LEGISLATION AND JUDICIAL SYSTEMS IN RELATION TO HIV AND AIDS

Report of a Seminar 19-21 APRIL 2007

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Prepared by National AIDS Trust

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1 Introduction and background

The seminar on 'Legislation and Judicial Systems in relation to HIV and AIDS', held in London from 19 to 21 April 2007, was hosted and organised by the National AIDS Trust for AIDS Action Europe, the Pan European NGO Partnership on HIV and AIDS. A total of 37 individuals participated, from 29 countries, including 19 EU member states, and there were also representatives from WHO, the European Commission, UNDP, and UNHCR. Those who attended the conference can be found at Annex A and the seminar programme at Annex B.

The seminar is part of a series of European best practice seminars that are organised by AIDS Action Europe and its partners as part of the project 'European Partners in Action on AIDS'. This project aims to strengthen knowledge, capacities, discussion and exchange among HIV-related NGOs in Western and Eastern Europe in order to encourage concerted action and the acceleration of innovation in their approaches in the fight against HIV and AIDS. Please visit www.aidsactioneurope.org if you wish to learn more about AIDS Action Europe, its projects and the other European best practice seminars.

The seminar was the central output of a broader work package which included a pre-seminar survey and report. The pre-seminar survey was conducted in late 2006/early 2007, and the pre-seminar report was published in March 2007. It is available for download from the AIDS Action Europe website at www.hivaidsclearinghouse.eu.

One of the aims of the seminar was to identify best practice in relation to HIV, legislation and judicial systems. Difficulties immediately present themselves. The possible legislation relevant to people living with HIV is vast. The different legal and judicial traditions of the European region also make detailed prescription impossible and inappropriate. At the same time, we already have very useful generic guidance on how human rights apply to HIV in the International Guidelines produced by UNAIDS and the Office of the High Commissioner for Human Rights (OHCHR), and the IPU/UNAIDS Handbook for Legislators. What then can usefully emerge from our pre-seminar report and the seminar itself, which avoids merely repeating universal standards and yet identifies relevant priorities and actions applicable across the European region?

What emerged from the report and seminar was a set of priorities from the voluntary sector across Europe which does not claim to be exhaustive but is important and pressing. Our best practice recommendations therefore take the form of an agenda for action to meet these immediate concerns, addressing above all national government and European institutions but also community and voluntary sector organisations. This agenda is summarised in the Executive Summary at the front of this report. AIDS Action Europe will use the agenda for action outlines in this report in its advocacy work within such bodies as the EU HIV/AIDS Civil Society Forum and the EU HIV/AIDS Think Tank. Further ideas for action will no doubt emerge for individual readers from the more detailed minutes and slides of presentations and workshops.

The seminar was made possible by support from the European Commission and GlaxoSmithKline’s Positive Action, Bristol-Myers Squibb and the Levi Strauss Foundation.

Yusef Azad
Seminar Coordinator
Member Steering Committee AIDS Action Europe
National AIDS Trust

2 Executive summary

European Union discrimination law

There is welcome anti-discrimination law at the European Union level, covering for example sexual orientation, disability and gender, but it does not explicitly address HIV status. Whilst some national legislative systems have stated that HIV positive status should from the moment of diagnosis be considered a disability (see for example United Kingdom Disability Discrimination Act 2005), and thus be covered by discrimination law, there is no EU requirement for such a provision. Furthermore, EU protection from discrimination on grounds of disability does not extend as yet to the provision of goods and services.

> **Recommendation 1:** The European Union should explicitly require protection from discrimination for people living with HIV (for example, by including people with HIV in the definition of disability from the point of diagnosis). This protection should include protection from discrimination in the provision of goods and services.

The European Convention on Human Rights

The European Convention on Human Rights (ECHR) sets out fundamental human rights which if accessed could significantly benefit people living with HIV across Europe. Relevant litigation could well over time establish useful case law for people living with HIV. The issue of access to rights and effective use of systems of redress is one considered below.

Not every country in the WHO European region is a member of the Council of Europe (in particular Central Asian republics such as Kyrgyzstan and Uzbekistan, which were represented at the seminar).

Furthermore, there are additional human rights instruments with far fewer signatories which were identified at the seminar as of value for people with HIV, in particular Protocol 12 of the ECHR, which extends the human right not to be discriminated against to any action of a public body and to any right enshrined in law, and the European Social Charter which guarantees social and economic rights including the right to health. Importantly, an Additional Protocol to the European Social Charter provides for a collective complaints mechanism to the European Committee of Social Rights, accessible to, amongst others, national NGOs. Only a minority of Council of Europe member states have signed and ratified ECHR Protocol 12 or the Additional Protocol of the European Social Charter.

> **Recommendation 2:** The provisions of the European Convention on Human Rights, including Protocol 12, and of the European Social Charter, including the Additional Protocol on collective complaints mechanisms, need to apply across the whole European region. International and national NGOs, along with international human rights bodies, should strongly advocate to national governments the adoption of a comprehensive human rights framework which can provide full protection and real redress for people living with HIV.

Engaging with European institutions

> **Recommendation 3:** There are as yet unused opportunities to take matters forward at the European level through engagement with European institutions and in particular the European Parliament. Advice at the European level, perhaps via AIDS Action Europe, on how best to address and interact with the European Parliament should be developed.

Recommendation 4: Contact needs to be made with the EU data protection working group to encourage consideration of Europe-wide standards on health-related information in general and HIV-related information in particular.

Recommendation 5: Further research should be conducted into opportunities to raise matters of concern around HIV and human rights with the institutions of the Council of Europe, including the Council of Europe High Commissioner for Human Rights.

Judicial systems and legal redress

From both the pre-seminar report and the seminar itself it is very clear that it is often not the law itself which is the problem, but the way the law is implemented, breached and ignored, and the absence of effective means of legal redress. In particular those living with HIV are often from groups which experience significant discrimination within the legal system, for example injecting drug users and sex workers. They have little or no recourse to funds for legal action and have great difficulty accessing legal aid.

People with HIV in general know little of their rights and those in the legal and judicial systems know little about HIV. There are also relatively few NGOs with experience in either litigating on behalf of people living with HIV, or of supporting individuals with HIV through the legal system.

A particular and significant barrier for people with HIV to accessing the judicial system is the loss of confidentiality of HIV positive status and possible public and media attention.

There must also be consideration of how non-judicial processes of redress can be used and accessed to defend and promote the rights of people living with HIV. In particular, ombudsmen and state human rights institutions need to be willing to defend the rights of people living with HIV.

Recommendation 6: A human rights priority for the European region is the establishment of genuinely non-discriminatory judicial systems which are accessible to those with little or no funds. To that end effective and adequate legal aid should be available across the European region for all, including those without documented residency rights.

Training for judges, lawyers and court officials, as well as for police, prison officers and other law enforcement professionals has shown some success but is only occasionally provided.

Recommendation 7: Training should be provided across the European region for judicial and law enforcement systems on HIV, with some agreed core components, to be identified with support from international bodies such as the EU and UNAIDS. To be effective, the training must also include discrimination issues in relation to those groups most affected by HIV such as gay men, injecting drug users, sex workers and migrants.

Recommendation 8: Professional best practice guidelines are necessary for police, lawyers and judges to end the irrelevant reference to HIV status in court processes and the inappropriate claim of HIV positive status as an aggravating factor in sentencing.

As important for effective legal redress, is a system which to an appropriate extent protects the medical confidentiality and HIV status of those who come to court.

Recommendation 9: There needs to be advocacy for effective reporting restrictions across Europe to protect the identity of HIV positive litigants and complainants, and also consideration of the confidentiality rights of defendants prior to conviction.

Recommendation 10: Ombudsmen and human rights institutions need to be engaged across Europe on HIV issues and are possibly more effective on occasion as means to promote collectively the rights of people living with HIV.

Capacity building amongst NGOs

Recommendation 11: A network of NGOs and of relevant experts needs to be established to provide mutual support and advice on HIV and legal/human rights issues across the European region.

Recommendation 12: In particular, best practice should be drafted for NGOs on how best to advocate and litigate around HIV and legal issues.

Recommendation 13: NGOs should also consider the innovative use of legal procedures, such as affidavits, as valuable tools in campaigning and advocacy work.

Recommendation 14: Funders need to provide support for efforts of NGOs to develop capacity in engaging with legal processes and in education work for both professionals and for people living with HIV on legal rights.

Recommendation 15: Better and more strategic links need to be made by HIV NGOs with non-HIV legal specialists and support organisations (including human rights NGOs and pro bono lawyers) to promote the rights of people living with HIV.

Recommendation 16: There should be consistency across the European region in permitting NGOs legal status before courts, and in particular the ability to bring class actions.

Recommendation 17: The proposed network of legal experts on HIV across Europe should consider more detailed comparative work reviewing HIV-relevant legislation across the region, as well as the possibility of drafting a model anti-HIV discrimination statute.

Migrants, mobility and travel

Recommendation 18: Universal access to HIV treatment must be provided to all migrants including those who are undocumented or without lawful residency status. Any system which presents barriers to migrants readily accessing HIV treatment, for example unaffordable charges, does not comply with the commitment to universal access. These principles should be explicitly stated for the avoidance of doubt by WHO, UNAIDS, the UN General Assembly, the European Parliament and the Parliamentary Assembly of the Council of Europe.

Recommendation 19: The principle of universal access to HIV prevention, treatment, care and support also means that there should be no discrimination against or disadvantage for migrants in the allocation of HIV-related resources.

Recommendation 20: HIV testing amongst migrants must conform to the highest international ethical standards. In particular there should be no mandatory or non-consensual HIV testing, confidentiality of results should always be strictly respected, appropriate treatment and support should always be available for those who test HIV positive, and there should be no negative impact of an HIV positive result on immigration processes or residency status.

Injecting drug users, sex workers and prisoners

Recommendation 21: Decriminalisation of sex work and drug use should be considered across Europe to ensure effective access to healthcare and all public services.

Recommendation 22: Harm reduction principles and measures should be agreed across Europe and consistently applied to ensure effective and safe access to high quality prevention, treatment, care and support for sex workers, injecting drug users and prisoners.

Recommendation 23: Prevention, treatment, care and support should be available to all prisoners in Europe according to the principle of equivalence of healthcare. In particular, international bodies such as the Council of Europe and the European Union should explicitly support the provision of clean needles in prison settings.

Financial services

Recommendation 24: Companies should have to prove a reasonable actuarial basis for any refusal of insurance/financial services provision.

Recommendation 25: The burden of proof should be reversed so that insurance companies have to demonstrate the actuarial reasons they have to believe the health prospects of someone with HIV are worse than those with other health conditions who can access cover.

Recommendation 26: More information should be collected on how people with other long-term health conditions such as diabetes access financial services, to ensure appropriate parity of service provision.

Recommendation 27: A ‘basic insurance’ scheme for people living with HIV, and others with relevant health conditions, to enable access to fundamental rights such as health and housing is possible and necessary.

Recommendation 28: Welfare system reform needs to be monitored, especially where privatisation takes place, to ensure this does not put at risk the rights of people with HIV.

Recommendation 29: Financial services companies need to be approached to discuss the reasons why they should look at the market for financial services amongst people living with HIV.

Recommendation 30: The European Commission should be urged to propose the extension of discrimination law on the provision of goods and services to people with HIV.

Confidentiality in healthcare settings

Recommendation 31: UNAIDS and the ILO should provide definitive international guidance on the very limited circumstances in which there may be issues around people living with HIV undertaking certain occupations. All European countries must as a priority end any occupation-related restrictions for people living with HIV which do not comply with such international standards.

Recommendation 32: There is a need for training of both clinicians and law enforcement officials on confidentiality and data protection in relation to medical information. The EU Data Protection Working Group should identify appropriate standards across the EU, with any necessary further research funded by the European Commission as appropriate.

Recommendation 33: People with HIV need to understand their rights to confidentiality in healthcare settings – NGOs can play an important part in disseminating this information. They also need access to effective processes for redress should confidentiality rights be breached.

Recommendation 34: Doctors who come across real dilemmas around confidentiality in healthcare should have access to confidential and expert advice (an ‘ethics helpline’).

Recommendation 35: Clear international guidelines are necessary in this area, in particular on testing and partner notification best practice, involving national governments, the EU, Council of Europe, UN and WHO.

Recommendation 36: There must be an end to compulsory HIV testing. Instead HIV testing across Europe should be free and confidential/anonymous.

Recommendation 37: Underlying issues of HIV-related stigma and discrimination in healthcare settings need to be addressed.

Confidentiality in legal proceedings

Recommendation 38: Courts and law enforcement bodies must stop publicising HIV status when this is legally irrelevant information

Recommendation 39: More clarity is needed on the possibility of imposing and accessing reporting restrictions, with real enforcement and sanctions when such restrictions are breached by the media.

Recommendation 40: There should be protection of identity or anonymity for HIV positive defendants prior to conviction, as well as for HIV positive complainants.

Recommendation 41: The inappropriate use of HIV positive status as an aggravating factor in other charges/prosecutions should end. UNAIDS should support legal experts in addressing this issue and arriving at best practice.

Recommendation 42: Court officials, judges, lawyers and the police should receive training on HIV issues and their relevance to the legal environment. Further work is necessary across Europe to support consistent provision of useful and accurate information.

The role of NGOs in legal proceedings

Recommendation 43: The legal standing of NGOs before the courts must be clearly established, and in particular the possibility of taking ‘class actions’ on behalf of people living with HIV. This issue needs to be addressed at the international level by both the European Union and the Council of Europe.

Recommendation 44: Training should be provided for lawyers on HIV issues by NGOs, and indeed for their own staff who may be called on to act as expert witnesses.

Recommendation 45: NGOs should communicate clearly to people living with HIV how they or other NGOs can support individuals in court proceedings and legal action.

Recommendation 46: NGOs should review the impact of existing law and court cases on people living with HIV.

Recommendation 47: Training and capacity-building are necessary for many NGOs if they are to interact effectively with legal processes. It is extremely important to build up expertise across Europe on HIV and legal issues, and to do so the HIV sector should build better links with legal and human rights NGOs, public interest lawyers, law students, trade unions and human rights academics.

Recommendation 48: NGOs should consider not only representations to domestic legal bodies but also submitting views and recommendations to international review and monitoring bodes linked to international human rights bodies, for example of the Council of Europe or the United Nations.

Recommendation 49: NGOs should support or take appropriate cases to the European Court of Human Rights, the European Court of Justice, and other international fora such as the Human Rights Committee established under the International Covenant of Civil and Political Rights.

The role of ombudsmen and human rights institutions

Recommendation 50: Ombudsmen and state human rights bodies have the potential to act effectively on behalf of people living with HIV, especially where they are free of political interference.

Further work and research is necessary on the various powers of ombudsmen and state human rights institutions and how they might best be accessed to benefit people living with HIV. Europe-wide associations of ombudsmen, and the European Ombudsman Institute also, should be approached to put HIV on their agendas.

Knowledge of rights amongst people living with HIV, and knowledge of HIV in legal and judicial systems

Recommendation 51: Funding and support should be made available to inform people living with HIV of their rights across the European region. There needs to be a differentiated understanding of the information needs of the various groups most affected by HIV, for example migrants and ethnic minorities, gay men, injecting drug users, sex workers and prisoners, all of whom will have distinct needs.

Recommendation 52: Effective legal actions and court cases should be well publicised as a further way to disseminate understanding of rights.

Recommendation 53: Legislation and judicial systems across Europe continue to display evidence of poor understanding of HIV, clinically, biologically and socially. International action should identify key information and training needs of legislators, civil servants and lawyers on HIV.

