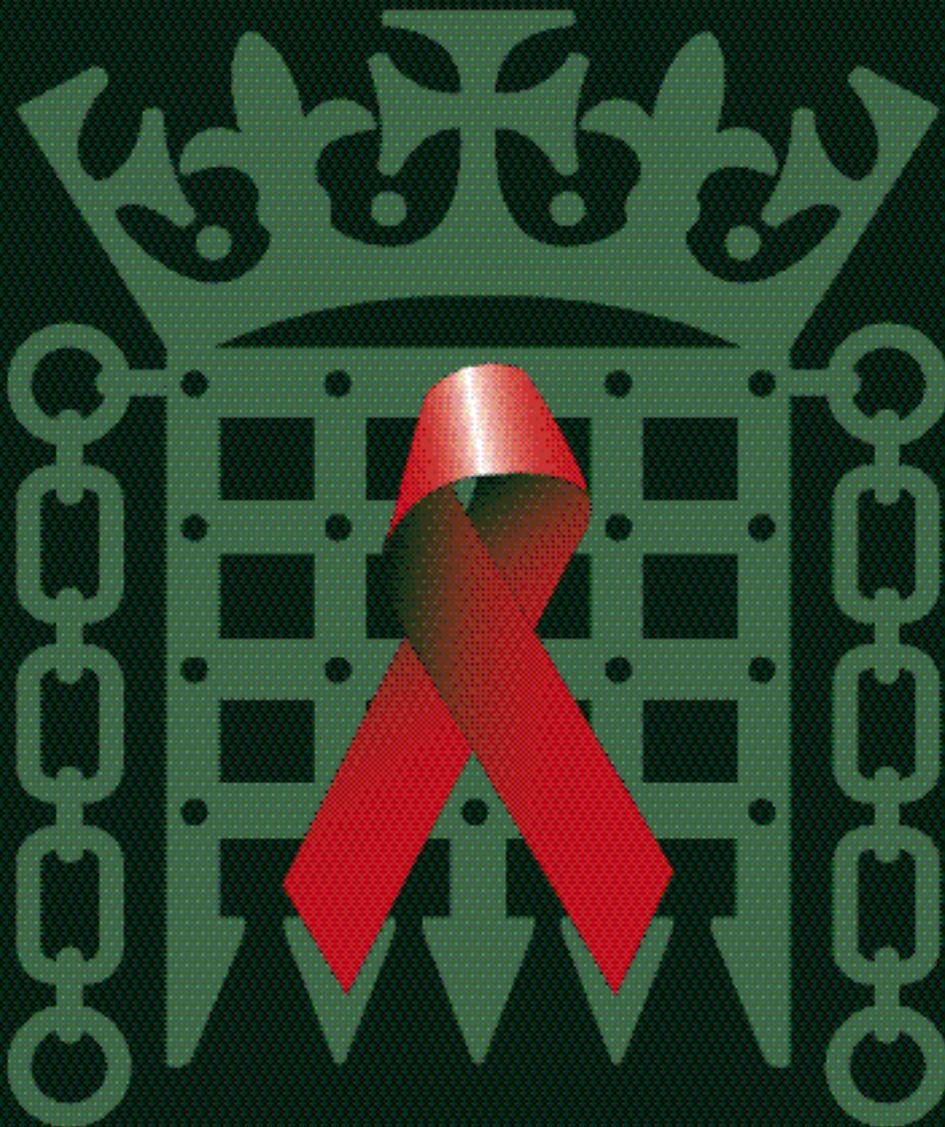


All-Party Parliamentary Group on AIDS

The UK, HIV and Human Rights:
recommendations for the next
five years



Sponsorship

The All-Party Parliamentary Group on AIDS received donations to allow it to carry out this Inquiry, in particular to have a transcript of the sessions of oral evidence, to print and launch the Report and to reimburse expenses of witnesses who came from outside London.

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All-Party Parliamentary Group on AIDS

The UK, HIV and Human Rights: recommendations for the next five years
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**Report of the Inquiry into the UK's respect for and promotion
of the International Guidelines on HIV/AIDS and Human Rights,
with recommendations for Government action.**

“Significantly, the success of various HIV/AIDS interventions has been shown to be directly proportional to the degree to which human rights are promoted and protected in the context of these interventions. These realities, demonstrated time and again over the course of the HIV/AIDS epidemic, make clear that the protection and promotion of human rights must be an integral component of all responses to the epidemic.”

UNAIDS, 1997,
The UNAIDS Guide to the United Nations Human Rights Machinery

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Preface – Neil Gerrard MP

Chair of the All-Party Parliamentary Group on AIDS

In November 1999, the All-Party Parliamentary Group on AIDS was honoured to launch the Handbook for Legislators on HIV/AIDS, Law and Human Rights at the House of Commons, with video links to the devolved assemblies in Scotland, Wales and Northern Ireland and journalists in several African countries. Produced by UNAIDS (the United Nations Joint Programme on HIV/AIDS) and the Inter-Parliamentary Union, the Handbook is an invaluable guide for Parliamentarians around the world, introducing the International Guidelines on HIV/AIDS and Human Rights and giving examples of policies and laws which respect them. David Borrow MP, one of the Group's Vice-Chairs, was a member of the working group that developed the Handbook.

