction between sickness and disability is therefore easier to draw in these cases than in the case on which the Supreme Court of the United States of America had to rule, where it held that even an asymptomatic HIV infection may constitute a disability within the meaning of the ADA 1990. Whether a person’s complaints constitute a limitation in a particular set of circumstances is a matter for assessment by the court of the Member State.

35. There is nothing in the wording of Directive 2000/78 to indicate that its scope of application is limited to a certain degree of severity of disability. Since, however, this issue has been neither raised by the referring court nor discussed by the parties to the proceedings, it does not need to be definitively resolved here.”³⁰

²⁹ Ibid, 239

³⁰ Op Cit n 2

The problem HIV presents is that it is not a static condition but one that evolves with time. In the early stages of infection, it is stigma associated with the virus that is disabling rather than the virus itself. Indeed at the point of diagnosis many PLHA are fit and healthy and, with access to appropriate treatment, will remain so for a number of years. However if the virus progresses it becomes functionally disabling in addition to socially disabling. The virus has the potential to manifest itself via AIDS defining illnesses and thus render the individual disabled from both a medical and social perspective. It is only at this point that the virus becomes disabling from the perspective of the medical model.

As previously noted, the issue of whether HIV could amount to a disability and whether a minimum level of severity is required before an impairment can be considered a disability was touched upon by the Advocate General in *HK Danmark (Ring and Skouboe Werge)*. Advocate General Kokott stated, "*The distinction between sickness and disability is therefore easier to draw in these cases than in the case on which the Supreme Court of the United States of America had to rule, where it held that even an asymptomatic HIV infection may constitute a disability within the meaning of the ADA 1990.*"³¹ The United States' Supreme Court decision referred to is that of *Bragdon v Abbott*³². In this case the claimant, Abbott, disclosed to her dentist that she was HIV positive prior to requiring treatment in order to fill a cavity. Abbott's dentist refused to treat her in his office and instead offered to treat her at a hospital where she would be responsible for the increased costs associated with the use of hospital treatment. Abbott argued that this treatment contravened the Americans with Disabilities Act 1990 ("ADA") and the key legal issue for the Supreme Court was whether PLHA fell within the definition of disability under the ADA. The ADA defines disability as:

"(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;

"(B) a record of such an impairment; or

"(C) being regarded as having such an impairment."³³

The Supreme Court decided that PLHA did fall within the definition of disability for the purposes of the ADA as the virus substantially limited one of Bragdon's major life activities. After referring to medical evidence, the Court concluded that HIV substantially limited Bragdon's ability to reproduce which they considered a major life activity³⁴.

In the Supreme Court's opinion although conception and childbirth are not impossible for PLHA, they "are dangerous to the public health"³⁵ and so amount to a substantial limitation for the purposes of the ADA.

With these facts in mind, it must be questioned whether PLHA will be able to fall within the definition of "disability" advanced by the CJEU in *HK Danmark (Ring and Skouboe Werge)*. Bragdon was able

³¹ Op cit n2, para. 34

³² 524 U.S. 624 (1998)

³³ Americans with Disabilities Act 1990, s1202

³⁴ The Americans with Disabilities Act 1990 contains no definition of what constitutes a "major life activity". Chief Justice Rehnquist, Justice Scalia and Justice Thomas dissented with the majority of the court on this point, considering reproduction not to be a major life activity.

³⁵ Op cit n28, para 641

to persuade the Supreme Court that she should fall within the remit of the ADA as HIV substantially limited one of her major life activities, her ability to reproduce. Yet clearly a restriction on one's ability to reproduce does not hinder the participation of an individual in professional life as required by the CJEU's functional conception of "disability". It is hoped that in future the CJEU broaden the concept of disability for the purposes of the Framework Directive to encompass individuals who are prevented from participating fully and effectively in society and not just, as the law currently stands, professional life. The case of *Bragdon* illustrates that whilst a condition like HIV may not hinder an individual's functional participation in professional life it certainly is able to limit an individual's full and effective functional participation in society. Indeed, the fact that it does hinder functional participation in society only serves to exacerbate stigma against PLHA who may be perceived as "other" or "different" from the able bodied majority due to their inability to fully participate in some aspects of society. This stigma knows no boundaries; it exists within the place of work of PLHA and outside of it. The CJEU ought to recognise that individuals who are prevented from participating fully and effectively in society due to stigma are "disabled" and should fall within the remit of the Framework Directive.