3 Presentations and workshop notes Thursday 19 April 2007

3.1 Presentations and associated questions

3.1.1 Legislation and judicial systems in relation to HIV and AIDS

Yusef Azad (NAT)

Legislation and Judicial Systems in relation to HIV and AIDS

Yusef Azad

Director of Policy and Campaigns

National AIDS Trust

Seminar background

Seminar third in a series organised by AIDS Action Europe – 'European Partners in Action on AIDS'

Agreed outputs:
- Pre-seminar survey and report
- Seminar attended by a wide range of delegates from across EU and the wider WHO European region
- Report of Seminar proceedings
- Guidelines for 'best practice' to help advocate for 'a human rights-based legal and judicial framework that addresses HIV-related stigma and discrimination'

The Dublin Declaration

Dublin Declaration: 'Confirming that the respect, protection and promotion of human rights is fundamental to preventing transmission of HIV, reducing vulnerability to infection and dealing with the impact of HIV/AIDS'

- 20. '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 human rights for people living with HIV/AIDS and members of affected communities'

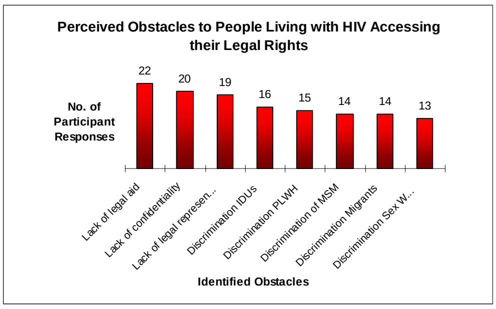
Findings from the pre-seminar survey 1

- Significant levels of legal protection in statute against discrimination for PLWH across Europe – but also significant differences in the nature of that protection (e.g HIV-specific, generic equality, disability)

- Significant continuing absence of legal protections for key affected groups including IDUs, prisoners, sex workers and migrants

- Lack of legal protection in accommodation, migrants' access to healthcare, prisons and financial services

Findings from the pre-seminar survey 2



Findings from the pre-seminar survey 3

'a huge disproportion between reality and what the law is in theory'

- Low levels of trust in and use of legal redress to protect rights
- Majority of countries do not have voluntary sector engaging effectively with the legal system
- Few countries have HIV training for lawyers, judges and court staff
- Majority of countries say PLWH's knowledge of their rights is low

Seminar objectives 1

Experiences of discrimination:
- Gather detailed and accurate information on current experiences of discrimination and the current effectiveness of legal protection and remedy
- Revise your country's survey response
- Share details of what is going on in your country

Seminar objectives 2

Legislation:
- Identify 'best practice' in protections from discrimination
- Identify current national and international law we should be using to promote rights of PLWH and affected communities
- Identify those areas where, nationally and internationally, we need new legislation to promote and protect rights

Seminar objectives 3

Judicial Systems:
- Agree strategies on how to improve access for PLWH and affected communities to legal redress
- Identify how NGOs can effectively engage with the legal system in support of PLWH
- Identify how legal processes can best be used to promote the rights of PLWH and when it is best not to go to law

Seminar objectives 4

Next steps:
- Identify how we should engage the European Commission and other EU institutions on these issues
- Identify how we can best support each other in working for improvement at the national level
- Identify how we can continue to share experiences, developments and best practice

3.1.2 HIV, AIDS and discrimination: the role of the European Union Prof. Mark Bell

HIV, AIDS and discrimination:
the role of the European Union

Prof. Mark Bell

Specific measures on HIV & discrimination

- Council Conclusions on AIDS & place of work [1988] OJ C28/2
- Case T-10/93 A v Commission [1994] ECR II-179

Refusal to appoint HIV+ applicant to a post involving work in developing countries

Mark said that the first move by the European Union to act in relation to HIV and discrimination came in the form of non-binding 'Conclusions' in 1988 on 'AIDS & place of work'. The Conclusions stated that there should not be any screening for HIV infection in the workplace. Over time it seems that these Conclusions have been rather forgotten, not least by the Commission itself which was taken to court by a job applicant living with HIV who was refused a job for his own 'health and safety' ostensibly because of the risk to his health from the work required in the relevant post in developing countries. The court ruled that the Conclusions are not legally binding but should be taken into account by the Commission in its employment practice.

EU anti-discrimination law framework

- Article 13, EC Treaty: power to take measures to combat discrimination on grounds of sex, racial or ethnic origin, religion or belief, age, disability and sexual orientation

Fields of protection in EC legislation:
- Employment: all grounds
- Goods & services (inc. health): ethnic origin & sex
- Education & social protection: ethnic origin

Using EU anti-discrimination law in relation to HIV and AIDS

- Related discrimination on grounds of ethnic origin or sexual orientation
- The definition of 'disability'
    - Case C-13/05 Navas, 11 July 2006
    - Case C-303/06 Coleman v Attridge Law
- Right of NGOs to legal standing to bring cases on behalf or in support of individuals

The turning point came in 1999 with the establishment of the EU anti-discrimination law framework. Article 13 of the EC Treaty significantly expanded the power of the EU to legislate. There was then a quick move to follow this up with anti-discrimination legislation and an anti-discrimination 'action programme'. One issue of concern is the fact that the anti-discrimination legislation introduced was inconsistent in its scope. Discrimination in the workplace is forbidden on all 'grounds' (ethnic origin, age, gender, disability and sexual orientation). It has been forbidden in respect of gender since 1976. Discrimination in the field of goods and services is only forbidden on grounds of ethnic origin and, since 2004, gender (i.e. not disability or sexual orientation). For education and social protection, protection against discrimination is limited to ethnic origin. In other words, EU anti-discrimination legislation is very inconsistent, with the political emphasis on racism. 2007 is the European Year of Equal Opportunities for All. This is probably an important opportunity to push forward the anti-discrimination agenda at the European level and ensure the needs of people living with HIV are properly addressed.

How does current EU anti-discrimination law apply to HIV? To an extent some of the relevant discrimination might be captured in legislation on the grounds of ethnic origin or sexual orientation. With regard to disability, there is no definition of disability at the EU level but there is some case law. The *Navas* case saw the European Court of Justice establish a difference between sickness and disability. Disability involved a 'limitation' which could be a physical, mental or psychological impairment which lasted a long time. In other words, this was a medicalised definition focussing on impairments which hindered participation in the workplace.

There is also a pending case *Coleman v Attridge Law* which concerned the application of disability anti-discrimination legislation to discrimination 'by association'. The particular case involved someone who complained of discriminatory treatment in the workplace linked to the fact she was a carer for a disabled son.

According to the EU Directives, NGOs may act 'on behalf of or in support of' an individual victim of discrimination. In some states this is interpreted as permitting legal standing for NGOs to bring cases in their own name.

Migration / access to healthcare

- EU citizens: equal access to healthcare (Directive 2004/38)
- Non-EU nationals:
  equal access for refugees and long-term residents (2004/83, 2003/109)
  emergency care / essential treatment only for asylum-seekers (2003/9)

Further information

- general info on EU & discrimination:
http://ec.europa.eu/employment_social/fundamental_rights/index_en.htm

Detailed legal info on national laws on discrimination:

http://ec.europa.eu/employment_social/fundamental_rights/policy/aneval/legnet_en.htm

There is in EU law a fundamental distinction between EU citizens and those who are not EU citizens. Whilst EU citizens have a right to equal access to healthcare, non-EU nationals are treated differently. Refugees and long-term residents do have equal access to healthcare but asylum seekers only have a legal right under EU law to emergency care/essential treatment, but rights beyond this are not clearly spelled out.

HIV status should not be a basis to restrict travel for EU citizens between EU member states. However, if an EU national is not moving as a worker, a member state could insist on comprehensive sickness insurance to be in place for the individual. But once resident in another member state for 5 years one is legally considered to be permanently resident. Family members of EU nationals can access the same standard of protection, irrespective of their nationality.

None of the above directives on non-EU nationals apply to Denmark, the UK and Ireland who have opt-outs on these issues.

More broadly, the right of entry into a member state is an issue for national competence.

There is considerable potential to use EU immigration law to promote the rights of people living with HIV. For example, they may be protected under provisions applying to refugees and asylum-seekers with ‘special needs’.

Questions for Mark Bell

Q: Can the definition of disability used in EU anti-discrimination law include psychological impairment, or emotional? A: Mark said there is nothing in EU law to exclude such an interpretation. It is a question the courts have discussed and it is something of a grey area. Only a few countries have defined disability in their law.

Q: Are the side effects of HIV treatment considered a disability in EU law? A: There is a debate within Europe at the moment as to what disability is in the context of discrimination. In Mark’s view, people should be able to rely on a definition of disability which makes a real difference and operates as an actual, practical resource.

Q: Who decides whether an NGO has the right in a national jurisdiction to bring a case under discrimination law? – the phrase ‘NGO of legal standing’ sounds a bit like ‘government-approved’? A: Some states do indeed have a list of approved NGOs whilst others define them simply according to the organisation’s aims. In Austria, there is an umbrella body for all NGOs to pursue such matters in the courts. The UK tends to take a minimalist line in its interpretation of the directives and there are no special rules here on providing legal standing for NGOs.

Q: How widely did NGOs use this power to litigate under anti-discrimination law? A: The power is used more in some countries than others. There has, for example, been some significant litigation by Roma rights organisations in central Europe. On the whole, however, there is a low level of litigation by NGOs. This could be because of the way the directives are framed – they still require the identification of an individual victim in order to bring litigation.

Q: In terms of EU law stating asylum seekers only had a legal right to access to emergency care/essential treatment, was there legal acknowledgment of enhanced responsibilities in relation to asylum seekers in detention? A: Mark said that detention is controversial in debates on discrimination. The Directive covers issues of accommodation but there is no particular provision on healthcare in detention. There is perhaps potential in the provision for ‘particularly vulnerable persons’ which have been used for example to protect the rights of those who have been tortured – this is a non-exhaustive list where states have more extensive duties. The state’s responsibility for healthcare is taking on greater prominence in court judgments.

Q: Does there need to be some clarity on the relationship between HIV infection and disability? How does the idea of disability apply in court cases – it is not always enough simply to have HIV in order to be considered disabled?

Q: How does the prohibition under Article 3 of the European Convention on Human Rights (ECHR) on inhuman and degrading treatment apply to denial of access to treatment? And is there any application to economic and social issues? A: The issue of HIV (and how it relates to disability) is not being addressed in the Commission’s current consultation on discrimination law, but pressure should be put on the Commission to consider the issue. ECHR cases could of course go to the European Court of Human Rights but additionally the European Court of Justice is now confronting health and housing issues – there has not, however, been any European Court of Justice cases as yet.

3.1.3 HIV, AIDS and Discrimination: the role of the European Convention Karon Monaghan (Matrix Law)

HIV, Aids and Discrimination:
The Role of the European Convention

Key Convention Rights
Article 3
Article 8
Article 14

Karon Monaghan, from Matrix Law chambers, said that the European Convention on Human Rights is profoundly important. It informs the scope of the European Union law which Mark had previously expounded, and was referred to in terms in the EU Treaty. Thus it is very important also for domestic law in EU member states.

There are at least three ECHR rights of great importance for people living with HIV. Article 3 – an absolute right – forbidding torture, or inhuman or degrading treatment; Article 8 on the right to privacy and family life; and Article 14 which forbids discrimination.

Article 3

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

- Absolute right
- High threshold
- Right to treatment and appropriate health care (D v UK; Price v UK; BB v France; Karara v Finland; SCC v Sweden ; Ndangoya v Sweden ; Amegnigan v Netherlands)

Article 3 is an absolute right (in other words there was never an issue of 'balancing' this right against competing rights or duties) but there is a high threshold in ECHR law for a breach of the Article to be proved. There is a need to demonstrate very severe treatment. It is a useful right to cite in arguing for HIV treatment and appropriate healthcare. It may also be used to prevent deportation to places where treatment is not accessible.

The high point of such protection was the case of *D v UK* which prohibited removal from the UK of a man in the late stage of HIV disease progression, about to die, and with no place to stay and no carers in St Lucia, where he was to be deported. *BB v France* was also a helpful decision, though made at a lower level of the ECtHR process. But since then there has been a stepping back from the implications of *D* – now such protection from deportation under Article 3 is only available in exceptional circumstances. To access this protection more than an HIV positive diagnosis is now necessary, even if the absence of treatment in the home country will mean death. Some prospect of treatment, even if in reality not accessible or too costly, is enough to allow deportation to take place. To be protected under Article 3 it is necessary to prove the absence of any care at all.

There may also be implications of Article 3 for those held in detention. In the case of Price v UK a disabled woman was held to have been a victim of inhuman/degrading treatment even though she was treated the same as other prisoners. The inappropriateness of such ‘equal’ treatment for the woman in her particular circumstances resulted in inhuman/degrading treatment. There could possibly be implications of this judgment for the treatment in custody of people living with HIV.

Article 8

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well - being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

- physical and personal integrity and identity covered, including discrimination on the grounds of a person’s disability status or sexuality will fall within the scope of Article 8 (Botta v Italy; Smith & Grady v UK; Pretty v UK)

In Article 8 the key word from the perspective of people living with HIV will be ‘private’ - ‘private life’ has been broadly construed. It covers physical and personal integrity, as well as identity, which includes discrimination on grounds of disability or sexuality. The Ministry of Defence in the UK, for example, was held to be in breach of the Article with reference to the ban on gay men and lesbians serving in the armed forces. In particular the MoD’s scrutiny of the private lives of soldiers was held to be a breach of the right to a private life.

Article 8 is not an ‘absolute right’ – in other words, the right can be interfered with lawfully. But any such interference has itself to be lawful and can only be on grounds of national security, public safety or public health. There is a ‘necessity’ test for any such interference on grounds of public safety or public health, defined as ‘meeting proportionately a pressing social need’.

- Privacy rights (Smith & Grady v UK)
- Positive obligations; Fair balance; direct and immediate link between measures sought by an applicant and latter’s private and/or family life (Botta).

- Discrimination based on status (Smith & Grady; Botta)
- Right to choose treatment (Glass v UK)
- Criminalising sexuality/sexual acts (Dudgeon v UK)

The state has positive obligations to protect the right to private and/or family life (in other words a member state can breach the right by not doing something necessary as well as by doing something unlawful). The Court has ruled that there must be a direct and immediate link between the measures sought by an applicant and the applicant’s private and/or family life (*Botta*).

Case law from the European Court of Human Rights is very underdeveloped when it comes to disability. The Court has ruled that Article 8 applies to issues of sexual identity, for example the banning of gay men and lesbians from the armed forces in the UK (*Smith and Grady v UK*), to the right to choose treatment (*Glass v UK*) and criminalising sexuality/sexual acts (*Dudgeon v UK*).

Article 14

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

- Other status: disability/health status (Botta)
- Ambit test
- Direct and indirect discrimination; reasonable accommodations (Thlimmenos)

Article 14 prohibits discrimination on a number of specified grounds ‘or other status’. ‘Other status’ would include disability or health status (*Botta*). This Article therefore has an important relevance for discrimination experienced by people living with HIV. The limitation of the Article lies in the fact that the discrimination only breached the ECHR if it relates to the enjoyment to other Article rights. But Article 8’s ambit would very often apply to relevant cases.

There is limited case law on Article 14. It can protect from both direct and indirect discrimination. There has been no definition of ‘disability’. There was some prospect that the Court was persuadable to take on a more social model of disability.

Protocol No 12 (2005)

- The enjoyment of any right set forth by law shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.
- No one shall be discriminated against by any public authority on any ground such as those mentioned.

- Equality rights in legal rights
- Freestanding against public authorities

Protocol 12 to the ECHR provided a more free standing discrimination law, prohibiting discrimination in relation to ‘any right set forth by law’, not just the rights set out in the European Convention on Human Rights. It also prohibits discrimination by any public authority on any ground which includes ‘other status’. It thus offers important protections for those living with HIV. It only applies, however, in those countries which have ratified the Protocol, and only a few countries have as yet done so (Albania, Armenia, Bosnia and Herzegovina, Croatia, Cyprus, Finland, Georgia, Netherlands, San Marino, Serbia).