We decided to hold an Inquiry into the UK's response to the International Guidelines as part of our desire to see the Guidelines respected and promoted in the UK and in other countries. Whilst we share the world's hopes for a cure, a vaccine, or widely-available treatments, as politicians we are naturally concerned about the social and cultural factors which are behind the pattern of spread and the impact of HIV on individuals, families and communities. In this Inquiry, we have largely avoided discussing treatments or what is usually understood as health promotion (these subjects were considered during our 1998 Inquiry which focussed on UK health policy).

At the 2000 International AIDS Conference in Durban, South African President Thabo Mbeki was criticised for discussing poverty rather than HIV/AIDS. While we are clear that the HIV virus causes the syndrome AIDS, we also believe that poverty, and other inequalities, are fundamentally connected to the spread of the virus and its impact. If we try to address HIV merely as a medical condition, we will fail to learn the lessons that this devastating virus could teach us. And perhaps, we will fail to prevent other health problems, now and in the future, that thrive in conditions of poverty, of denial of rights, of discrimination, of stigma.

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During this Inquiry, inequities and injustices have been highlighted. The most glaring, however, is between our concerns in the UK and our concerns for developing countries. In the UK, where prevalence of HIV is approximately 0.1% and treatments are currently proving effective, the concerns we heard are about living with a stigmatised and still-terrible condition. In developing countries, and in particular Sub-Saharan Africa, the number of people dying of the same stigmatised and terrible condition is altering the very fabric of societies. The more detailed evidence we received concerned the UK epidemic whilst the international crisis was dealt with in much broader terms. It is the hope of the All-Party Parliamentary Group on AIDS that it is possible to consider both the international crisis and UK's HIV situation, to accord them both importance, without diminishing either concern.

Our Inquiry has concluded that the UK can be relatively proud of its record in protecting the human rights of people with HIV and those vulnerable to it, both at home and abroad. However, there are significant areas of omission and other areas where the UK needs to do much more than it has. We have highlighted these as recommendations, collected at the beginning of the Report. I would like to give my commitment that the All-Party Parliamentary Group on AIDS will actively pursue these recommendations through parliamentary questions, debates and direct contact with Ministers.

I would like to thank, first and foremost, all those who submitted written evidence to this Inquiry or appeared in front of the panel, for their help in guiding us through these issues. I am particularly pleased that, of 31 witnesses who spoke to the panel, 13 were people living openly with HIV. I also would like to record my thanks to my fellow Parliamentarians who gave their time to sit on the panel of this Inquiry, the sponsors who made it possible for us to produce this report and the Group's Policy Adviser and Co-ordinator, Simon Wright.



Neil Gerrard MP

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The All-Party Parliamentary Group on AIDS

The All-Party Parliamentary Group on AIDS is a backbench group of 160 MPs and Peers from all political parties at Westminster. Whilst not official committees of Parliament, All-Party Parliamentary Groups are recognised by the Speaker and entitled to use facilities in order to enable Parliamentarians to develop their areas of interest. The AIDS Group was started in 1986 by Lord Kilmarnock who remains its Honorary Patron. Its objectives are to raise the profile of HIV/AIDS, both as a domestic and an international issue, to encourage cross-party consensus and to act as a bridge between Parliament, Government and the people living with or working with HIV/AIDS.

The current Officers of the All-Party Parliamentary Group on AIDS are:

Neil Gerrard MP (Labour, Walthamstow), Chair
David Borrow MP (Labour, South Ribble), Vice-Chair
Baroness Cumberlege (Conservative Peer), Vice-Chair
Rt Hon Lord Fowler of Sutton Coldfield, (Conservative Peer), Vice-Chair
Baroness Masham of Ilton (Crossbench Peer), Vice-Chair
Laura Moffatt MP (Labour, Crawley), Finance Officer
Dr Jenny Tonge MP (Liberal Democrat, Richmond Park), Vice-Chair.

The following Members took part in this Inquiry:

Baroness Barker (Liberal Democrat Peer)
David Borrow MP (Labour, South Ribble)
Baroness Gardner of Parkes (Conservative Peer)
Neil Gerrard MP (Labour, Walthamstow)
Sandra Gidley MP (Liberal Democrat, Romsey)
Baroness Masham of Ilton (Crossbench Peer)
Laura Moffatt MP (Labour, Crawley)
Dr Doug Naysmith MP (Labour/Co-operative, Bristol North West)
Rt Hon Dr Gavin Strang MP (Labour, Edinburgh East and Musselburgh)
Dr Jenny Tonge MP (Liberal Democrat, Richmond Park).

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Devolution

This is the first Inquiry the Group has undertaken since devolution of certain powers to the Scottish Parliament, Welsh Assembly and Northern Ireland Assembly. For example, areas such as international development and anti-discrimination remain as reserved powers at Westminster and recommendations therefore apply to the whole of the UK. Education and health are the responsibilities of the devolved assemblies and therefore the recommendations apply only to England. Criminal law in Scotland is the responsibility of the Scottish Parliament, and therefore recommendations in this area relate only to England, Wales and Northern Ireland.

The Inquiry has not considered these boundaries in any depth. Therefore the All-Party Parliamentary Group on AIDS, as a group of Westminster Parliamentarians, wishes to make clear that it wholly respects the autonomy of the devolved assemblies and does not intend to make recommendations on areas which are outside our responsibility.