In addition, it is somewhat troubling as to why Advocate General Kokott questioned whether a certain degree of severity of disability is required for the purposes of the Framework Directive. By referring to HIV and questioning whether a minimum level of severity is required, Advocate General Kokott fails to take into account the fact that PLHA, in common with many other individuals with disabilities, face discrimination within employment not solely because of functional limitations due to the severity of their condition but often because of the substantial stigma associated with their condition. Indeed, due to recent medical advances in the treatment of HIV, PLHA within employment are now arguably more likely to be discriminated against because of the stigma associated with their condition as opposed to any functional limitations. By questioning whether a certain degree of severity is required and using HIV as an example, it would appear that Advocate General Kokott moves the concept of disability away from the social model of disability. Kokott appears here to be focusing solely on any conditions degree of impact upon an individual's functional ability. If the CJEU is to fully embrace the social model of disability, such considerations should not come into play. So, under the social model, disability is any societal factor which imposes restrictions on disabled people. Thus the correct focus of any future CJEU decision concerning the definition of disability for the purposes of the Framework Directive should be to examine what factors limit the individual in question from participating fully and effectively in society. Focusing on the restricting factors of an individual's impairment and examining degrees of severity, as was suggested in the *HK Danmark (Ring and Skouboe Werge)* case, merely undermines any attempt at effectively implementing the social model of disability into EU law.

The hope must be that at the point that the question as to whether a minimum level of severity is required for the purposes of the Framework Directive, the CJEU will recognise that the barriers which hinder the full and effective participation of disabled people in professional life go beyond just the environmental or physical but include attitudinal and psychological barriers. As such, a definition of disability which is firmly grounded in the social model needs to be adopted. Such a definition would recognise that an individual could be classified as "disabled" for the purposes of the Framework Directive notwithstanding the fact that their condition does not functionally limit them in any way. The definition would also recognise the fact that individuals with disabilities are prevented from participating fully and effectively not just in professional life, but in all aspects of society.

The social backdrop

Where does this leave both PLHA and the definition of disability for the purposes of European Union law and does this really matter or is this just an academic question? This paper utilised the example of HIV to illustrate the extent to which European disability law has managed to develop in a seemingly incoherent and inconsistent manner.

To say that the law relating to HIV discrimination is complex would be an understatement. In attempt to protect PLHA from discrimination, various pieces of legislation have evolved. Whilst each has at its heart the objective of protecting PLHA from discrimination, the collective result is a multifaceted collection of various pieces of legislation often overlapping and sometimes contradictory. To decipher the possible legal protection of PLHA, regard might for example be had to the UN Convention, European Union law and any applicable law of the individual member state³⁶. The net result is that many lawyers now struggle to comprehend the law as it relates to discrimination. This is somewhat troubling as discrimination is surely one of the key areas in which the law should be accessible and interpretable to laypeople in order that they may utilise its protection. The current situation fails entirely in this regard. The EU has committed itself to combatting HIV and a clear and consistent legal framework in relation to, not only HIV, but disability as a whole needs to form a significant part of its approach. Failing to tackle discrimination and stigma through the utilisation of a clear and consistent legal framework also raises a number of unintended consequences. To understand these unintended consequences, one must consider the medical and social background against which the virus operates.

Highly active antiretroviral therapy (“HAART”) consists of the use of at least three antiretroviral drugs to suppress the virus, decrease an individual’s viral load and slow the progression of disease. The use of HAART can also reduce the risk of onward HIV transmission by PLHA where the individual’s viral load is suppressed to a very low or undetectable level. Viral load is the term used to describe the amount of HIV present in an individual’s body and is usually measured in the blood. Testing is routinely undertaken in an individual’s HIV clinic every three to six months in order to help inform treatment decisions. It is measured in terms of the number of copies of HIV’s genetic material (RNA) per millilitre of blood. The measurement can be described as a ‘snapshot’ of how much HIV is found in the blood of an individual at the moment of the blood test. Although this may fluctuate mildly from hour to hour – and HIV may be present at different levels in other parts of the body, including the brain, breast milk, genital fluids, the gut and the mucosal lining of the vagina and the rectum – the viral load test is generally considered to be a broadly satisfactory surrogate marker of HIV levels throughout the body. However, an undetectable viral load result does not necessarily mean that the blood sample is completely free of HIV. In fact, most people with undetectable viral loads will still have some HIV in their blood.³⁷

In January 2008, a consensus statement from the Swiss Federal AIDS Commission created international controversy by publicly announcing that as long as someone has had an undetectable viral

³⁶ Depending on the facts of the case, regard might also be had to the European Convention on Human Rights

³⁷ Information in this paragraph is taken from Graz A. Luzzi, T.E.A. Peto, P. Goulder, and C. P. Conlon, “HIV/AIDS” in David A. Warrell, Timothy M. Cox, and John D. Firth (eds), *Oxford Textbook of Medicine* (OUP 2010)

load (which they defined as less than 40 copies/ml) for at least six months; remains adherent to their antiretroviral therapy, is evaluated regularly by their HIV clinician, and has no other sexually transmitted infections (STIs); then they are not sexually infectious, i.e. cannot transmit HIV through sexual contact³⁸. However, many other AIDS organisations, including the World Health Organization (WHO), Joint United Nations Programme in HIV/AIDS (UNAIDS) and the United States Centers for Disease Control and Prevention (CDC) have since stated that there is not yet enough evidence to support this statement³⁹. These organisations do however agree that people with an undetectable viral load are less infectious.