UN Convention

- UN Convention on the rights of persons with disabilities
- to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.’

- ‘respect for inherent dignity, individual autonomy including the freedom to make ones own choices, and independence of persons’
- ‘full and effective participation and inclusion in society’ and ‘respect for difference and acceptance of disability as part of human diversity and humanity.’

‘prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds’ and to ‘take all appropriate steps to ensure that reasonable accommodation is provided’

Positive Duties?

- Inherent in Articles 8 and 14
- Domestic duties?

Enforcing Rights

- Article 6, ECHR (‘fair hearing’)
- Practical and effective right
- Legal aid/support where lawyer indispensable for effective access (Airey v Ireland)

A further issue for consideration is the possibility of applying positive duties to public bodies. The concept of a positive duty to promote enjoyment of a right is, as has been stated, inherent in Articles 8 and 14. In the United Kingdom, public bodies have under the Disability Discrimination Act 2005 a positive duty to promote disability equality, which includes people living with HIV from the point of diagnosis. All countries should give serious consideration to the establishment of such a positive duty, which catalyses changes in law, policies and practice by public authorities rather than relying exclusively on the actions and advocacy of individuals.

With regard to the ECHR definition of disability, it has not been decided in terms that it applies to HIV but case law on Articles 14 and 8 suggests that HIV status is protected.

Mention should also be made of Article 6 on the right to a fair trial. This is no doubt going to be relevant to some of the issues around access to justice which have already been raised in the pre-seminar survey report and which are to be discussed further during the course of the seminar. The Court has made clear that this is meant to be a practical and effective right, and it includes a right to legal aid or the support of a lawyer for effective access to a fair trial.

Questions for Karon Monaghan

Q: What is the average time taken in making a complaint to the European Court of Human Rights? A: It does take a long time but there is the possibility of an expedited process for particular circumstances, for example if extreme conditions are involved or if it is a matter of life and death.

Q: How is the Social Charter of the Council of Europe relevant to HIV? A: The Social Charter of the Council of Europe is recently introduced and often overlooked. It contains fuller economic and social rights and is, importantly, a complaint based system. However, as with Protocol 12, not all Council of Europe member states have ratified it.

Q: Does the Social Charter include protection for people living with HIV? A: Only AIDS is mentioned. But it is a recent provision – 2006 – and it is still ‘bedding down’. There is also the Handicapped Act, where in the UK the definition is quite medical and includes aggravated health risks. In a separate part, from the moment of diagnosis, people living with HIV are protected from discrimination by law.

Q: In some cases it might be possible to get cases expedited to the European Court of Human Rights but in many other instances it is necessary to exhaust all levels of domestic legal remedy first. Is there a way to get round national legal systems and take cases directly to the ECtHR? Is there not a need to change the system? – national courts seem to be in denial about the problem
A: This is certainly a real concern and an effective solution has not yet been identified. Significant urgent cases for expediting have not emerged. More work and debate need to take place to remedy this problem.

3.2 Workshop notes Thursday 19 April 2007

3.2.1 Workshop 1 - Migration, mobility and travel

Introduction

Issues of migration, mobility and travel have always raised issues of law and human rights. Recently arrived migrant groups have often experienced stigma and discrimination, much of it legally sanctioned, arising from xenophobia and/or racism. When some of those migrants have a serious and infectious condition, there is of course an even greater possibility for fear, prejudice and inappropriate use of coercive powers. But at the same time, the higher prevalence of HIV in specific communities, and the ongoing greater vulnerability to infection, does suggest the need for differential treatment to meet particular healthcare needs. The question is how to achieve targeted support rather than discriminatory treatment.

The workshop on ‘Migration, Mobility and Travel Issues’ surveyed how legislation and judicial systems are affecting migrants living with HIV or at risk of HIV infection.

Case study 1: Moldova, Vitalie Slobozian

After the break-up of the Soviet Union the incidence of STIs in Moldova soared. Between 1988 and 1996 prevalence of syphilis increased from 7 per 100,000 to 200 per 100,000, and though it has since declined again it is still very high at 60.5 per 100,000 in 2004. These high figures can be attributed to budget deficits and resulting service shortfalls, loosening of social constraints, poor sexual health knowledge, unsafe sex, increased sex work and low access to preventive measures.

HIV surveillance has been in place since 1987 and since then 2,782 people have been diagnosed with HIV. There have also by the end of 2005 been 220 AIDS cases reported (64 in 2005 alone).

The majority of HIV cases have been amongst IDUs (a little over 80% of cases in 2000) but a growing share of cases is via sexual transmission. Of new HIV cases reported in 2004, a majority (55.4%) were from heterosexual transmission, 42.4% from IDUs and 2.23% from mother-to-child transmission. There was a corresponding increased risk of vertical transmission. Women accounted for 45% of people living with HIV in Moldova in 2004.

The greatest majority of newly registered cases are linked to migration issues. Male migrants from Moldova are going to work mainly in CIS countries whilst female migrants from Moldova are taking up mainly housekeeping and nursing work in the West. There are both individual and structural factors contributing to the increased risk of Moldovan migrants to HIV transmission.

Structural factors include lack of legal protection, poverty and marginalisation, lack of access to healthcare, including to preventive interventions and VCT. A recent IOM report stated that the loss of family and contextual norms could result in a loss of risk perception. Other vulnerability factors included lack of negotiating power, sexual violence, availability of alcohol and sex, availability of extra ready cash, peer pressure, sub-cultural norms of particular labour groups, single-gendered environments and lack of awareness of legal rights in country of destination.

The Moldovan Government has made attempts to address the problem, targeting migrant groups, for example through media campaigns. Outreach projects are being planned in countries of destination such as Italy and Russia. A roundtable on HIV and migration has taken place in November 2006 which has emphasised that HIV has to be tackled effectively in the countries of destination for Moldovan migrants. There has to be much more emphasis on cross-country projects to address migrant health and HIV needs. There also has to be consideration of how to respond effectively to possible HIV-related needs for those temporary migrants who have returned to Moldova.

Case study 2: Netherlands, Ronald Brands

The population of the Netherlands is 16 million of whom there are approximately 3 million migrants. There are about 12,000 people living with HIV, with 43% of this number being migrants, mostly from sub-Saharan Africa. A new HIV programme has been introduced which looks at the specific problems faced by Black and Minority Ethnic (BME) communities – work has previously been very gay-focused. A new programme is also being planned to address issues of stigma and discrimination.

Asylum seekers and illegal immigrants are a particularly vulnerable group. There is little understanding of how the legal system works and many try to avoid it because of fear and a lack of understanding.

There is access to legal aid but one has to pay an initial fee up-front, after which legal aid is free from then onwards. But many cannot afford the initial fee. Migrants do often win the right to stay in the Netherlands on the basis of the difficulty of accessing ARVs in the proposed country of return. Legal support is readily available – the difficulty is in initially accessing the system.

Discussion and further country examples

It is important to distinguish between different categories of migrants since this significantly affects legal rights and the challenges and risk factors faced. There are, for example, EU migrants, illegal migrants, asylum seekers, migrants in transit, migrants emigrating, migrants immigrating etc. It is important to ensure there is a right to access care and treatment irrespective of legal residency status. It is also important to restate the simple point that for many migrants their situation is not a 'choice' – fear of persecution, for example, means they have little choice as to where to go.

There are issues around access of children of migrants to education and thus to sex education.

In Lithuania, those born in Lithuania have immediate access to free treatments whilst migrants can access treatment after three months of work. Most migrants are leaving Lithuania for abroad and they do not have many incoming migrants from sub-Saharan Africa. It should also be remembered that movement and mobility carry the risk of interrupting HIV treatment.

In Denmark, legal migrants and taxpayers both have a full right to access healthcare but there are problems in reality in the process. Another issue to be aware of is deportation following criminal conviction (including for HIV transmission), even for those with legal right of residence. On one case an individual being deported was successful in securing ARVs for life.

In Norway, many of the prosecutions for HIV transmission are amongst African men. Individuals are entitled to access HIV treatment regardless of residency status. But difficulties in accessing ARVs in the country of return are not necessarily enough to protect someone from deportation – it is necessary to prove they are extremely difficult to access.

In Finland there is 'voluntary' HIV testing for new migrants as part of the health check given at refugee centres. You are entitled to HIV treatment if you have permanent residency status and HIV positive status is not a reason to refuse someone residency. Voluntary counselling and testing is readily available free of charge, and can be provided anonymously if requested. Anonymous testing is also available in Finland in several different NGO settings, which could possibly have advantages in reaching these vulnerable communities.

In Romania, the two groups most affected by HIV are young boys acting as sex workers in Amsterdam, exposed to HIV through sex or drug use, and trafficked women. About 80% of people who need treatment currently receive it. There is an issue with Romanian migrants in Germany who receive HIV treatment there but when they turn eighteen are deported back to Romania. Poor Romanian communities are at risk of HIV because of their vulnerability through poverty.

In Ireland, there was a surge in migration whilst the law stated that a woman who had a child in Ireland then had right of residence. The law has since been changed. Access to HIV treatment is free but social care and support, whilst available from NGOs and clinics are much more limited. Some people do not access treatment because they fear HIV positive status might get back to their countries of origin or affect their asylum application. Sex work, particularly with drug users selling sex to access funds, is also becoming an issue.

There is also a developing issue of Irish people travelling and potentially being exposed to the risk of HIV transmission when abroad.

In Poland, there is currently a debate as to whether to introduce compulsory screening for migrants. 90% of migrants are from Chechnya. There is little budget for HIV treatment – it is currently being accessed by about 2,000 people. Polish people get priority and treatment is not generally provided to migrant workers. Illegal migrants are not provided with treatment. Testing is more about monitoring than providing treatment.

The influence of the Catholic Church on the Government means young people are not being provided with sex education, and more young people are getting infected. The prevention budget is very small – only about 5% of the money spent on HIV is for prevention, 95% goes on treatment. There is a general prejudice that HIV does not happen to white people but only to black people. This both undermines prevention efforts and increases the marginalisation of black communities.

Issues

- Key issues identified are:
- access to HIV treatment for migrants
- detention of migrants,
- protection of privacy/confidentiality for migrants,
- the perception and actuality of mandatory testing,

- criminal prosecutions for HIV transmission disproportionately affecting migrant communities,
- language barriers and safer sex education,
- children of migrants and sexual health support,
- the politics of resource allocation
- the need for cross-border cooperation to tackle HIV infection amongst migrant groups
- vulnerability to infection of those who travel abroad for work or pleasure.

Recommendations

Universal access to HIV treatment must be provided to all migrants including those who are undocumented or without lawful residency status. Any system which presents barriers to migrants readily accessing HIV treatment, for example unaffordable charges, does not comply with the commitment to universal access. These principles should be explicitly stated for the avoidance of doubt by WHO, UNAIDS and by the UN General Assembly.

The principle of universal access to HIV prevention, treatment, care and support also means that there should be no discrimination against or disadvantage for migrants in the allocation of HIV-related resources.

HIV testing amongst migrants must conform to the highest international ethical standards. In particular there should be no mandatory or non-consensual HIV testing, confidentiality of results should always be strictly respected, appropriate treatment and support should always be available for those who test HIV positive, and there should be no negative impact of an HIV positive result on immigration processes or residency status.

3.2.2 Workshop 2 - Access to rights: IDUs, sex workers and prisoners

Case study 1: Estonia, Jury Kalikov

There are currently 5,700 HIV positive people in Estonia, with the majority infected during 2000/01 which was the peak of the heroin-using epidemic in Estonia. There is no special legislation protecting the rights of people living with HIV. The AIDS Information Support Centre has in the last year established a network of people with HIV across the country, which is helping but it is a small group.

There are about 13,000 IDUs in Estonia, almost all addicted to heroin, who started using drugs at a very young age. The most affected group is the group between the ages of 15 and 25. About 50% are covered by harm reduction needle exchange programmes. Because the Government responded late to the problem, there is a very big challenge. Although a comprehensive programme was promised in response it has not as yet been implemented. Only about 700 people have been able to access a methadone treatment programme funded by the Global Fund.

Only about 350 IDUs with HIV are accessing HIV treatment. Most know they do not have a realistic prospect of accessing treatment. The treatment is only provided in three hospitals which is not a good solution, given the numbers who need to travel long distances.

Sex work in Estonia is neither legalised nor criminalised. In Latvia and Lithuania the situation is better since sex work is at least partially legal. There are as a result services in those countries which attempt to provide testing services and improved healthcare for sex workers. Prisoners in

Estonia still have no access to needle exchange programmes. The Government has yet to act despite developing strategies in response to NGO pressure.

The real burden of stigma and discrimination is not from government but from society itself, and this includes stigma from low-ranking state officials. There is significant corruption amongst law officers who impose as a ‘punishment’ on an offender a requirement to share a cell with an HIV positive prisoner. Similarly, law officers recently leaked the fact a woman in their custody was a sex worker to the media out of malice.

Case study: Kyrgyzstan, Ernist Abdiraschitov

Ernist works at the Global Health Initiative in Psychiatry, an NGO dealing with the mental health aspects of HIV. The population of Kyrgyzstan is small and it is hard to maintain anonymity. According to the National AIDS Centre there are 1,170 people living with HIV in the country, 80% of whom are IDUs. By 2005, 60% of all registered HIV-infected people were in prisons. But after 2005 with adoption of a national AIDS law which prohibited involuntary HIV testing in prisons, the proportion of registered HIV cases in prisons decreased to 10% of total HIV cases. Heroin use is being fuelled by the war in Afghanistan and the increase in the opium trade.

There are about 7,000 registered drug users in Kyrgyzstan, 700 of whom are injecting drug users. Registration at addiction centres is required in order to be eligible for methadone substitution programmes. But for IDUs, registration at the branches of National Addiction Centre is associated with the fear of disclosure of their drug use and most often HIV-positive status. IDUs with possession of needles or syringes are easy victims for police abuse. This inevitably decreases interest for IDUs to enrol for needle exchange programmes. Whilst there is needle exchange in prison, there is no methadone. Prison authorities are aware of the advantages of methadone in prisons, but they don’t dare to introduce it, fearing possible disorders in prisons organised by inmate leaders. Since most of the inmate leaders maintain their leadership over the rest of the contingent by the power of drugs. And methadone would be competing product for illegal drugs smuggled into prisons.

Similarly, access to courts can only be achieved with the assistance of local police, depending on the registered place of residence. But Kyrgyzstan faces large-scale internal migration, and bureaucratisation of residence registration prevents displaced people from officially registering with local authorities. So these displaced people are refused by local police offices permission to appeal on any criminal or administrative cases because of they are not locally registered. NGOs are beginning to address these problems but progress is slow.

Most of the sex workers are known to police officers. Therefore reference for legal assistance meets reluctance from police officers, since prostitutes are considered people with less value and rights. So cases of sex workers will only be considered if there is additional payment or reward for police officers. Therefore, some NGOs are organised for the defence of the rights of sex workers. Meanwhile these NGO also raise knowledge and awareness of HIV and AIDS. According to their report (NGO Tais Plus), in 2005 there was an increase in the number of sex workers who went for voluntary HIV testing.

Discussion and further country examples

In relation to sex work, it was stressed that it is important to distinguish between sex work and trafficking, and identify human rights and health needs separately for each group. In Serbia there has been work taking out VCT through mobile units to sex workers, which is reaching people who would otherwise not be accessing these services.

Some feel that it is decriminalisation which is needed, not necessarily legalisation.