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The Inquiry

Announced in December 2000, the Inquiry invited interested parties to submit written evidence in answer to the question:

How well has the UK respected and promoted the International Guidelines on HIV/AIDS and Human Rights?

Over 40 items of written evidence were received. A range of people and organisations were invited to elaborate their evidence during three sessions of evidence held in February 2001.

Wednesday 14 February: Processes and monitoring

Witnesses:

Julia Häusermann, Rights and Humanity
Dr Barry Evans, Communicable Disease Surveillance Centre, PHLS
Derek Bodell, National AIDS Trust
Nick Partridge OBE, Terrence Higgins Trust
Neil Wooding, Welsh HIV/AIDS Reference Group
Cephas Mosinghi, Network of Self-Help HIV/AIDS Groups
Bernard Forbes, UK Coalition of People Living with HIV/AIDS
Fiona Pettitt, International Community of Women Living with HIV/AIDS
Julian Hows, Global Network of People Living with HIV/AIDS
Sue Lucas, International HIV/AIDS Alliance

Thursday 15 February: Law and discrimination

Witnesses:

Andrew Little, UK Coalition of People Living with HIV/AIDS
Maria Dickson
Paul Ward, Terrence Higgins Trust Lighthouse
John Godwin, National AIDS Trust
Hilary Kinnell, EUROPAP
Erin O'Mara, National Drug User's Network/Black Poppy
Stephanie Sexton, National AIDS and Prisons Forum
Leigh Neal, Positively Women/International Community of Women Living with HIV/AIDS
Ken Bluestone, VSO
Jon Pender, GlaxoSmithKline
Martin Foreman, UK NGO AIDS Consortium

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Wednesday 28 February: Social change

Witnesses:

Susan Crane, International Family Health

Karen Newman, International Planned Parenthood Federation

Winnie Ssanyu-Sseruma, African HIV Policy Network

Dorothy Mukasa, African HIV Policy Network

Martin Kirk, UK Gay Men's Health Network

Ron Mowbray, George House Trust

Basil Williams, Mainliners

Simon Blake, National Children's Bureau

Ruth Webb, UK Coalition of People Living with HIV/AIDS

Miriam Maluwa, UNAIDS

The full transcripts of these sessions are available from the Group's website. The Report highlights observations and recommendations, organised under each of the twelve Guidelines. The Report was approved by the Panel and issued at the start of the new Parliament after the 2001 General Election. Members will direct Ministers and officials to relevant sections of the report and seek responses on whether action will be taken during this Parliament.

We have not been able to reflect every point that was made in written or oral evidence. The recommendations are a summary of a number of priorities that the All-Party Parliamentary Group on AIDS wishes to take forward. As is normal, the recommendations do not reflect the individual views of the whole Group. Rather they reflect where there was agreement amongst the Panel, on behalf of the All-Party Parliamentary Group on AIDS, that a recommendation was appropriate, realistic and practical.

Written evidence was submitted by the following organisations:

- African HIV Policy Network
- Blackliners
- BMA Foundation for AIDS
- British Red Cross
- Brook
- Childline
- Commission on Human Rights
- David Patterson
- Disability Rights Commission
- EUROPAP - European Network of HIV and STD Prevention in Prostitution
- European Committee for the Prevention of Torture (CPT)
- European Forum on HIV/AIDS, Children and Families

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- European Network for HIV/STD Prevention in Prostitution
- Francesca Simms
- George House Trust
- Global Network of People Living with HIV/AIDS (GNP+)
- Helen J. Self
- HelpAge International
- International Community of Women Living with HIV/AIDS (ICW)
- International HIV/AIDS Alliance
- International Working Group on Microbicides
- John Mordaunt Trust
- Mainliners
- National AIDS and Prisons Forum
- National AIDS Trust
- National Children's Bureau/Sex Education Forum
- National Drug User's Network (joint submission with National AIDS Trust)
- Network of Self-Help HIV/AIDS Groups
- Oxfam
- Prison Reform Trust
- Public Health Laboratory Services Communicable Disease Surveillance Centre
- Rights and Humanity
- Society for the Advancement of Sexual Health/Sheffield Centre for Sexual Health and HIV
- Strutton Housing Association
- TAMPEP - Transnational AIDS/STD Prevention Amongst Migrant Prostitutes in Europe Project
- Terrence Higgins Trust Lighthouse
- UK Coalition of People Living with HIV/AIDS/Positive Futures
- UK Gay Men's Health Network
- UK Public Health Association
- VSO
- Welsh Reference Group on HIV/AIDS and NAT Cymru
- World Vision

Epidemiology: the picture of HIV

At the start of the Inquiry, Dr Barry Evans of the Public Health Laboratory Services Communicable Disease Surveillance Centre gave an overview of the HIV epidemic in the UK and internationally. This was particularly helpful in identifying the rationale for discussing vulnerable groups, a key element of the International Guidelines on HIV/AIDS and Human Rights.