To be sure HIV may have grave consequences if undiagnosed or untreated but to simply construct HIV as possibly fatal or life-threatening within the context and era of HAART merely contributes to the stigma already faced by PLHA. Such stigma, it is submitted, may act as a deterrent for a number of these people to undertake HIV testing. Indeed messages regarding the efficacy of HAART, are difficult to transmit amongst “at risk” groups when the virus is stigmatised. There is often a myth that PLHA, in common with other individuals with disabilities, are “other” or “not normal” and this may lead members of such groups to fail to accept that they themselves may actually be at risk of HIV and so present themselves for testing. This is borne out by the figures which show that although an estimated 96,000 people were living with HIV in the UK by the end of 2011, approximately one quarter of whom were undiagnosed and unaware of their infection⁴⁰. These individuals who are HIV positive but not aware of their status obviously do not present themselves for treatment and so do not receive HAART. The consequence of this failure to access HAART leads to such individuals posing a greater risk of transmitting the virus onwards to sexual partners which raises questions regarding the general health of the public.

The adoption of a coherent definition of disability grounded in the social model would ensure that PLHA are adequately protected from discrimination across the EU and, in addition, would be a significant effort in tackling the heightened levels of stigma directed at PLHA. Indeed tackling such stigma will enable the wider public to realise that PLHA are in fact “normal”, that HIV can be adequately managed and that PLHA can progress to old age provided appropriate medical treatment is accessed at an early stage. This should persuade citizens of the European Union to realise that HIV is not, as often mistakenly portrayed, a terminal condition and consequently promote greater acceptability of the condition and an increase in individuals presenting for HIV tests. Such a move would potentially lead to the normalisation of both HIV and individuals presenting for testing across the European Union. It would enable more individuals to be diagnosed at an early stage and improve their individual health. By way of example one study found that for HIV-infected individuals who managed to suppress the virus, the rate of progression from HIV to AIDS or death was reduced by 86%⁴¹.

³⁸ Vernazza P et al., “Les personnes séropositives ne souffrant d’aucune autre MST et suivant un traitement antirétroviral efficace ne transmettent pas le VIH par voie sexuelle” (2008) *Bulletin des médecins suisses* 89 (5)

³⁹ Granich RM et al., “Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model.” (2009) *Lancet* 373, 48

⁴⁰ Health Protection Agency, *HIV in the United Kingdom:2012 Report* (Health Protection Services, 2012)

⁴¹ Sterne JAC and others, “Long-term effectiveness of potent antiretroviral therapy in preventing AIDS and death: a prospective cohort study” (2005) *Lancet* 366

Conclusion

The decision of the CJEU in *HK Danmark (Ring and Skouboe Werge)* represented the CJEU's first opportunity to revisit the concept of "disability" employed by the Framework Directive since the ratification of the UN Convention by the European Union in 2010. In this case, the CJEU conceptualised disability as being an impairment which, in interaction with various barriers, hinders the full and effective participation of an individual in professional life. The decision represents a welcome step in the direction of the social model but the decision illustrates that the CJEU still has some way to go until a definition of disability primarily based upon the social model of disability is adopted. Future decisions of the CJEU need to build upon the decision in *HK Danmark (Ring and Skouboe Werge)* but also acknowledge that the question of disability is not solely concerned with an individual's functional limitations. Some conditions, of which HIV is an example, impose limited functional limitations upon an individual. Certainly if the concept of disability is solely concerned with functional limitations which restrict an individual's ability to fully participate in professional life, then it is questionable whether PLHA will gain the protection of the Framework Directive. This would be an unexpected outcome given the marginalised nature of large numbers of PLHA within the European Union. Thus, it is hoped that in future the CJEU broaden the concept of disability for the purposes of the Framework Directive to encompass individuals who are prevented from participating fully and effectively in society and not just professional life.

It must also be hoped that the CJEU does not impose a requirement for an impairment to have a minimum degree of severity before it can be classified as a "disability". The CJEU must recognise that the barriers which hinder the full and effective participation of disabled people in professional life go beyond just the environmental or physical but include attitudinal and psychological barriers. As such, a definition of disability which is firmly grounded in the social model needs to be adopted. Such amendments to the concept of disability would have far reaching beneficial consequences for not just PLHA but all individuals with disabilities across the European Union.