There is a need to decriminalise drug use if injecting drug users are to receive and access the care they need. Criminalisation of drug use and sex work is a form of harm which creates environments in which HIV is spread more easily. Law reform is necessary but this would mean engaging not only Health Departments but also Justice Departments. National AIDS Committees and Country Co-ordination Mechanisms can be important in this regard. Such Country Coordination Mechanisms can usefully bring in helpful Global Fund interventions.

Even where programmes such as needle exchange are available for vulnerable groups it is very important to identify the real extent of coverage and impact. Criminalisation certainly undermines any such effort. An example of the problems encountered is the fact that in Croatia doctors are refusing to provide methadone treatment to those under 18, since they are classified as children.

It was recommended that people from such vulnerable groups be accompanied by voluntary sector workers when attempting to access health services – that way discrimination is less likely to occur. It is also a good way of keeping in touch with the reality on the ground.

International human rights instruments have non-discrimination measures which are important levers for change, and which should be strongly advocated for at national and international levels. But for these vulnerable groups it is also necessary to consider the special measures which are needed to ensure genuine access to healthcare. It is especially good to go with 'what works'.

Issues

Discrimination is thus evident in laws and policies, access to prevention and testing, access to healthcare, employment, law enforcement abuse, privacy and confidentiality, and access to justice.

Best practice must therefore include law reform, in particular decriminalisation, public awareness campaigns, peer education and outreach work, cross-governmental work, monitoring and reporting, litigation at both national and international levels.

Recommendations

Decriminalisation of sex work and drug use should be considered across Europe to ensure effective access to healthcare and all public services.

Harm reduction principles and measures should be agreed across Europe and consistently applied to ensure effective and safe access to high quality prevention, treatment, care and support for sex workers, injecting drug users and prisoners.

Prevention, treatment, care and support should be available to all prisoners in Europe according to the principle of equivalence of healthcare. In particular, international bodies such as the Council of Europe and the European Union should explicitly support the provision of clean needles in prison settings.

3.2.3 Workshop 3 - Insurance and financial services

Introduction

Financial services were probably the most frequently mentioned problem by those completing the pre-seminar survey. It therefore was decided to dedicate a workshop to consideration of the obstacles faced by people living with HIV in accessing banking and financial services.

Case study 1: Portugal, Andre Pereira

Life insurance is needed for any loan, and loans over 125,000 Euros require completion of a clinical questionnaire which include questions on HIV status – this of course is a serious incentive to take a HIV test. For loans of over 250,000 Euros insurance companies have the right to request a full health examination including an HIV test. This is clearly a violation of privacy for those living with HIV, and similarly offensive for other people with stigmatised health conditions.

There are anti-discrimination provisions in Portuguese law for those with disabilities or progressive health conditions, though HIV is not explicitly mentioned. HIV should not be treated differently from analogous health conditions. The law prohibits discrimination in selling and renting of goods, including house credits and insurance, but does accept differential treatment on the basis of actuarial data.

Whilst people in Portugal have a right to housing, they do not have a right to own a house. Insurance companies require access to medical records and there really is not an opportunity to refuse.

Case study 2: Poland, Michal Minalto

In Poland a recent ‘mystery shopper’ exercise revealed that not a single private financial services provider was willing to consider provision of credit or insurance to someone living with HIV.

Poland has reformed the pensions system so it is now two thirds private and one third public. Pensions are very important in Poland, and almost thought of as savings accounts. For access to the privately funded part of the pensions scheme a form has to be filled out which includes information on health and HIV status. Those who are HIV positive cannot access the private half of the pension entitlement. This is impoverishing older people who had HIV. It also has implications for their bank accounts and insurance access.

People with HIV are in theory protected from discrimination under the constitution and the labour code. Other people are protected against such intrusive questions. However, an intervention from the ombudsman has meant the question was changed to more indirect questions such as ‘Do you have family members living with HIV?’ or ‘Have you ever been advised to have an HIV test’ which of course merely extends discrimination and acts as a powerful disincentive to ever seek an HIV test. This is a particular problem for pregnant women who are being dissuaded from having ante-natal HIV screens because of the possible implications for pension entitlement in the future.

Discussion and further country examples

Bulgaria has the same problem for those retiring. In the new private pension forms, and for loans of over 50,000 Bulgarian levs, people are required to have an HIV test, a hepatitis B and a hepatitis C test. Access to medical information can not be refused. False reports in the past have meant that companies only accepted tests done in designated centres chose by the companies.

In Belgium there is a legal requirement to inform the insurance company of relevant risks (and indeed this is generally true in European countries). It was pointed out that though one is expected to inform the company of a HIV positive diagnosis, there does not appear to be a requirement to inform them of risk-taking sexual behaviours.

A roundtable on HIV and insurance was held recently. Companies claimed they are not discriminating since HIV status is not directly linked to the refusal of insurance or the particular financial service. They claim to have accepted individual requests for cover from people living with HIV but are unable to specify how many and under what circumstances. Whilst life insurance is not a requirement in order to take out a loan, it is possible for loans to be denied if the individual does not have life insurance.

Refusal of financial services to people living with HIV is often linked to side effects of HIV treatment such as cholesterol and heart problems.

In the Netherlands people recently diagnosed with HIV are finding it easier to access financial services than those who have progressed to AIDS or been living with HIV for longer. The financial services industry is beginning to acknowledge the HIV positive market. One insurance company in the Netherlands has decided to provide cover for HIV positive applicants because it saw a gap in the market. Perhaps this is the best approach – to persuade companies it is in their financial interests to provide a service.

In Italy life insurance companies do not provide cover for people living with HIV due to a ‘lack of long-term studies’ to allow risk assessment calculations. When such studies were forthcoming, they said that cover might be possible. They were not interested in the view of the Ministry of Health but wanted to conduct their own studies. It is doubtful, however, whether they treated comparable diseases and health conditions in the same way – the judgements made were not genuinely actuarial and thus, in the speaker’s view, breached the constitution’s anti-discriminator provisions. They have not, however, been able as yet to take the matter to court. There is a problem for people with HIV where pensions are linked to life insurance. Most employers provide life insurance which involves filling in medical questionnaires. If you refuse the offer, suspicions could be raised as to HIV status.

The group was informed that in the United Kingdom the Association of British Insurers has changed their Code of Best Practice so that insurers could no longer ask about whether or not someone has ever had an HIV test, or about someone’s sexual orientation. They only have the right to know whether someone has received an HIV positive test result.

Recommendations

Actuarial evidence

> Companies should have to prove a reasonable actuarial basis for any refusal of insurance/financial services provision.

In the case of gender discrimination in insurance and financial services, the EU has legislated that it is permissible if insurance companies use actuarial data to justify their premiums (unlike discrimination on grounds of ethnicity in insurance which is absolutely prohibited).

Furthermore,

> the burden of proof should be reversed so that insurance companies have to demonstrate the actuarial reasons they have to believe the health prospects of someone with HIV are worse than those with other health conditions who can access cover.

More information should be collected on how people with other long-term health conditions such as diabetes access financial services.

Basic insurance

In Belgium a basic insurance is made available to all those with chronic diseases, even though some within that group might be at higher risk, because this is considered a right.

A ‘basic insurance‘ scheme for people living with HIV, and others with relevant health conditions, to enable access to fundamental rights such as health and housing is possible and necessary.

Welfare system reform needs to be monitored, especially where privatisation takes place, to ensure this does not put at risk the rights of people with HIV.

Financial services companies need to be approached to discuss the reasons why they should look at the market for financial services amongst people living with HIV.

The European Commission should be approached to consider the extension of discrimination law on the provision of goods and services to people with HIV.

4 Presentations and workshop notes Friday 20 April 2007

4.1 Presentations and associated questions

4.1.1 Issues of confidentiality and privacy of data with relation to HIV

Douwe Korff (London Metropolitan University)

Who is Douwe Korff?
Not a specialist in this field, I fear, but a general human rights & data protection lawyer

(you can try the search box on the londonmet website: www.londonmet.ac.uk but it didn't work when I tried last time ☺)

first principle:

- my data (any data) are mine;
- my sensitive data are especially mine; and
- data on my HIV status are especially sensitive, in many ways

The context for discussion was the danger we all face of being dealt with by authorities on the basis of your file, rather than who you actually are. There were in particular concerns in relation to the use of IT and electronic data by the National Health Service in the UK. In preparing for this presentation, Douwe had been struck by the lack of information available on HIV and confidentiality. An HIV group in Switzerland has done some work and there is a 2002 German paper on the subject, but more work certainly needs to be done.

It is important to begin with some principles, of which the most important is that 'my data are mine' – which has been described in Germany as 'informational self-determination'.

two (connected) legal bases:

- European human rights law:
  (Eur Conv on Human Rights)
    right to private life (Art. 8 ECHR)
- European data protection law:
  (EC Directive 95/46/EC)
    "purpose-specification and –limitation"
    "informational self-determination"
    (right in principle to control over one's own data)

connection:
    dp law is increasingly strongly backed by ECHR

- ECHR & EC Directive implemented in all EU Member States (and beyond);
- similar principles elsewhere (if perhaps not as strongly set out);

in UK:
- ECHR implemented through the Human Rights Act (belatedly and imperfectly);
- EC Directive implemented through Data Protection Act 1998 (imperfectly)

The two main sources for privacy law are Article 8 of the European Convention on Human Rights (ECHR) and the European data protection law. Article 8 case law had originally been very limited and not very positive when it came to privacy protection. But this is now changing, human rights backing strong data protection principles. The view now is that any official body holding personal data implicitly interferes with that person's private life and has to be able to justify it.

Germany has a more developed concept of data protection than many other EU member states, including the UK. 'Informational self-determination' was a phrase coined by the German Constitutional Court in a case relating to the Census. Any exception to the fundamental right to privacy has to be based on 'the higher public interest', has to be lawful and has to be minimal.

The Directive from the EU – 95/46/EC – was one of the first human rights measures from the EU (derived from the EU's 'first pillar').

This means data protection has to be considered at the highest level, whether at the European Court of Human Rights in Strasbourg (for Art 8 claims) or at the European Court of Justice in Luxembourg (for EC Directive claims).

The basic principle that flows from both the ECHR and the EC data protection directive is that:
- Any demanding of info on, or recording of a person's HIV status, and especially any disclosure of such data against the person's will, is an interference with that person's rights under these instruments.
- This means that there must be a special, pressing reason to allow this, on a specific legal basis

TWO MAIN BUTs:

- ECHR and DP Directive both contain exception clauses; and
- DP Directive is imperfectly implemented, and very weakly enforced, especially in the UK

Whilst the legal requirement for a specific reason to interfere with privacy rights, on a specific legal basis, is clear, there are exception clauses. There is also a problem of weak enforcement.

Re exception clauses (1):

exceptions to right to private life/to keep one's HIV status private must:
- be based on a clear legal provision, the effect of which must be "foreseeable";
- serve a "legitimate aim" - such as public health;
- be "necessary in a democratic society" to achieve that aim - which means in particular that the exception must be "proportionate" to that aim, taking into account the importance to the individual of the right in question

Re exception clauses (2):

- there must be appropriate procedural safeguards to ensure compliance with the standards set out in the previous slide.

Re exception clauses (3):

- compliance is judged (ultimately, by the Eur Court HR) by European standards - BUT States are given a "margin of appreciation". This makes it difficult to predict exactly what is and what is not allowed, and what kinds of procedural safeguards are required or sufficient.

Re implementation of data protection directive (1):

- processing of personal data - and disclosure of personal data! - must be based on "consent" OR on a clear legal provision aimed at serving a "higher" public interest - BUT in principle such "public interest" conditions must comply with the ECHR standards: they must be strict and clear and foreseeable, and any inroads on privacy should be as minimal as possible.

Re implementation of data protection directive (2):

- special data subject rights: to be informed in advance of what will happen to one's data; to be told so more specifically afterwards (including info on disclosures); to object "on legitimate grounds".

Re implementation of data protection directive (3):

- special supervisory bodies: data protection authorities (in UK: Information Commissioner) (as well as courts).

PROBLEMS (general):

- ack of clarity of exception clauses
- clauses often too wide, esp. for supposed public interest purposes - proportionate?
- courts are expensive
- what is “consent”?? esp. in a contractual context - such as insurance, employment
- data protection law, esp in the UK, often contains excessively wide rules allowing for disclosures of data, e.g. for “health” purposes and/or research

PROBLEMS (UK-specific):

- the special clause re dissemination of sensitive data for (extremely-widely defined) “health” purposes, including medical “research” in the UK Data Protection Act violates the EC data protection directive and in my view also the ECHR;
- enforcement of the DP Act by the UK Information Commissioner is very weak (in other countries - France, Germany - there is more awareness of the issues, and the dp authorities take stronger stands - but practice still also remains weak).

There are significant problems with the permitted exceptions to data protection and privacy rights. In many jurisdictions exceptions are permitted with a very wide specification of purpose, for example for health or policing purposes. In fact the exceptions should be far more narrowly and specifically framed in terms of purpose. Thus in German law there is a much more helpful distinction around police use of data, depending on whether the data is necessary to prevent crime, for public order purposes or for police administration.

There was also debate on the real meaning of consent in the context of data protection. It should be ‘specific, informed and free’. But there is a question as to whether consent is really ‘free’ when, for example, HIV test results are required for access to life insurance. Consent can only be given to relevant data sharing. Personal data is defined as data which can be linked directly or indirectly to an individual person.

Data protection is weakly enforced and redress through the courts can be very expensive.

CONCLUSION (1):

- there are good possibilities in principle for invoking European human rights and –data protection laws to protect individuals from improper demands that they reveal their HIV status, or from information on this status being improperly disclosed by authorities or private bodies to other authorities or private bodies. **BUT**: this will need very considerable effort to be put into effect.

CONCLUSION (2):

- it would be good to get this on the agenda of the European data protection working group (established under the EC directive), and to work out principles with this group;
- a comparative-legal/multidisciplinary study of rules and practice in major European countries (including any that have given the issues special attention) would be a good start.

Questions for Douwe Korff

Douwe began by restating the value of engaging proactively with the EU Data Protection Working Group both to secure objectives and identify areas of research relating to HIV and personal information.

Q: What is included in personal data? Is it just names or does it include other details? A: It includes any information that links to the individual. This may be in the form of names or pictures or whatever. As long as you are identifiable, it is personal information.

Q: How can we ensure that data use is genuinely proportionate to legitimate objectives (a basic concept in human rights law)? This links to the debate in many countries, such as Ireland, as to whether HIV should be a notifiable disease, and whether any notification should include patient-identifying information or be anonymous. Clinicians sometimes see opponents of notification as implicitly criticising their trustworthiness and confidentiality processes. It is important to win ‘hearts and minds’ to achieve change. A: With regard to notification for public health purposes it is important to identify best practice which can be replicated internationally, in which enough information is provided for surveillance and public health purposes but where appropriate confidentiality is maintained.

Q: There are problems in Canada of police officers, often of low rank, disclosing personal HIV data. A UK case was also mentioned where police wished to disclose a teacher's HIV positive status to his school because someone had made an initial allegation of reckless HIV transmission against the teacher and even though the allegation had later been withdrawn. There was discussion of what penalties are available against those who improperly disclosed information in this way. A: In the UK case child protection issues seem irrelevant in the particular circumstances so disclosure would be wrong. There is a question of whether it should be a criminal offence to disclose personal information unlawfully.