The transcript contains his full evidence but some key points he highlighted were:

- Of approximately 20,000 people living with diagnosed HIV in England and Wales, about 12,500 acquired it through sex between men, 6,500 through heterosexual sex, 1,000 through injecting drug use and 500 through blood products.
- Approximately 3,000 people are being newly diagnosed each year in the UK. There has been an increase in the number of diagnoses (as opposed to transmissions) in heterosexuals, the majority of these infections are believed acquired abroad, making Africans living in the UK the second largest group. Transmission through sex between men has seen little or no decrease throughout the 1990s and remains the main method of transmission in the UK. There has been very limited spread of HIV into the general heterosexual population.
- Internationally, 70% of the 36 million people believed living with the virus are in sub-Saharan Africa, with national rates of infection over 15% among adults in eight countries. Important factors in transmission include separation of male migrant workers from their families, sex workers, stigma and high STI rates.
- Eastern Europe is seeing very high rises through injecting drug use with commercial sex workers threatening a more widespread epidemic. Areas such as the Caribbean and South America have concentrated epidemics whilst South East Asia has the potential for a more widespread epidemic to develop.

International Guidelines on HIV/AIDS and Human Rights

The International Guidelines on HIV/AIDS and Human Rights were developed in 1996 at the second International Consultation on HIV/AIDS and Human Rights, convened jointly by the UN High Commissioner for Human Rights and UNAIDS.

¹ p.26, Handbook for Legislators on HIV/AIDS, Law and Human Rights, UNAIDS/IPU 1999

The Guidelines provide explicit benchmarks to implement and measure performance in developing an effective rights-based response to the epidemic. They clarify obligations in existing human rights instruments. Many of these use the term “or other status” which the UN High Commissioner on Human Rights has resolved “should be interpreted to include health status, including HIV/AIDS.”¹

Julia Häusermann, Director of Rights and Humanity, told the Inquiry that the Guidelines “have been called for and endorsed by the Commissioner on Human Rights of the UN which is the highest intergovernmental Human Rights body... Now, guidelines like this do not have a formal legal status, but just like the universal declaration, when people recognise that it is useful and helpful, it becomes a part of the adoption of a government programme.” Miriam Maluwa, UNAIDS Human Rights Adviser, told the Inquiry: “the legal basis for the Guidelines is the international human rights treaties and conventions which are legally binding on states that are parties to them and also to states as members of the UN family, because you have tools such as the Universal Declaration of Human Rights which is customarily binding on all UN members irrespective of ratification to all the other treaties. That is the framework where the Guidelines draw their status from. However, as long as they are at a guidelines level, they remain more of a persuasive nature as opposed to being legal in nature.”

The link between human rights and health

“Those people who were marginalised, stigmatized and discriminated against before HIV/AIDS arrived – have later become, over time, those at highest risk of HIV infection”. Jonathan Mann

The link between health and human rights has been posited as key to understanding and addressing the “root causes” of the HIV epidemic. In *From Vulnerability to Human Rights*, Jonathan Mann and Daniel Tarantola summarised the link as follows:

² p.463, *From Vulnerability to Human Rights in AIDS In the World II*, eds. Jonathan Mann and Daniel Tarantola, 1996 OUP.

“Since contextual factors have an impact on the personal, programmatic and societal vulnerability to HIV, a human rights analysis strengthens the ability to identify and to address the root causes, or the underlying conditions of society which create and sustain vulnerability to HIV... [this insight] creates an opportunity to intervene at the deepest societal level, and thereby combat the epidemic.”²

Giving evidence to the panel, Julia Häusermann said: “the public health response to HIV and AIDS has sometimes, itself, violated human rights... human rights provides a positive framework for effective action. If you empower people to participate and if you inform them of the risks of HIV and AIDS, and if you enable them to exercise their rights, you are playing a very important role in prevention. If you care for people in a dignified way and if you treat them with dignity in the health care setting, you are helping with the public health response to HIV and AIDS.”

Miriam Maluwa summarised the rationale for a human rights-based approach to HIV as threefold:

“first of all that where human rights are not protected there is increased negative impact of the epidemic, so if a person is HIV positive... they also have to deal with a lot of loss of consequential rights because of being infected...”

“The second level is that we also have found that where human rights are not protected there is increased vulnerability to infection, so where economic, social or cultural rights are not respected you find that people who are not enjoying those particular rights are placed in a worse position to be infected.

and thirdly,

“The last level is relating to response where human rights are not protected at national level or international level... where there is any kind of censorship law in terms of what information you can give out or restriction on freedom of movement people cannot get together and effectively contribute and input into the epidemic.”

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All the evidence presented to us suggests that work to address the devastating HIV/AIDS epidemic must be multi-faceted. It is acknowledged that simply informing people about how the virus is transmitted remains a priority in some parts of the world. Services for people infected or affected by HIV are clearly desperately needed, especially where community-based services can be developed. Medical treatments have shown the capacity to dramatically reduce the rate of death and need to be expanded to the poorest, worst-affected countries. Research to develop a cure or new technologies capable of preventing transmission must continue and be targeted at those countries which need it most.

However, this Report shares the analysis outlined in the Handbook for Legislators - that only by considering the structural reasons for the spread of the virus and its effects, only by addressing the human rights of people vulnerable to the virus, only by striving to change the social and cultural factors that drive HIV will the world be able to confront, and ultimately stop, this devastating epidemic.