4.1.2 Creative lawyering and the promotion of the rights of people living with HIV AIDS

Dr Matthew Weait (Keele University)

Creative Lawyering and the Promotion of the Rights of People Living with HIV and AIDS

Dr Matthew Weait

Keele university

Background / Context

- Pre-seminar Report suggested that there were significant barriers to PLHA accessing justice and that reasons for this included
  - a lack of adequately motivated and / or competent lawyers
  - the non-availability of legal aid
- Report also suggested that it was rare for voluntary sector / civil society organizations to intervene in cases on behalf of PLHA (by providing written evidence or acting as an amicus curiae ('friend of the court')

Addressing the Problem

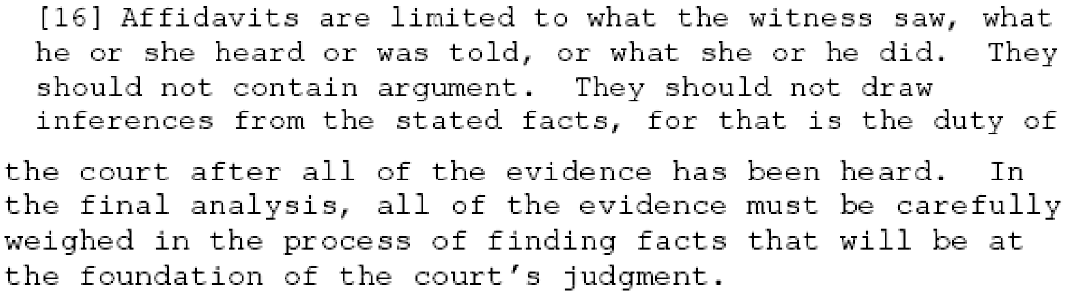
- These problems stem from
  - Lack of understanding
  - Lack of resources, or lack of political will / motivation to allocate those resources to PLHA
  - Lack of structural mechanisms that allow beneficial intervention
- But the biggest problem is REACTIVITY. They are problems that, in part, arise from the fact that
  - The law is understood as a responsive mechanism (a means of resolving claims and disputes
  - That the role of the lawyer is understood in terms of problem-solving
- This does not necessarily the case!

Creative Law / Creative layering

- Thinking about legal mechanisms and the role of lawyers more creatively can be beneficial
- One way of doing this is
  - through the creative use of written evidence about the experience of PLHA, and
  - using that evidence proactively and for the community rather than merely to support (reactive and individual) cases

The Status and Function of the Affidavit

- What is an affidavit?
- What is the nature of affidavit evidence?



[16] Affidavits are limited to what the witness saw, what he or she heard or was told, or what she or he did. They should not contain argument. They should not draw inferences from the stated facts, for that is the duty of the court after all of the evidence has been heard. In the final analysis, all of the evidence must be carefully weighed in the process of finding facts that will be at the foundation of the court's judgment.

Using Affidavits Creatively

- Research visit to Pivot Legal Society in Vancouver, Canada, December 2006. Pivot's philosophy:

PIVOT **Advancing** the interests and **improving** the lives of **marginalized persons** through **law reform, legal education,** and **strategic legal action.**

- Although legal remedies for marginalization exist, the laws protecting rights and entitlements make many assumptions about the functionality, knowledge, and resources of those requiring protection.
- In reality, marginalized people are poorly integrated into the structures of mainstream society and rarely in a position to effectively participate in the formal processes necessary to challenge those structures.
- Without financial resources, and without a means to strategically and effectively advocate on their own behalf before government and the courts, marginalized persons often cannot obtain the benefits of the socially progressive developments in the law enacted during the last century.

Using Affidavits Creatively

- One way in which Pivot seeks to put this philosophy into practice is by using affidavits to gather evidence about the lived experience of people who
    - Have experienced police brutality
    - Who are homeless, or living in poverty
    - Who are involved in commercial sex work
- People for whom the assertion of legal rights is problematic / impossible because of their socio-economically marginalized status

How Pivot obtains Affidavits

- Pivot is a community legal organization, and takes the law TO that community

DRUG USERS

Have you ever been beaten up by police?

Have you ever been searched by police just because of who you are or the way you look?

Would you like to help stop police harassment?

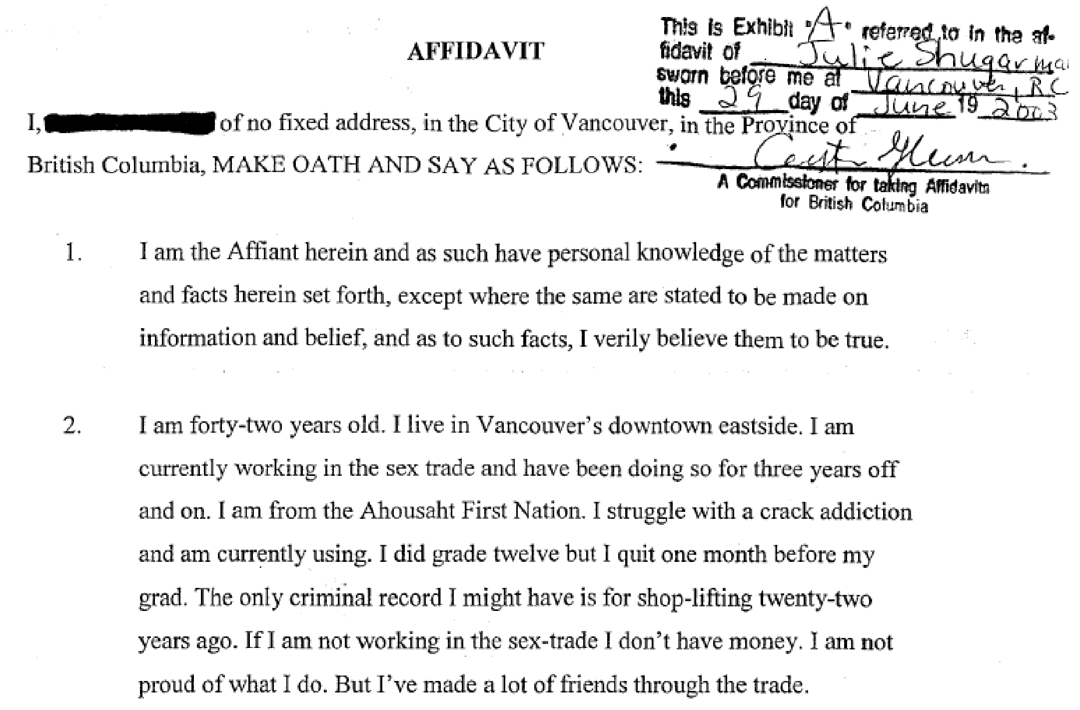
If so...tell your story!

SWEAR AN AFFIDAVIT!

WHERE: 327 CARRALL STREET
WHEN: EVERY TUESDAY, 10AM TO 12PM

PIVOT

Example of an Affidavit



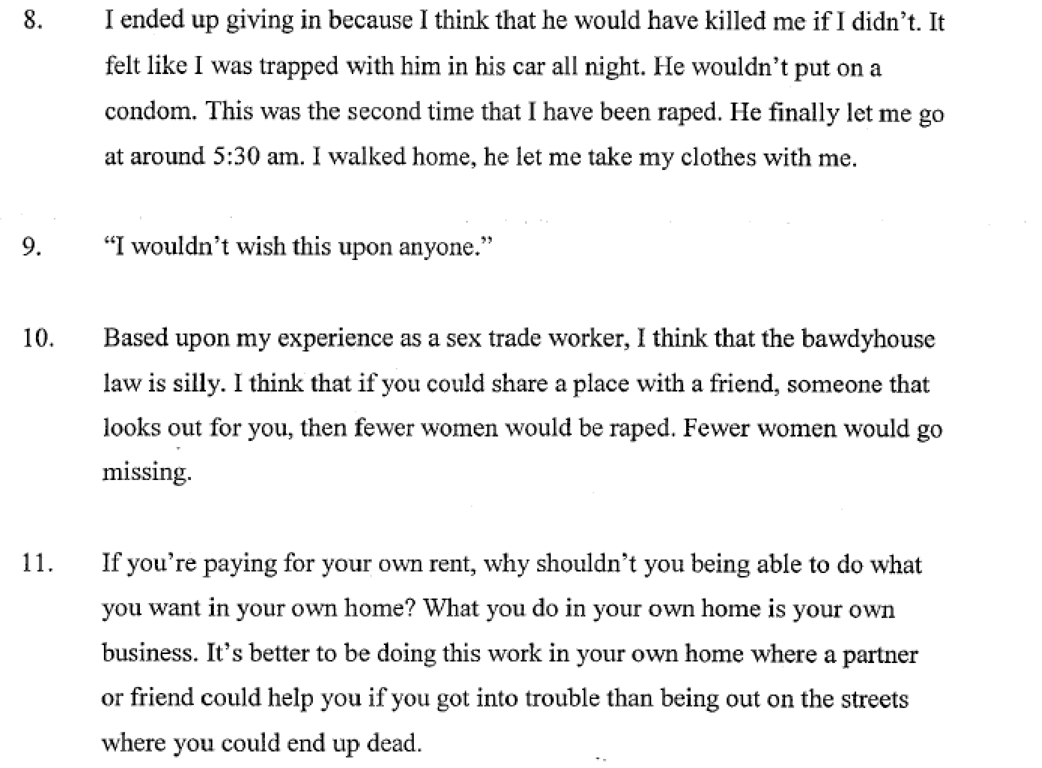
This is Exhibit "A" referred to in the affidavit of Julie Shugarma
sworn before me at Vancouver, BC
this 29 day of June 19 2003
A Commissioner for taking Affidavits
for British Columbia

AFFIDAVIT

I, [redacted] of no fixed address, in the City of Vancouver, in the Province of British Columbia, MAKE OATH AND SAY AS FOLLOWS:

1. I am the Affiant herein and as such have personal knowledge of the matters and facts herein set forth, except where the same are stated to be made on information and belief, and as to such facts, I verily believe them to be true.

2. I am forty-two years old. I live in Vancouver's downtown eastside. I am currently working in the sex trade and have been doing so for three years off and on. I am from the Ahousaht First Nation. I struggle with a crack addiction and am currently using. I did grade twelve but I quit one month before my grad. The only criminal record I might have is for shop-lifting twenty-two years ago. If I am not working in the sex-trade I don't have money. I am not proud of what I do. But I've made a lot of friends through the trade.



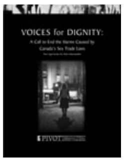
8. I ended up giving in because I think that he would have killed me if I didn't. It felt like I was trapped with him in his car all night. He wouldn't put on a condom. This was the second time that I have been raped. He finally let me go at around 5:30 am. I walked home, he let me take my clothes with me.

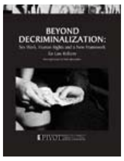
9. "I wouldn't wish this upon anyone."

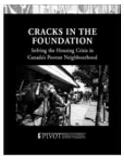
10. Based upon my experience as a sex trade worker, I think that the bawdyhouse law is silly. I think that if you could share a place with a friend, someone that looks out for you, then fewer women would be raped. Fewer women would go missing.

11. If you're paying for your own rent, why shouldn't you being able to do what you want in your own home? What you do in your own home is your own business. It's better to be doing this work in your own home where a partner or friend could help you if you got into trouble than being out on the streets where you could end up dead.

What Pivot does with Affidavits







Cheap Rooms Off the Block?
Rare deal could save Eastside SRO.
By Tom Sandborn
Published: March 20, 2007
By Monday morning, when demonstrators gathered outside the Carl, Eby was able to announce an imminent deal to save the Rooms as affordable SRO housing.
The RCMP found that 11 of Pivot's 50 complaints were substantiated and noted in its report to the OPCC that some Vancouver "officers failed to substantively and meaningfully fulfill their legislated duty to account during this public trust investigation.
Only Magazine, Tuesday April 3, 2007

Pivot unveils sex worker study
SEX LAWS / Sullivan refuses to meet with researchers

Tom Sandborn / Xtra West / Thursday, June 22, 2006 DEMANDING FAIR TREATMENT: Pivot Legal Society Katrina Pacey (left) and researcher John Lowman want parliament to repeal Canada's archaic solicitation laws (Michelle Mayne photo)

Key Points

- Affidavits are acknowledged to be evidence (not just anecdote): they have LEGITIMACY
- The evidence of experience is powerful, because it is taken from real people
- The more evidence there is, the harder it is to deny that there is a problem – cumulative
- Affidavits show that legal techniques can be used creatively, proactively and politically to
    - Raise consciousness
    - Achieve change
- There is every reason to think that affidavits could be used to do this for PLHA

Acknowledgements:

- Government of Canada Faculty Research Programme
- Pivot Legal Society

Contact:
m.weait@law.keele.ac.uk
http://www.keele.ac.uk/research/lpj/Law_HIV-AIDSProject/index.htm

Questions for Matthew Weait

Q: Are the affidavits recognised in the courts, and is there a danger of a perception in the courts that the lawyers who take the depositions are biased in some way? And are those who give depositions later questioned on their content in court? A: As long as the evidence contained in the affidavit is factual, it will be received by the court as valid and recognised. The real strength of the affidavit process lies in the cumulative power of testimonies, which can embarrass local authorities when they reveal what is really going on.

Those who provide affidavits do not need to appear in court or provide personal evidence. During and after a case is brought, there is usually an expert witness who exhibits the affidavits and who can answer questions regarding their content.

Q: Are the identities of those interviewed made public or anonymous? A: The identities are not made public though they are known to the lawyer.

Q: How are issues for affidavits identified, and how are personal and community agendas balanced? A: When conducting the interviews the interviewer will of course have to have some idea of the issues which he or she wants to see addressed. One should keep in mind that one issue can very often snowball and lead on to others raised or emerging from those being interviewed.

Q: NGO accountability is important – people must always be told precisely the purpose for the collecting of evidence and how it will be used.

Q: There is clearly significant political impact to be gained from such an imaginative use of an originally legal process – but how are these affidavits actually used in court? A: As yet they have not been used in a big legal case but rather as evidence in lower level legal processes. The important point is how this work re-imagines the 'legal' from outside the law, seeing how legal instruments can be used by communities to engage legal and political processes.

4.1.3 NGOs, activism and litigating rights

Iain Byrne (Interights)

NGOs, activism and litigating rights

Interights

Activism and change

- Community mobilization
- Human rights education
- Campaigning
- Networking
- Policy work
- Standard setting
- Lobbying

and…

Litigation!!!

- Part of the tool kit
- Goals:
  - to provide redress for clients
  - to create social change through the use of the judicial system

Social change through courts…

How is this achieved?

- Establish precedent
- Challenge statutes and existing case-law
- Document and expose injustices in society
- Promote accountability
- Client empowerment

Strategic litigation

- Use law to create lasting effects beyond the individual through law and policy reform to further social justice
- Use law to promote the rights of disadvantaged
- Enhance access to justice
- Remedy specific breaches of rights

Ask…

What is the ultimate goal of this case?

- Redress for individual client?
- Highlight an issue either in the judiciary or the press?
- Set precedent in the courts?
- Empower future clients to litigate?

Also ask….

- What is my role?
- What is not currently being done?
- Where can I add value?
- How to be involved without doing two jobs at once?
- Being realistic… Who can I work with?

Law is not magic!!!

- You don't need to be a lawyer to use the law, the European Convention and the Court
- Find parallels to your daily work: documenting cases, working with clients…
- Ethics of conducting a case: sticking with clients, client support etc.

Seeking support…

- Use local lawyers
- Friendly assistance: amicus curae briefs, use of researchers and academia, national human rights bodies, and other NGOs
- Publicity
- Applicant's needs: family and community status

Likely effects of litigation

- Is the decision likely to be enforced? How to enhance chances of change?
- What are the potential consequences for the Applicant after the case is over?
  - Potential for retaliation, negative publicity etc.

And remember…

- DO NOT BE INTIMIDATED!!!
- Collaboration is vital
- Focus on the Applicant
- Intersectional nature of law and discrimination
- Communicate outcomes widely
- "Losing" is sometimes winning

Questions for Iain Byrne, Interights

There was discussion of the use of 'amicus curiae' by NGOs – only two organisations represented in the room have ever attempted to engage with the courts in this way.

Q: What are the rules on how to submit views as an 'amicus curiae'? A: The rules will differ between countries and unfortunately there has been a tradition of some courts not accepting such approaches which can deter people and organisations from attempting it.

Q: There would be value for European NGOs in listing the various possible legal approaches and their various legal standings and impacts – for example, amicus curiae submissions, 'expert opinions' and affidavits. A: That would be useful. It is worth noting that the amicus curiae is a proactive legal measure which can be very significant in effecting the considerations and decisions of the court.

4.2 Workshop notes

4.2.1 Workshop 1 - Confidentiality in healthcare settings

Case study 1: Croatia, Iva Jovovic

Iva mentioned some recent examples of breaches of confidentiality in relation to HIV in healthcare settings. Croatia has only a small number of people with HIV – about 600 – so Iva's organisation can keep track of how individuals' cases are dealt with. One case in Zagreb involved a nurse in a psychiatric ward who tested positive for HIV and was subsequently fired because of the 'accidents' which could occur in this healthcare setting. This was a terrible outcome for the person concerned, but the doctor who leaked the nurse's private medical information was disciplined.

In another case, someone was sending anonymous letters to the media alerting the general public to the claim that there were six sex workers with HIV transmitting HIV in the community. Even if it was meant as a public health warning, it turned into a witch hunt. Police were then requesting the personal and medical data relevant to the case. Instead the police were sent for training on discrimination and privacy issues relating to HIV, so there was a positive result from this case.

Discussion

There was then a discussion on confidentiality in healthcare settings which began with issues around HIV testing.

In some countries there are testing requirements relating to employment. In Italy, for example, a ban on making enquiries on the HIV status of current or future employees was judged unconstitutional when a chain of supermarkets went to court to get the right to test employees. It was determined that there should be an exception allowing testing for those in relevant health-sensitive professions (e.g. nurses). The NGOs had tried to argue that there was no risky profession, just risky behaviours and that universal precautions should be sufficient to guard against infection.

In Poland there are prohibitions on people with HIV working as policemen, as medical professionals, as food producers, caterers, or as migrant workers. Kyrgyzstan also has a rule that migrants found to be HIV positive should be deported.

In Uzbekistan many professions are forbidden to people with HIV. There is even compulsory HIV testing before getting married which only a few lawyers and academics have challenged and refused. In Cyprus there is mandatory HIV testing for young women coming to work in the bars and cabarets – a positive test meaning you are sent home. It simply encourages complacency about HIV transmission in the general population.

There was discussion of the possibility of open access anonymous testing, which is provided in GU services in the UK. In a number of other countries it is only available where point of care testing is provided, and such testing is not that widespread, as well as being difficult in small communities and in specialist services. There is, however, a tension, and sometimes contradictory guidance, between the possibility of anonymous testing and the questions asked either for public health monitoring purposes (such as possible route of transmission) and for partner notification.

Another relevant issue for confidentiality is partner notification. There is a danger of violating Article 8 of the European Convention on Human Rights if this is done badly – the right to private and family life.

In some countries such as the Netherlands the partner notification system is totally voluntary. In Finland, whilst the clinician is obliged to ask a diagnosed patient about current and former partners for contact tracing purposes, the patient can refuse to provide the information. In Norway confidentiality is strictly maintained. In other countries such as Uzbekistan confidentiality seems to be much more a matter for the decision of the individual doctor.

In some countries the situation is more confused. In Croatia, for example, whilst unauthorised disclosure can be punished, if the doctor can demonstrate that he or she was acting in the interests of someone else punishment will in all probability not occur. Similarly a case in Portugal has raised questions over the liability of doctors who do not inform identifiable persons that they are at risk of HIV infection.

Forensic evidence from the Centre for Disease Control has also been used in criminal proceedings. There is a real issue of the ability of the police to seize confidential medical information. If this went on unchecked it could seriously undermine trust in healthcare systems.

There are tensions and confusion amongst doctors on their ethical responsibilities in this area and how they related to law. Much greater clarity is needed in procedures in this area.

Conclusions and Recommendations

UNAIDS and the ILO need to provide definitive international guidance on the very limited circumstances in which there may be issues around people living with HIV undertaking certain occupations. All European countries must as a priority end any occupation-related restrictions for people living with HIV which do not comply with such international standards.

There is a need for training of both clinicians and law enforcement officials on confidentiality and data protection in relation to medical information. The EU Data Protection Working Group has to be approached to identify appropriate standards across the EU.

People with HIV needed to know their rights to confidentiality in healthcare settings – NGOs can play an important part in disseminating this information. They also need access to effective processes for redress should confidentiality rights be breached.

Doctors who come across the real dilemmas in this area need access to confidential and expert advice (an ‘ethics helpline’).

Clear international guidelines are necessary in this area, in particular on testing and partner notification best practice, involving national governments, the EU, Council of Europe, UN and WHO

There must be an end to compulsory HIV testing. Instead HIV testing across Europe should be free and confidential/anonymous.

Underlying issues of HIV-related stigma and discrimination need to be addressed.

4.2.2 Workshop 2 - Confidentiality in Legal Proceedings

The pre-seminar report has identified lack of confidentiality and privacy as a significant obstacle for people with HIV accessing their rights. The same point is also made in many of the comments added to survey responses, for example, ‘Big disadvantage of public trials is that private information can go out via the press’.

Case study 1: United Kingdom, Yusef Azad

In the 12 prosecutions for reckless transmission of HIV to date in the UK all the complainants have had their identity protected through reporting restrictions, but only two of the defendants. In those two defendants' cases the reasons given were to protect the identity of the complainant.

There are measures in English law available in courts for 'vulnerable or intimidated witnesses' 'to improve the quality of the witnesses' evidence'. 'Special measures' include clearing the public gallery in sexual offences cases or cases involving intimidation, and use of screens or television link for evidence. Such special measures are available to adults 'who may be considered vulnerable because of incapacity, such as a physical or mental disorder' 'This includes someone who is living with a particular condition which may inhibit them from pursuing a prosecution if that fact is going to be widely broadcast'. This clearly applies to HIV, though only to the complainant.

Other measures include reporting restrictions, 'preventing the reporting of certain details of witnesses in the media that may lead to their identification' – this lasts for the lifetime of the witness. In making its decision on such an order the Court must consider whether it is in the interest of justice to make the order and the public interest in avoiding a substantial and potentially unreasonable restriction on the reporting of proceedings'.

Family law proceedings currently take place in private with no public or media access. The Government recently undertook a consultation on whether or not to change these rules and extend media access, but in the end it was decided more or less to maintain the current position.

In relation to civil law, whilst the general rule is that hearings should be in public [Civil Procedure Rules Part 39 'Miscellaneous Provisions relating to Hearings'], the court can order that the identity of any witness or party not be disclosed if necessary to protect that person's interests. A hearing, or any part of a hearing, can also be in private if

- Publicity would defeat the object of the hearing
- It involves confidential information and publicity would damage that confidentiality
- A private hearing is necessary to protect the interests of any child or patient
- The court considers this to be necessary, in the interests of justice

There is it seems considerable scope for people with HIV to seek protection of identity when they are complainants in court cases. This is not almost certainly as widely understood as it should be. People with HIV in the UK are thus probably not accessing their rights to the extent they could.

Could HIV positive defendants also have their identity protected? Or would that further stigmatise the condition?

Case study 2: Romania, Maria Georgescu

There have been improvements in law, healthcare and child protection following pressure from the EU. People with HIV are protected by a special law on HIV as well as disability and child protection legislation. A survey is currently being undertaken in Romania of the numbers of people with HIV who is in fact able to access free treatment, social care and additional support.

Disability status acts as a gateway to a number of benefits and to a reduction in certain bills. But accessing these protections as well as social care requires disclosure, multi-disciplinary commissions, doctors' assessments etc. There are also serious concerns as to the quality of information provided to people with HIV who want to navigate the system and access their rights.

With regard to legal proceedings, a recent court decision in a case of benefit entitlement revealed the problems which had to be faced. The court decision had sent the judgment in an unsealed letter to the claimant's home, where it was opened by his mother, who had previously been unaware of her child's HIV positive status. There was no recognition of confidentiality in the court processes – their response to a complaint on the matter was simply that these were the rules as to how judgments had to be delivered.

Discussion and other country examples

In Greece people with HIV have lost their jobs when their status became known to their employer but they have been unwilling to go to court because of fears of adverse publicity. Fear of costs was another reason. There has been one successful case where an employer was taken to court for 'leaking' someone's HIV positive status to colleagues but such court cases are rare.

In Serbia similarly there has been a terrible case involving a doctor who disclosed the HIV positive status of another adult whose child attended the same school as his own child. The individual could have taken the doctor to court on a number of different offences but chose not to, wanting to 'move on'. Similarly, though a third party such as NGO could have gone to court, they decided not to after discussions with the individual with HIV.

There was discussion of confidentiality in prosecutions for transmission. In Sweden you have to disclose HIV positive status in a sexual relationship, and a sex worker was taken to court for non-disclosure. She challenged the initial judgment against her, saying that whilst she did not disclose she had used a condom. She won and was free, and was provided with some identity protection. It remains unclear whether this was a legal precedent on disclosure cases, but it is good news in terms of identity protection in court cases. Defendants in Canada and Poland in transmission cases had their identities widely broadcast by the media, in one case with the stated aim of finding more partners of the accused. Stigma increased in this latter case in particular against migrants.

Another issue is the reference to HIV as a supposedly aggravating factor in court cases, or sometimes reference when HIV positive status is wholly irrelevant. Reference in a Polish case to the HIV positive status of someone prosecuted for paedophilia was on the basis that the status was an aggravating factor against him but an intervention from the Office for Data Protection established that such information could not be used in the trial in this way. It did not prevent the media using the information to further stigmatise. It was also pointed out that in certain countries in prisons where there have been altercations there is pressure to disclose the HIV status of assailants and this could be an aggravating factor in a court case.

Belgium also has found HIV used as an aggravating actor in court cases, though they have not as yet had any prosecutions for transmission. Anonymity is granted in court cases. The Centre for Equal Opportunities could take court cases on behalf of individuals to protect their anonymity.

There has been some anonymity provided in deportation cases involving HIV positive asylum seekers, (the cases of D and N, for example, both of which were from the United Kingdom).

There was discussion of the place and role of NGOs in taking cases to court. Whilst this could be an important function, it is vitally important always to put the interests and wishes of the individual client first, rather than as the tool in some wider campaign.

Problems have been experienced in the attitude of the police to confidential information. In Poland police investigating a clinic charged with having fictional HIV patients on its books attempted to access clinic data and when this proved difficult contacted a patient and asked him to reveal information on fellow patients.

There is a need to increase the sensitivity of judges, lawyers and courts to HIV and to people with HIV. Reporting restrictions have to be applied for, but also acceded to by judges. They also have to be properly enforced. Initiatives are necessary to train judges and lawyers on HIV – in the Ukraine many lawyers refused to represent clients with HIV and new efforts are being made to train lawyers in that country.

Perhaps it is time to revisit the assumption that almost all court cases should take place in public.

Recommendations

Courts and law enforcement bodies must stop publicising HIV status when this is legally irrelevant information

More clarity is needed on the possibility of accessing reporting restrictions, with real enforcement and sanctions when such restrictions are breached by the media.

There should be protection of identity or anonymity for HIV positive defendants prior to conviction, as well as for HIV positive complainants.

The inappropriate use of HIV positive status as an aggravating factor in other charges/prosecutions should end. UNAIDS should support legal experts in addressing this issue and arriving at best practice.

Court officials, judges, lawyers and the police all need training on HIV issues and their relevance to the legal environment. Further work is necessary across Europe to support consistent provision of useful and accurate information.

4.2.3 Workshop 3 - The Role of NGOs in legal proceedings

Introduction

In considering the difficulties many people living with HIV encountered in accessing legal systems, an important question is how NGOs and other HIV support organisations might assist them, whether providing advice and support to individuals litigants, or submitting evidence to courts in their area of expertise when relevant to a case, or indeed actually litigating themselves. Evidence from the pre-seminar survey was that examples of such activity were relatively rare across Europe.

Case study 1: Canadian HIV/AIDS Legal Network, Alana Klein

Alana set out how her organisation, the Canadian HIV/AIDS Legal Network, has engaged with legal proceedings. They do not represent clients in legal proceedings but do get involved as expert witnesses, interveners etc. To date they have not had formal ‘standing’ in a court case but they are currently contemplating bringing a needle exchange case. However, because they are not a directly involved party there might be some difficulties in bringing the case under Canadian law. They could instead be granted standing as a ’concerned party’. In Canadian law this can happen if a serious issue is raised in court and the organisation is viewed as having a genuine involvement, and there is no other way to bring the case before the court.

A previous case of this kind involved a Canadian organisation looking for potential claimants who would be willing to take a case to court on access to methadone in prisons. A prisoner willing to take a case was found, and the organisation then supported the prisoner in bringing the case.

In the end the case was settled successfully out of court. The prison service agreed to provide methadone more widely in prisons (it had previously only been available for those who had been on methadone maintenance prior to incarceration). Whilst this was a welcome outcome, it meant there is no precedent in law for an organisation to bring a case on behalf of an individual.

Organisations can also intervene in court cases as ‘expert witnesses’. The Legal Network has been especially active on criminal prosecutions for HIV transmission. The first case of this kind in Canada, the Courier case, went to the Court of Appeal and the Legal Network made a submission. Although the court upheld the conviction, the judge’s summing up did usefully take account of points made by the Legal Network, including the use of condoms as a defence. It also noted the concern over the deterrent effect on testing but said this was a matter for legislators rather than the courts.

The Legal Network has also been involved in two other court cases relating to HIV transmission, one involving a sex worker charged by a client with exposing him to the risk of HIV transmission through unprotected sex; and one involving a girl who had begun a sexual relationship with a man at the age of 13, the man pressing charges for exposure to HIV ten years later.

Another area of law in which the HIV/AIDS Legal Clinic of Ontario engages is custody inquests – a legal inquest which takes place in Canada involving a jury of five people whenever someone dies in custody. A coroner can designate an organisation as a party of substantial interest in a case and they can give evidence. The jury at the end of the case can issue public recommendations on how to avoid such deaths in the future.

The Ontario clinic intervened in two cases – in both prisoners had been infected with HIV in prison and had died of an AIDS-related illness. In both cases the jury made recommendations about needle exchange in prison, though in the second case was less clear. There were also issues around compassionate release for those suffering from a terminal illness and access to palliative care in prison (there was difficulty accessing opiates because they were drug users).

The Legal Network has also made a submission to the European Court of Human Rights on the Shelley case on needle exchange in English prisons.

Discussion and other country examples

Five of those in the discussion group were from organisations which have got involved in legal processes – from Canada, Finland, Ireland, the UK and Uzbekistan.

The role and standing of NGOs

It was noted that in some countries NGOs have legal standing whilst in others they do not. What an NGO can do, of course depends on the nature of their legal standing.

In Ireland the Irish Penal Reform Trust has been involved for some time in a case now before the Supreme Court which is about the rights of concerned parties to stand. The Trust is trying, on the basis of two terrible cases of poor mental healthcare for prisoners, to bring a case on behalf of every prisoner who has suffered similarly bad care.

Individuals living with HIV are often afraid to go to court because of the probable public disclosure of their HIV status. Class actions brought by NGOs would therefore be very useful in advocating for the rights of people living with HIV. The US and India have a history of class actions but there is not as yet comparative and comprehensive information on whether and where class actions are possible.

In the absence of legal standing, NGOs could train both defence and prosecution lawyers to ensure they can make the most effective and well-informed arguments possible in court. They could also provide support workers to give evidence at hearings. For example, in Canada support workers gave evidence following conviction to make sure that any sentence took account of someone's HIV status and their healthcare needs. It is very important to 'educate the courts'. In Finland, the NGO both pointed people living with HIV to good legal advice and acted, albeit very rarely, as expert witnesses in court proceedings.