Summary of recommendations

- **Paragraph 3:** The All-Party Parliamentary Group on AIDS recommends that the Social Exclusion Unit in the Cabinet Office undertake a one-off investigation into all aspects of HIV in the UK during the lifetime of this Parliament.
- **Paragraph 6:** The Group recommends that, on domestic HIV issues, the Department of Health should co-ordinate regular cross-departmental liaison including the Departments for Education and Skills, Work and Pensions, Health, Home Office, Trade and Industry and Offices for Scotland, Wales and Northern Ireland.
- **Paragraph 8:** The Group recommends that the Expert Advisory Group on AIDS should be expanded to become a cross-departmental advisory body assuming a wider role in addressing the social and human rights aspects of HIV/AIDS and operating with greater openness and a wider range of expertise.
- **Paragraph 11:** The Group recommends that, in international HIV issues, the Department for International Development should co-ordinate ongoing cross-departmental liaison between government departments, including Trade and Industry, Treasury, Defence, Foreign and Commonwealth Office.
- **Paragraph 15:** The Group recommends that departments in addition to Health should consult people with HIV about the impact of policies relevant to HIV/AIDS.
- **Paragraph 17:** The Group recommends that, where advisory bodies are established, they should have representation from all the main affected communities and should also seek to develop the capacity of affected communities to contribute at this level.
- **Paragraph 19:** The Group recommends that representatives of people with HIV and vulnerable groups should contribute to and jointly agree local AIDS (Control) Act Reports.
- **Paragraph 22:** The Group recommends that DFID should go further in supporting the voices of people with HIV and vulnerable communities, especially women, children and minority groups with high risk of infection, not only in "consultation" but at all stages of programme planning, delivery and evaluation and to develop the capacity of people with HIV and vulnerable communities to make decisions about work that affects their lives.

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- **Paragraph 26:** The Group recommends that the AIDS (Control) Act, or its implementation, should be updated with wider reporting requirements and greater consultation with local organisations and representatives of affected groups.
- **Paragraph 30:** The Group recommends that the UK Government should be explicit in its contacts with foreign governments that restrictive public health legislation is inappropriate and is more likely to contribute to the spread of the epidemic rather than reduce it.
- **Paragraph 32:** The Group recommends that the Home Office take forward the recommendations made in Setting the Boundaries and ensure that criminal law does not discriminate between homosexual and heterosexual acts.
- **Paragraph 34:** The Group recommends that “harm reduction” approaches to injecting drug use should be maintained and extended where appropriate.
- **Paragraph 35:** The Group recommends that laws relating to injecting “paraphernalia” should be amended so that additional items which reduce the risk of infection (particularly of Hepatitis C) can be provided and carried.
- **Paragraph 38:** The Group recommends that laws relating to prostitution should be subject to comprehensive review and that the health impact of current legislation is considered and opportunities sought to reduce the harm which prostitution exposes people to, for instance to encourage safer ways of working as well as seeking to reduce pressures to sell sex.
- **Paragraph 40:** The Group recommends that the evaluation of pilot provision of cleansing tablets in prisons should be published and, if evaluated as successful, expanded throughout England and Wales.
- **Paragraph 41:** The Group recommends that, in principle, needle exchange schemes should operate inside prisons on the same basis as outside, in parallel to other health promotion measures and work which aims to reduce the incidence of drug use and treat drug addiction, and therefore should be piloted.
- **Paragraph 43:** The Group recommends that a Prison Service Instruction should be issued to ensure that all prison staff know that they have a duty to provide condoms in an effective and confidential way and not merely through medical officers.

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- **Paragraph 45:** The Group recommends that the Home Office in conjunction with the Department of Health develop clear guidelines and implementation mechanisms across the prison service, to ensure that, as far as is possible, the treatment of people with HIV in the prison system reflects practice outside and works towards equivalence.
- **Paragraph 49:** The Group recommends that any change to the law on transmission of disease should not refer to HIV in isolation and the public health impact of any law should be considered carefully.
- **Paragraph 51:** The Group recommends that the British Government, through any and all appropriate routes, raise human rights abuses with international bodies and the governments concerned, especially drawing attention to situations where inappropriate criminalisation is likely to encourage HIV transmission.
- **Paragraph 54:** The Group recommends that in considering review of the Disability Discrimination Act, the Disability Rights Commission should investigate how anti-HIV discrimination affects people who are presumed to be infected or discriminated against because of their association with HIV.
- **Paragraph 56:** The Group recommends that a cross-departmental HIV/AIDS Strategy should consider where further anti-discrimination legislation would help address the social exclusion of vulnerable groups and the subsequent contribution to HIV transmission.
- **Paragraph 58:** The Group recommends that human rights elements of aid programmes to address HIV/AIDS are vital and cannot be seen as an optional extra or something which it is hoped will implicitly occur. Instead the promotion of the human rights of vulnerable groups and people with HIV should be an explicit aim of HIV/AIDS programmes.
- **Paragraph 60:** The Group recommends that spending priorities should be clearly directed by epidemiological evidence of transmission and not by historical tradition, prejudice or scarcity of funding.
- **Paragraph 62:** While noting that the issue of access to patented medicines is currently under discussion in various fora, as part of its Human Rights Inquiry, the Group recommends that DFID's Commission on TRIPS seeks to balance the needs of the Northern-based pharmaceutical industry with the needs of developing countries experiencing devastating national emergencies. In particular, the Group believes that the British Government must make greater efforts to avoid appearing to side with its pharmaceutical industry in disputes.