It is very important that NGOs make clear nationally what their role is in court proceedings and what support they can provide.

Knowledge of legal issues

NGOs need to review existing laws and court cases to assess the current and potential impact on people living with HIV. This is of course relevant to prosecutions for HIV transmission but also, as was the case in Uzbekistan, for example, in cases where HIV status is being taken into account and resulting in more severe charges and sentences.

Capacity and training issues

Bosnia pointed out that in many countries NGOs would need capacity and support and training to get involved in legal and court issues. They do not currently have the capacity or expertise. There was general agreement that across Europe there is currently a lack of real legal expertise on HIV issues (though it was noted as one progressive instance that the Global Fund has provided funds to one law firm in Uzbekistan to help people with HIV).

One way forward would be to increase collaboration between HIV NGOs and legal NGOs across Europe – working across sectors, building networks and partnerships. Links also need to be made with individual lawyers who would love to use the knowledge and expertise available within the HIV sector. Other sources of support are parliamentary human rights committees.

If there is a capacity issue, one solution is to divide up a particular area of work amongst a number of committed NGOs. This has been done in Canada to good effect.

Further sources of help identified are law students, who often give assistance pro bono, trade unions (an Italian NGO was even considering attempting to register as a Trade Union for people living with HIV as a way of improving its legal standing and access), human rights academics and organisations such as Amnesty and staff of the UN Right to Health Rapporteur.

NGOs and international human rights law

There is also potential for national and local NGOs to intervene and address concerns to relevant United Nations or Council of Europe bodies which examine the compliance and progress towards implementation of treaty obligations by national governments. Such bodies welcome submissions from NGOs, and national governments also sometimes then need to engage with NGOs to discuss issues brought to the attention of these committees since the government ministers or representatives will be questioned on the matter.

Two successful examples are lobbying about harm reduction in Kyrgyzstan, which got the matter on the political agenda, and the raising of the question of HIV in prisons at a meeting in Ireland with a visiting Council of Europe committee. Larger and international NGOs which know the system fairly well need to help and support smaller NGOs in accessing these mechanisms.

The media and court cases

There was extended discussion of the stigmatising and sensationalist way in which the media covers cases involving HIV, especially prosecutions for reckless or intentional HIV transmission. It was felt by some that the negative coverage actually encouraged the police to investigate such cases. There was also concern as to how the media gains access to information about these cases, in some instances before the trial, which could have an influence on outcomes.

There is encouraging experience from Canada, the UK and Finland of NGOs working sometimes individually and sometimes collectively to improve media coverage – for example, stopping media reports claiming individuals have transmitted HIV intentionally when they are charged with reckless transmission only. HIV training for journalists was considered valuable (Sweden and Finland for example) and it was suggested that a toolkit for journalists on how to work with the media would be valuable. NGOs could position themselves as trusted authorities for the media on accurate information about HIV.

A linked issue raised from Uzbekistan was the harm of media coverage of court cases disclosing the identity of people living with HIV. It is important to review the national systems which exist for the protection of identity in court cases.

Conclusions and Recommendations

The legal standing of NGOs before the courts must be clearly established, and in particular the possibility of taking ‘class actions’ on behalf of people living with HIV. This issue needs to be addressed at the international level by both the European Union and the Council of Europe.

Training should be provided for lawyers on HIV issues by NGOs, and indeed for their own staff who may be called on to act as expert witnesses.

NGOs need to communicate clearly to people living with HIV how the NGO can support individuals in court proceedings and legal action.

NGOs should review the impact of existing law and court cases on people living with HIV.

Training and capacity-building are necessary for many NGOs if they are to interact effectively with legal processes. It is extremely important to build up expertise across Europe on HIV and legal issues, and to do so the HIV sector should build better links with legal and human rights NGOs, public interest lawyers, law students, trade unions and human rights academics.

NGOs should consider not only representations to domestic legal bodies but also submitting views and recommendations to international review and monitoring bodes linked to international human rights bodies, for example of the Council of Europe or the United Nations.

NGOs should support or take appropriate cases to the European Court of Human Rights, the European Court of Justice, and other international fora such as the Human Rights Committee established under the International Covenant of Civil and Political Rights.

4.2.4 Workshop 4. The Role of Human Rights Commissioners and Ombudsmen in Securing Rights

Introduction

Litigation is not the only possible way in which to use law to promote and protect the rights of people living with HIV. Increasingly across Europe ombudsmen and human rights institutions are being established with a variety of legal powers, some of which have the potential to act as a useful alternative to what might otherwise be costly and public litigation. The extent to which these bodies have been engaged on HIV was explored in the pre-seminar report and the workshop was an opportunity to discuss this issue in more detail.

Case study 1: Belgium, Koen Block

In Belgium the Centre for Human Rights has jurisdiction to tackle and address all forms of discrimination, including sex, descent, race, nationality, sexual orientation, religion etc. The belief underpinning its remit and work is that discrimination on any grounds whatsoever is unacceptable and has no place in society. The wording in law relevant to HIV is ‘current or future state of health, physical or other disability’.

The role of the Centre is not to protect individuals but to create and set precedents. It does this by identifying a key issue or complaint, investigating the issue, and providing advice. The Centre takes the view that going to court is not always the best approach since there can be negative consequences. Rather then going to court the Centre can seek to change decisions and practice.

The Centre also works with local groups, exchanging information and expertise. It also has a fund to enable people to go to court. This was previously a fund for medical care which has now been expanded to provide support in legal proceedings.

The Centre also runs public anti-discrimination campaigns; has a media profile so it can comment on relevant issues; and campaigns on legal issues. It has taken the right-wing, anti-gay party ‘Vlaams Belang’ to court in the past.

The Centre is a statutory body. The Centre has been involved and is still involved in a case involving the dismissal of an HIV positive employee. The court decided the dismissal was wrong but made no mention of the individual’s HIV status in its judgment.

Case study 2: Croatia, Kristijan Grdjan

There are three ombudsmen in Croatia potentially relevant to HIV issues, the Human Rights Ombudsman, the Rights of Children Ombudsman and the Gender and Sexual Orientation Ombudsman.

Whilst none of the Ombudsmen has specific jurisdiction for HIV-related issues, they can all consider individual cases linked to constitutional rights. The relevant articles relating to HIV are anti-discrimination, legal equality, self-determination, private and family life, and access to health services.

The Human Rights Ombudsman can only investigate complaints against actions of the Government or a public body. The ombudsman can issue warnings and make recommendations, as well as proposing changes to policy and legislation. The ombudsman has no obligation to take up a case and can be selective. Whilst the Croatian media have reported on a number of cases of possible human rights abuses relating to HIV, they have failed to elicit a response from the

Human Rights Ombudsman. Indeed he does not appear to have ever investigated a case involving HIV.

Investigations undertaken to date have mainly involved inhuman and degrading treatment in detention and judicial issues. The position is closely associated with the political authorities in the country.

The Gender Equality Ombudsman was established in 2003 with a remit around equality in gender, sexual orientation and marital status. There is no explicit link to HIV. This Ombudsman did, however, make a recommendation to the relevant Minister on the rights of gay men to donate blood. This request was framed as an instance of HIV-discrimination linked to sexual orientation. There has not as yet been a response form the Ministry.

The Children's Ombudsman has been involved in HIV cases in relation to a child's right to receive an education. For example, where parents have applied pressure to have a child who is HIV positive excluded from a particular school from fear that other children might be infected. These cases attract a lot of media attention in Croatia.

The Ombudsman took one case to Parliament, arguing there had been a breach of the child's right to a private life, and one which could result in violence against the child. Parliament accepted this and agreed that the breach of human rights should be punished.

In theory there is no need to establish an HIV-specific Ombudsman in Croatia – the Human Rights Ombudsman has all the necessary powers. But the proximity of the position to the political authorities is in practice a problem. Whilst in theory parliament holds the ombudsman to account through an annual report process and could demand his resignation, this form of accountability does not in practice exist. Kristijan had co-written a report making recommendations for institutional reform to enable the Human Rights Ombudsman to engage on HIV-related issues.

Discussion and other country examples

Advantages of the Ombudsman system

One advantage of the ombudsman in the Ukraine is its separation from a judicial system badly affected by corruption. As a result many NGOs make appeals directly to the Ombudsman, for example in relation to children with HIV and their right of access to education and treatment. The ombudsman is appointed by parliament and her decisions could be binding through a system of 'telephone rights', which give her significant power at the local level. She is highly respected since she has a good track record of challenging politicians. Now is an important time to push forward the rights of people living with HIV in the Ukraine, with the Global Fund providing methadone and HIV treatment.

In Albania they have found it valuable to have an ombudsman/human rights body looking specifically at HIV issues. This body has brought an action against the state on behalf of children infected with HIV through blood transfusions, and has also acted on behalf of people with HIV who are not receiving the state financial support to which they were entitled.

One advantage in certain Ombudsman systems is the fact that the ombudsman can take a case to court and enjoy legal standing in a court process where NGOs cannot. This did, for example, appear to be the case in Poland, where the ombudsman can take a class action whilst NGOs are not able to. Similarly the Ombudsmen in Belgium and Sweden can take cases to court.

In other jurisdictions, for example Croatia, the ombudsman does not have this power. In Croatia the ombudsman only has legal standing on constitutional matters before the Constitutional Court.

Another advantage identified is the capacity of the Ombudsman/Human Rights Office to raise public awareness (for example in Belgium). In the United Kingdom the new Commission for Equality and Human Rights should have a similar function.

Ombudsmen do usually have the power to make recommendations for change in both policy and practice. For example in Portugal the ombudsman has recommended an end to mandatory HIV screening in the military and improved confidentiality, as well as reforms which would improve the access of people with HIV to insurance – though the latter set of recommendations have not as yet been implemented by the Ministry of Finance. Some Ombudsmen can also make specific recommendations for legislation.

Problems with an Ombudsman system

There was a discussion of the need for genuine independence for the Ombudsman/human rights office. This is particularly relevant to the question of who funded the office. There can be difficulties where the office is funded by those whom the ombudsman is meant to monitor. In the UK the Ombudsman is funded directly by Parliament rather than a government department in an attempt to secure such independence.

There are also difficulties where the ombudsman is too closely connected to a particular political party or position. Difficulties in Croatia with the Human Rights Ombudsman have already been raised. Similarly in Poland, whilst in theory the ombudsman is able to take class actions on behalf of people living with HIV, in reality at the moment the two key Ombudsmen are very unsympathetic to HIV issues and are closely linked to conservative and religious positions. Instead people are increasingly turning to the Helsinki Foundation, an NGO operating in Poland since 1989, to support legal cases (www.hfhrpol.waw.pl/en).

Conclusions and Recommendations

Ombudsmen and state human rights bodies have the potential to act effectively on behalf of people living with HIV, especially where they are free of political interference.

Further work and research is necessary on the various powers of these bodies and how they might best be accessed to benefit people living with HIV. Europe-wide associations of ombudsmen, and the European Ombudsman Institute also, should be approached to put HIV on their agendas.

4.2.5 Workshop 5 - Knowledge of Rights amongst People living with HIV, and knowledge of HIV in the legal system

Introduction

The pre-seminar survey had asked respondents to provide information on the awareness of rights of people living with HIV. Such awareness is of course an essential prerequisite for rights being litigated, promoted and protected. Robust empirical evidence of knowledge of rights at the population level is uncommon but here are a number of examples of good practice in attempts to inform people of their rights, including help lines, websites, leaflets and the use of institutional grants from such bodies as the European Union. There is also evidence both that training of legal and judicial officials is rare but that when it takes place it has some beneficial impact.

Case study 1: Serbia, Momcilo Janjic

There are 2,200 people registered as HIV positive in Serbia out of a total population of between 8 and 9 million. The majority of people with HIV (80%) live in Belgrade. A number of laws exist covering HIV issues – for example the Constitution forbids discrimination. There is also guaranteed social security for disabled persons and rights to public health provision and to work. But there are also legal difficulties for people with HIV. There is for example punishment for HIV transmission. There has been one prosecution for intentional transmission and even exposure to the risk of HIV transmission by someone undiagnosed is theoretically prosecutable. Exposure to the risk of HIV transmission is punishable by a sentence of up to two years; intentional up to twelve years; if death results from transmission 15 years; if the defendant is undiagnosed between 6 months and 5 years.

Other legal difficulties arise from legislation on the protection of the public from disease which is used to limit the use of public spaces and recreation centres by people with HIV. Similarly there are concerns about data protection in particular in relation to electronic data and children's privacy.

Case study 2: Norway, Inger-Lise Hognerud

There is human rights and employment law protection for people living with HIV in Norway, and there was a successful legal case in 1988 involving someone who had been unfairly dismissed from his job in a bar which became a legal standard for protection of people with HIV from dismissal from employment. Criminal laws are however fairly strict and there is concern to engage with the 2008/09 review of the Criminal Code to ensure people with HIV are granted better support and protection. In summary, in Norway there is less concern over whether people with HIV are aware of their rights and more worry at the level of understanding of HIV and of the experiences of people with HIV within the legal system.

Discussion and other country examples

Only five countries in the pre-seminar report said that people with HIV in their country have a high awareness of their rights. In the Netherlands there is a sense that there is a good understanding of HIV-related rights in the gay community but there is much less confidence that such knowledge is being effectively communicated to migrant communities. In Estonia there is a similar divide amongst groups affected by HIV – but there it is sex workers who have a good understanding of their rights and injecting drug users who tend to have a poor awareness. There are also problems around HIV awareness in minority groups. There is, for example, a lack of Russian language materials for the Russian-speaking minority.

In Ireland whilst more established communities are aware of their rights, this is often not the case for newly arrived communities. There is also low awareness of rights among prisoners.

The point was made that treatment literacy might be an important first step and 'way in' for wider knowledge and understanding of rights.

It was felt that court and tribunal cases on behalf of people with HIV are an effective way of improving understanding of rights. In Poland however there is the problem that it is necessary to pay a fee if one wants to approach a court to challenge employment discrimination.

School education around HIV can also be effective in improving society's understanding – in Serbia, however, there is nothing on HIV in the school curriculum.

In Bulgaria HIV service provision is strongly centralised through medical provision in the capital in ‘disease hospitals’. This creates some problems for those wanting to access care and also means NGOs are quite dependent on the State. This in turn has an impact on what NGOs feel they can do and provide, including on access to knowledge of rights.

There was overall a consensus that there is a low awareness of rights, and there could be value in campaigns across Europe raising awareness especially amongst groups previously neglected. There was also a sense that currently legal and penal systems have a poor understanding of HIV and what it is like to live with the virus.

Conclusions and Recommendations:

Funding and support should be made available to inform people living with HIV of their rights across the European region. There needs to be a differentiated understanding of the information needs of the various groups most affected by HIV, for example migrants and ethnic minorities, gay men, injecting drug users, sex workers and prisoners, all of whom will have distinct needs.

In addition, effective legal actions and court cases should be well publicised as a further way to disseminate understanding of rights.

Legislation and judicial systems across Europe continue to display evidence of poor understanding of HIV, clinically, biologically and socially. International action should identify key information and training needs of legislators, civil servants and lawyers on HIV.

5 Presentations and discussion Saturday 21 April

5.1 Presentations and associated questions and answers

5.1.1 Three Priorities

Yusef Azad (NAT)

‘Three Priorities’

Yusef Azad

Director of Policy and Campaigns

National AIDS Trust

The question

“From all the issues discussed at this seminar, please write down what you believe should be our three top priorities for action and change across the European region”

28 responses from 25 countries

The seminar had covered a lot of ground. It was important on the final morning to try to capture some of the overall conclusions to have emerged, and some of the ways we could work together to take forward across Europe reform of legislative and judicial systems to benefit people living with HIV.