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- **Paragraph 63:** The Group recommends that the pharmaceutical industry should make much faster and more meaningful progress towards differential pricing for medicines used to treat HIV and opportunistic infections than is currently being achieved.
- **Paragraph 65:** The Group recommends that all future discussions about preventative tools, medicines and treatments need to be based on principles of equality of access and respect for the human rights of all people.
- **Paragraph 68:** The Group recommends that people with HIV, their families or communities should be able to access specialist legal advice in order to enforce their rights or challenge violations.
- **Paragraph 71:** The Group recommends that developing and strengthening the capacity for in-country legal advocacy for HIV-related human rights is an appropriate use of development funding and may be an extremely effective and cost-effective intervention.
- **Paragraph 76:** The Group recommends that, internationally, increased efforts to respect the UN Convention on the Rights of the Child are key to decreasing the vulnerability of children to HIV infection and its impact.
- **Paragraph 78:** The Group recommends that the Department for Education and Skills should review and update its guidelines for children with HIV as a matter of priority and make support available from national and regional educational sources.
- **Paragraph 82:** The Group recommends that work to address the HIV epidemic must take account of the social context in which vulnerable groups live their lives – not merely to promote their access to “services”. In particular in developing countries, where high level epidemics are mainly transmitted through heterosexual sex, the realities of women’s lives, their ability to control their reproductive health and their social and economic circumstances must be addressed.
- **Paragraph 85:** The Group recommends that the environment in which gay men grow up and live is addressed in order to affect the impact it has on self-esteem, assertiveness and, ultimately, health.
- **Paragraph 87:** The Group recommends that the Department for International Development should continue to fund innovative work with vulnerable and stigmatised communities in developing countries in order to reduce emerging epidemics in vulnerable communities before they develop into more generalised ones.

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- **Paragraph 90:** The Group recommends that the Home Office should specifically investigate the impact that the asylum system, in particular dispersal and vouchers, is having on asylum-seekers with HIV.
- **Paragraph 94:** The Group recommends that reviews of the UK Anti-Drugs Strategy should ensure that the health impact of drug use and blood-borne viruses are accorded specific attention, reinforcing a “harm reduction” approach alongside other action.
- **Paragraph 96:** The Group recommends that the UK government, through its international influence, should support work directed towards alleviating the impact of HIV on older populations and to attempt to understand the levels of infections in the over 50s.
- **Paragraph 101:** The Group recommends that HIV education in schools should prioritise addressing stigma and discrimination, both towards HIV itself and vulnerable groups, and that this should be encouraged through Department of Education and Skills guidance, Ofsted inspections and National Healthy Schools Standard assessments.
- **Paragraph 106:** The Group recommends that any media campaigns targeting the general public in the UK should have, as their first objective, challenging the stigma and discrimination associated with HIV and those groups who are most vulnerable to it.
- **Paragraph 112:** The Group recommends that action to reduce discrimination and stigma in developing countries through education and campaigns, particularly with the involvement of national leaders and politicians is essential and should be a very high priority.
- **Paragraph 117:** The Group recommends that joint codes of practice relating to employment of people with HIV should be developed by the Department for Work and Pensions in partnership with the private sector, positive organisations, NGOs and the Disability Rights Commission.
- **Paragraph 120:** The Group recommends that the Department for Work and Pensions should look into the means of enabling people with HIV to go back into or remain in the workplace, considering HIV alongside other fluctuating and/or chronic conditions, whilst acknowledging the especial nature of the stigma and discrimination directed towards HIV.
- **Paragraph 122:** The Group recommends that the Joint Select Committee on Human Rights ensure that HIV issues are incorporated into audits of compliance with the Human Rights Act.

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- **Paragraph 126:** The Group recommends that the Foreign and Commonwealth Office Human Rights Annual Report should identify HIV-related human rights abuses and report action that the British Government has taken or intends to take to help address it.
- **Paragraph 128:** The Group recommends that the UK Government should now begin to prepare a substantial response to the UN Secretary-General's 2002 request on the UK's actions to implement and promote the Guidelines.
- **Paragraph 135:** The Group recommends that the Department for International Development should develop and strengthen its linking of human rights and health, particularly HIV, and make efforts to bring together its work in these areas.

Guidelines and report

GUIDELINE 1:

STATES SHOULD ESTABLISH AN EFFECTIVE NATIONAL FRAMEWORK FOR THEIR RESPONSE TO HIV/AIDS WHICH ENSURES A CO-ORDINATED, PARTICIPATORY, TRANSPARENT AND ACCOUNTABLE APPROACH, INTEGRATING HIV/AIDS POLICY AND PROGRAMME RESPONSIBILITIES ACROSS ALL BRANCHES OF GOVERNMENT.

1. The Handbook for Legislators recommends that “HIV/AIDS policies and programmes need to be integrated across the executive, legislative and judicial branches of government”. Nick Partridge, Chief Executive of Terrence Higgins Trust Lighthouse, said that we need to “look at HIV not just in terms of transmission, not just in terms of prevention campaigns, not just in terms of treatment and care, but what it means on a day-to-day basis and what the government can do to minimise social exclusion, minimise the degree of prejudice and discrimination people who have HIV face on a regular basis and which is not faced by most other people living with other potentially terminal illnesses.” Derek Bodell, Chief Executive of the National AIDS Trust, did not feel that the UK is currently succeeding in this aim: “As far as we can see, there is communication between government departments but it is not very transparent, it is not very consistent and it is not very reassuring.”
2. In Britain, policy and legislative decisions relating to HIV/AIDS are made in an ad-hoc way apparently without any cross-departmental co-ordination. The only moves towards a strategic approach to HIV in the UK have been focussed solely on health policy. We note that the Teenage Pregnancy report (1999) by the Social Exclusion Unit based in the Cabinet Office, recognised that the reasons for sexual behaviour are to be found in a wide range of social factors, much wider than the Department of Health’s responsibility. The BMA Foundation for AIDS pointed out that “social inequalities play a role in increasing vulnerability to HIV infection (some socially excluded communities are disproportionately affect by HIV) and HIV can also lead to social disadvantage, for example through discrimination resulting from HIV-positive status”.³
3. **The All-Party Parliamentary Group on AIDS recommends that the Social Exclusion Unit in the Cabinet Office undertake a one-off investigation into all aspects of HIV in the UK during the lifetime of this Parliament.**
4. It should look across all relevant government departments and address not only the way that HIV causes social exclusion for those infected, but also the way that social exclusion contributes to the transmission of HIV in the first place. It should develop policy to ensure that people with HIV and vulnerable communities can play an active part in society.

³ Written submission from BMA Foundation for AIDS

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5. The Handbook for Legislators recommends that interministerial committees are set up to co-ordinate government policy. As an example of good practice, it cites the UK's Special Cabinet Committee from 1986. The Group acknowledges that, given current UK infection rates, co-ordination at Cabinet level is unlikely to be appropriate. The All-Party Parliamentary Group on AIDS believes that previous good practice should not be forgotten and there should be ongoing cross-departmental liaison on HIV/AIDS at a lower level.
6. **The Group recommends that, on domestic HIV issues, the Department of Health should co-ordinate regular cross-departmental liaison including the Departments for Education and Skills, Work and Pensions, Health, Home Office, Trade and Industry and Offices for Scotland, Wales and Northern Ireland.**
7. The Handbook for Legislators on HIV/AIDS, Law and Human Rights says that "multisectoral advisory bodies with professional and community representation, both general and specialist, on legal and ethical issues can address the issues of review and reform." The Guidelines call for a strategic process to be participatory, transparent and accountable. Instead of the National AIDS Councils seen in some other countries, the UK has an Expert Advisory Group on AIDS providing medically-focussed advice to Chief Medical Officers.
8. **The Group recommends that the Expert Advisory Group on AIDS should be expanded to become a cross-departmental advisory body assuming a wider role in addressing the social and human rights aspects of HIV/AIDS and operating with greater openness and a wider range of expertise.**
9. Witnesses expressed much clearer support for the strategic approach that the Department for International Development has given to HIV generally, and to the human rights aspects of that work in particular.⁴ However, we note that the International Development Committee Report into HIV/AIDS felt that the subject was not yet being integrated into all development programmes of DFID.⁵ Derek Bodell was asked about the cross-departmental approach to HIV as an international issue. He said: "There does not appear to be an awful lot of communication between the different government departments".
10. The BMA Foundation for AIDS said that "Links are also important between the government's national and international policies on HIV, and between departments dealing with different aspects of UK overseas involvement - DFID, the FCO, Defence - to ensure congruent objectives and actions." It was also noted that the HIV in the UK is shaped by the international epidemic as more and more people infected abroad are being diagnosed here.

⁴ DFID issued its HIV/AIDS Strategy in May 2001.

⁵ International Development Select Committee, "Third Report: HIV/AIDS: the impact on social and economic development", 2001.

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- 11. The Group recommends that, in international HIV issues, the Department for International Development should co-ordinate ongoing cross-departmental liaison between government departments, including Trade and Industry, Treasury, Defence, Foreign and Commonwealth Office.**
12. Furthermore, it should be considered where there are appropriate links between HIV as a domestic issue and an international responsibility.

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GUIDELINE 2:

STATES SHOULD ENSURE, THROUGH POLITICAL AND FINANCIAL SUPPORT, THAT COMMUNITY CONSULTATION OCCURS IN ALL PHASES OF HIV/AIDS POLICY DESIGN, PROGRAMME IMPLEMENTATION AND EVALUATION AND THAT COMMUNITY ORGANISATIONS ARE ENABLED TO CARRY OUT THEIR ACTIVITIES, INCLUDING IN THE FIELD OF ETHICS, LAW AND HUMAN RIGHTS, EFFECTIVELY.

13. It is a vital principle that people with HIV are involved at all stages of programme implementation and evaluation and that support for organisations of positive people is necessary to develop their capacity to contribute. Fiona Pettitt, of International Community of Women Living with HIV/AIDS, pointed out that the wording of Guideline 2 implies that positive people should only be "consulted": "I would like to urge that positive people be involved at all levels, from consultation up to developments of policy and also development of programmes." Bernard Forbes of the UK Coalition said of positive groups: "half the time we are extremely bad at separating what we would like, from what we actually need because we are not involved in the process of discovering how to deliver the most for the least money out of the taxpayers' pocket."
14. We believe that, while the UK has made some efforts to involve and consult people with HIV on health policy and support organisations of positive people, much more could be done.
- 15. The Group recommends that departments in addition to Health should consult people with HIV about the impact of policies relevant to HIV/AIDS.**
16. We believe that the voices of communities vulnerable to HIV should also be heard in decision-making. Although the African HIV Policy Network is formally been involved in consultation on health policy, it pointed out that African organisations rarely receive funding and not comparable amounts to mainstream organisations. Cephas Mosinghi, Vice-Chair of the Network of Self-Help HIV/AIDS Groups said that "Ethnic minority communities are not a homogenous grouping, but rather comprise of many communities... Yet such communities find few effective and available advocates". The UK Gay Men's Health Network pointed out "a distinct lack of a systematic approach to consulting the gay community when developing policies... The participation of individual gay men in advisory groups is not adequate consultation. Effective strategies and/or legislation should demonstrate the involvement of gay men as an affected community [their emphasis]". The voices of drug users are conspicuously absent in a discussion of health policy, let alone drugs policy. Hilary Kinnell pointed out that congregation laws prevent sex workers from even meeting together and have meant that there is no representative national body.