People were therefore on the Friday at the end of the day asked the question above as a way of identifying key priorities to emerge from the seminar.

Privacy and Data Protection

10 responses focussed on data protection and privacy issues:

- 6 responses specifically referred to strengthening data protection legislation at the EU level
- 3 responses singled out confidentiality issues in healthcare settings

Developing NGO capacity

9 responses focussed on NGO capacity in this area:

- The main call was for best practice to be developed for European NGOs on how to advocate and litigate around HIV human rights issues
- Linked to that were calls for financial support, and mentoring for non-EU NGOs
- And for an improved legal standing for NGOs before the courts

There was great interest in the talk from Professor Douwe Korff and the subsequent workshops on confidentiality in healthcare and in the legal/judicial system. Therefore privacy and data protection emerged as the most frequently identified priority for action, both at the level of European data protection and implementation, and in terms of national healthcare systems.

The other main emphasis is on establishing and sustaining some development of best practice on how NGOs could best influence the legal system – this might for some countries involve issues around the legal status and standing of NGOs.

European coordination

8 responses stressed the need to continue and improve networking on legal, judicial and human rights issues:

- 2 responses mentioned the particular importance of this in relation to migrants, especially with the end of the AIDS & Mobility network
- Suggestions of a database, use of the internet, a ‘forum’, a ‘regional structure’
- A comparative review of existing legislation/implementation for advocacy purposes; monitoring violation of treaties

Other issues

- Access to treatment (7 responses esp. for migrants)
- Raise awareness of rights amongst PLWH (6)
- Raise awareness of HIV amongst courts, judges, police and lawyers (6 – linked to confidentiality in legal proceedings question)
- Non-discrimination in goods and services/insurance (5)
- End criminal prosecutions for HIV transmission (4)
- Agree European best practice on testing (4)
- Create ‘model anti-discrimination law’ re HIV (3)

Networking is another concern – establishing a sustainable network of NGOs who could share best practice, legal and constitutional information. This might involve a thorough comparative analysis of the legal systems of European countries. The loss of the AIDS and Mobility network is regretted.

Such a network would obviously require direction and resources. The question is: who will organise this and who will fund it?

Some of the other priorities identified are very specific and policy-related such as access to HIV treatment for migrants, the need for European best practice on HIV testing and concerns over criminal prosecutions for HIV transmission. All these issues demonstrate the need for PLWH and relevant NGOs to be able to make human rights arguments effectively both to politicians and in the courts, and the need to be able to make representations and support PLWH when they are at their most vulnerable within the legal system.

Others are linked to legal and structural questions which have emerged during the seminar, such as raising awareness of their rights amongst PLWH, raising awareness of HIV amongst the courts and the legal professions (this is linked to the debate about the provision of confidentiality in court hearings for PLWH), the possibility of a ‘model anti-discrimination law’ for PLWH, and the need to prohibit discrimination against PLWH in the provision of goods and services, especially insurance.

Discussion and questions and answers

There was a discussion of how we could continue to work together to improve legislation and judicial systems for PLWH.

There is a need to use data and knowledge better as a sector than we have done to date if we are going to be effective advocates for change.

It is important to know about and use opportunities for influence at the European level such as the consultation on the possible extension of protection from discrimination in goods and services to disability.

Increased and sustained networks across Europe are considered very important – the range of countries represented at the seminar was a real achievement in itself. Opportunities such as the AIDS Action Europe clearing house, the Civil Society Forum, National AIDS Strategies and campaigns.

5.1.2 Dadi Einarsson, European Commission

Dadi gave an introduction to work undertaken at European Union level on HIV issues. The Commission has drafted a Communication on HIV and AIDS building on the Dublin and Vilnius Declarations. This Communication sets out the priorities for the EU on HIV over the next years. A Task Force was also established – 14 Directorate Generals have an interest on HIV issues within Europe but there are a core group of six DGs which work in detail on HIV issues. There is in addition an EU Think tank on HIV and AIDS which has between 70 and 80 members in total comprising representatives not just from the EU members states but also from the European Economic Area, the accession states, Russia and Ukraine.

The Think tank has established a Civil Society Forum with a membership of about 30 organisations from across Europe, with others as observers. The CSF has raised human rights issues with the Think tank. The recent Bremen conference organised by the German EU Presidency has human rights as a fundamental part of the HIV agenda, but it is worth noting that at the EU-level human rights competencies are limited. There is a clearer mandate in areas such as discrimination, for example around employment. All the EU institutions are agreed on the main HIV issues.

When it comes to the question of how best to influence debate, the main route to influence Europe remains through national governments. These are the representatives with power in Europe, for example through the Think tank. The EU data protection working group is another body to approach. It is also important to participate in consultation exercises and always to provide EU institutions with examples of problems and abuses as these are always very powerful.

5.1.3 John Bowis (MEP)

The European Parliament has been putting pressure on the Commission to increase the importance of public health within Europe and move DG Sanco to Brussels from its current home in Luxembourg. John has roles as coordinator and spokesperson for the European People's Party group on both Environment and Health Committees in the European Parliament. He is also Vice-President of the Joint Parliament Assembly of the EU/ACP [African-Caribbean- Pacific]. Relevant reports on which he has been involved includes one on the establishment of ECDC, which was to take over Europe-wide responsibility for HIV surveillance next year; one on mental health (where there are important links with HIV issues); and patient mobility where there are challenges as people move across European borders in terms both of agencies and records.

Globally, John is working on both new prevention technologies and the Global Fund. He has particular concerns at the rise of multi-drug resistant TB. Next week is to see a debate in the European Parliament on HIV in both the EU and neighbouring countries. There is real concern at the significant increase in new diagnoses. Whilst infections are rising it seems from Euro barometer that awareness (and thus perhaps prevention effectiveness) has declined. The Report calls for improved national HIV data, referring to Dublin commitments. There is criticism of Spain and Italy for not sharing HIV data.

The Report welcomes the existence of the Civil Society Forum and looks forward to working in partnership with the CSF.

5.1.4 Nikos Dedes

The CSF seems to have good collaboration with the Commission but less with the Parliament, which perhaps mirrors the national situations – better links with Government departments than with parliamentarians. Nikos feels the European Parliament is an important new partner for the CSF. He thinks an important message from the seminar is the need to check whether national legislations are compliant with EU directives on, say, data protection and discrimination. In other words this is an issue of implementation. NGOs have an important role in advocacy to both Commission and Parliament, identifying problems and barriers to full enjoyment of rights. The CSF too is vital and it is important that the CSF be confident in its role. It is especially important to see that the European Parliament can be an important ally, less susceptible to short-term populism than some national parliaments might be. A briefing note on how to lobby the European Parliament might be helpful for HIV NGOs across Europe.

5.2 Questions and answers

Q: There was a question of the commitment of the European Parliament to harm reduction measures such as needle exchange in prisons and safe injecting rooms. A: One problem for the European Parliament is that parliamentary committees could only do a certain number of reports per year and there is obviously strong competition for subject-matter. But this is certainly something that should be looked at for the future – in his view harm reduction is less of a left/right issue and more one which energised faith communities. This is the sort of issue where the European Parliament could sometimes more readily take a ‘better’ line. In brief, the more the Parliament got to debate Europe and Health matters, the more possible this sort of work might be.

Q: Is there an HIV in Europe group within the European Parliament? A: The focus on HIV among parliamentarians tends to be the developing world and Africa in particular. There is no specific group on HIV in Europe (though there is one on development) and there is a limit on the number of all party and interest groups possible. No one has as yet put pressure on for such a group on HIV in Europe to be established. Whether that is the best approach is perhaps open to question. What MEPs certainly need is training and re-training on HIV issues since enlargement has brought a greater interest in health amongst parliamentarians.

Q: There was a comment that it is important to make aggressive and strong claims for the rights of PLWH across the European region. In Kyrgyzstan there were real concerns about the rights of IDUs, prisoners and the use of an internal passport system to regulate movement which means PLWH could not access the care only available in the capital.

Q: There were issues of equity and equivalence in access to healthcare for the many EU citizens who travel between member states be it for work or pleasure/tourism, and who need to access health services. Greater harmonisation of healthcare systems is necessary. There are real inequalities in healthcare provision across Europe. A: There should be renewed focus on intraregional collaboration to resolve these issues. John believes patient mobility would help catalyse greater equality within Europe, and there has certainly been some improvement since the drastic cuts in healthcare provision in Eastern Europe in 1991. It has also to be accepted, however, that there are economic inequalities between economies and it is not the role of the EU to remove such differences entirely.

Q: It was felt to be important as a follow up of the seminar to get better at sharing information and good practice through initiatives such as the AAE Clearing House. It is also important for NGOs to be better at insisting on follow-up to governmental commitments such as the Dublin Declaration and the EU Action Plan. A: John was sure there are opportunities and instruments which could be used effectively at the European and parliamentary level to bring about change. It is very important to communicate these issues to MEPs. Instruments to be considered include, for example, procurement and purchasing powers. In communicating with MEPs it is important to be personal, don’t use a megaphone or mass emails, identify politely what is wrong – and give thanks when things go right!

6 Annexes

6.1 Annex A: Seminar Participants

Name:	Organisation:	Country:
Kristijan Grdjan	Skorak/UNDP	Croatia
Inger-Lise Hognerud	HIV Norway	Norway
Thomas Kristensen	STOP AIDS	Denmark
Scott Purdon	GSK	(UK)
Andre Pereira	A Comunidade Contra a Sida	Portugal
Andriy Mykytyn	Solidarity	Ukraine
Sandra Essid	AIDES	France
Elena Birindgieva	Health without borders	Bulgaria
Jury Kalikov	AIDS Information and Support Centre	Estonia
Iva Jovovic	UNDP	Croatia
Magdalena Ankiersztejn-Bartczak	Foundation of Social Education	Poland
Michal Minalto	SIEC PLUS	Poland
Gonzalo Mazuela	Red 2002	Spain
Nikos Dedes	Synthesis/European AIDS Treatment Group in Belgium	Greece
Despo Hadjiloizou	Cyprus Family Planning Association	Cyprus
Matteo Schwarz	NPS Italia Onlus	Italy
Ophelia Haanyama Ørum	Noaks Ark Red Cross	Sweden
Ronald Brands	SOA AIDS Netherlands	Netherlands
Eva Melkova	Odyseus	Slovak Republic
Genci Mucollari	Aksion Plus	Albania
Timur Abdullaev	NGO 'Hope and Live'	Uzbekistan
Ernist Abdiraschitov	Mental Health and HIV/AIDS project of Global Initiative in Psychiatry	Kyrgyzstan
Emina Osmanagic	Association For Sexual and Reproductive Health XY	Bosnia Herzegovina
Koen Block	Sensoa	Belgium
Momcilo Janjic	JAZAS	Serbia

Angelina Namiba	Positively Women	UK
Corinne Bjorkenheim	AIDS Stukikeskus	Finland
Matthew Weait	Keele University	UK
Anna Zakowicz	Dematra	Lithuania
Ivan Vodneu	NGO Intersocaid	Belarus
Vitalie Slobozian	SOROS	Moldova
Deirdre Seery	Sexual Health Centre	Ireland
Maria Georgescu	ARAS	Romania
Jeffrey Lazarus	WHO Europe	
Alana Klein	Human rights Lawyer	Canada
Rick Lines	Irish Penal Reform Trust	Ireland
Julian Hows	Michael Bell Associates	UK
Iain Byrne	Interights	
Douwe Korff	London Metropolitan University	UK
John Bowis	MEP	UK
Dadi Einarsson	European Commission HIV/AIDS Taskforce	
Jacqueline Parlevliet	Deputy Representative UNHCR	UK
Damon Barrett	International Harm Reduction Association	
Mark Bell	University of Leicester	UK
Registered participants that didn't attend		
David Ananiashvili	Georgian Plus Group	Georgia
Pavel Chikov	Russian Harm Reduction Network	Russia
Achim Weber	Deutsche AIDS Hilfe	Germany

6.2 Annex B: Seminar agenda

‘Legislation and Judicial Systems in Relation to HIV and AIDS’

Seminar Agenda

Thursday 19 April –

Topic: The Experience of Discrimination by People Living with HIV and the Legal Protection Available

12:00-13:15pm - Registration and Lunch
13:15-13:45 - Welcome and Introduction to the Seminar:
- Deborah Jack – Chief Executive, National AIDS Trust
- Yusef Azad – Director of Policy and Campaigns, National AIDS Trust

13:45-14:15 – Presentation on EU Law and Discrimination
- Professor Mark Bell – Faculty of Law, University of Leicester

14:15-14:45 - Presentation on the European Convention on Human Rights
- Karon Monaghan – Barrister, Matrix Chambers

14:45-15:15 – Refreshments
15:15 – 16:30 – Workshops
Insurance and Financial Services
Chair: Yusef Azad
Case Studies: Andre Pereira [Portugal] and Michal Minalto [Poland]
Migration, Mobility, and Travel Issues
Chair: Dr. Matthew Weait
Case Studies: Ronald Brands [Netherlands] and Vitalie Slobozian [Moldova]
Access to Rights: IDUs, Sex Workers, and Prisoners
Chair: Deborah Jack
Case Studies: Jury Kalikov [Estonia] and Ernist Abdirashitov [Kyrgyzstan]
16:30-17:15 – Group discussion on Workshop topics
17:15-17:30 – Wrap-Up and next-day preparation

Friday 20 April –

AM Topic: Privacy and Confidentiality

9:45-10:00 - Introduction

10:00-11:00 – Presentations on Confidentiality for PLWH:

Professor Douwe Korff – Human Rights and Social Justice Research Institute, London Metropolitan University

Yusef Azad - National AIDS Trust

11:00-11:15 - Refreshments

11:15-12:30 – Workshops

Confidentiality in Healthcare Settings

Chair: Deborah Jack

Case Study: Iva Jovovic [Croatia]

Confidentiality in Legal Proceedings

Chair: Yusef Azad

Case Study: Maria Georgescu [Romania]

12:30-13:30 - Lunch break

PM – Topic: Practice and Barriers

13:30-13:45 - Introduction

13:45-14:30 - Presentation on Evidence in Court Cases:

- Dr. Matthew Weait – Lecturer, Faculty of Law, Keele University

14:30-15:15 - Presentation on NGOs as Litigants in Court Cases:

- Iain Byrne – Senior Lawyer, Interights

15:15-15:30 – Refreshments

15:30-16:45 – Workshops

The Role of Human Rights Commissions/Ombudspersons in Securing Rights

Chair: Yusef Azad

Case Studies: Koen Block [Belgium] and Kristijan Grdjan [Croatia]

Knowledge of Rights for PLWH and Knowledge of HIV in the Legal System

Chair: Jeffrey Lazarus

Case Studies: Momcilo Janjic [Serbia] and Inger-Lise Hognerud [Norway]

The Role of NGOs in Legal Proceedings

Chair: Nikos Dedes

Case Studies: Alana Klein [Canada] and Pavel Chikov [Russia]

16:45-17:15 – Wrap-Up and next-day preparation

20:00 – Dinner @ the Fish Shop on St. John Street

Saturday 21 April* –

Topic: Best Practice Guidelines and Wrap-Up

9:30-9:45 – Introduction:
John Bowis – Member of the European Parliament (Conservative, London)
9:45-10:15 – Feedback from the Conference and Emerging Priorities:
Yusef Azad – National AIDS Trust
Dr. Matthew Weait – Lecturer, Faculty of Law, Keele University
10:15-11:00 – Opportunities to Influence Change at the European Level:
Dadi Einarsson – Member of the European Commission HIV/AIDS Task Force
John Bowis – Member of the European Parliament (Conservative, London)
Nikos Dedes – EATG and Co-Chair of the EU Civil Society Forum
11:00-11:15 – Refreshments
11:15-11:45 – Discussion of Next Steps and Conclusions