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- 17. The Group recommends that, where advisory bodies are established, they should have representation from all the main affected communities and should also seek to develop the capacity of affected communities to contribute at this level.**
18. The Group believes that consultation should also happen at local level and involve people with HIV and affected communities.
- 19. The Group recommends that representatives of people with HIV and vulnerable groups should contribute to and jointly agree local AIDS (Control) Act Reports.**
20. In many other countries, the involvement of people with HIV in programme planning and delivery has been even less successful than in the UK. Julian Hows, on behalf of the Global Network of People Living with HIV, said that "Sometimes very little serious thought is given into how this might actually translate or does translate into action on the ground."
21. Sue Lucas of the International HIV/AIDS Alliance discussed the need to involve communities, especially vulnerable groups. She said: "I think it has been shown adequately with work in the past that programmes which ensure participation are both more effective and more sustainable." Furthermore "participation itself can lead to enhancement of their rights by increasing people's ability, by their knowledge and understanding of how they can promote and protect their own rights." The Group welcomes the inclusion of human rights in DFID's HIV/AIDS Strategy.
- 22. The Group recommends that DFID should go further in supporting the voices of people with HIV and vulnerable communities, especially women, children and minority groups with high risk of infection, not only in "consultation" but at all stages of programme planning, delivery and evaluation and to develop the capacity of people with HIV and vulnerable communities to make decisions about work that affects their lives.**

GUIDELINE 3:

STATES SHOULD REVIEW AND REFORM PUBLIC HEALTH LAWS TO ENSURE THAT THEY ADEQUATELY ADDRESS PUBLIC HEALTH ISSUES RAISED BY HIV/AIDS, THAT THEIR PROVISIONS APPLICABLE TO CASUALLY TRANSMITTED DISEASES ARE NOT INAPPROPRIATELY APPLIED TO HIV/AIDS AND THAT THEY ARE CONSISTENT WITH INTERNATIONAL HUMAN RIGHTS OBLIGATIONS.

23. In the UK, despite regular calls in the early years of the epidemic, punitive responses to HIV/AIDS or public health laws which compromise human rights have not been a significant part of the UK's response to HIV/AIDS. For example, HIV/AIDS was not made a notifiable disease and measures such as confinement or prosecution have occurred very rarely and with widespread debate.

24. The Group believes that it is important to celebrate the fact that public health measures which compromise human rights have generally been avoided. Whilst avoiding complacency, we should be proud of the character of the UK's response and commit to continue in this spirit.

25. As during our 1998 Inquiry, concerns were expressed about the current impact of the only public health legislation introduced specifically for HIV, the AIDS (Control) Act 1987.⁶ Neil Wooding of the Welsh Reference Group for HIV/AIDS raised a number of problems with the way that the report now operates and called for it to be updated. He argued that there is no requirement for health authorities to match their spending on vulnerable groups to the epidemiology and no monitoring of reports: "My perception was that it fell into a vacuum... so it was an accountable statement, but I often wondered who it was accountable to?" Derek Bodell pointed out that the National AIDS Trust report *Are Health Authorities Failing Gay Men?*⁷ showed that "despite the epidemiology showing that gay men were the highest [HIV] population in all districts around the country, very little money was actually being spent on gay men."

26. The Group recommends that the AIDS (Control) Act, or its implementation, should be updated with wider reporting requirements and greater consultation with local organisations and representatives of affected groups.

27. The Reports should require health authorities to explicitly compare spending with local epidemiology and account for discrepancies. Reports should use HIV data rather than AIDS diagnoses. Reports for England should be compiled into an annual report by the Department of Health and placed in the Libraries of both Houses. The Group recommends that there should be an explicit requirement that the local social context is discussed, that the work of agencies other than Health are included. The Group recommends that health authorities should receive feedback on their reports, helping them to identify areas where change is needed.

⁶ The Act originated in a private member's bill from Dr Gavin Strang MP and places a requirement on all health authorities to account for their spending and activity on HIV/AIDS and give local data. Dr Strang, who took part in this Inquiry, initiated an adjournment debate on 5 July 1999 setting out the reasons why he believes the Act needs to be updated.

⁷ 1999, National AIDS Trust.

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28. Looking internationally, Martin Foreman, Chair of the UK NGO AIDS Consortium, pointed out that although “almost all [public health] law enacted in this field does have the admirable good of wanting to restrict the spread of HIV. The problem is that some laws trespass on human rights and may inadvertently create situations where the transmission of the virus is more rather than less likely.” He discussed a range of public health measures enforced around the world which are restrictive of people’s rights including mandatory testing for vulnerable groups, compulsion to disclose HIV status to sexual partners and criminalisation of transmission.
29. It should not be assumed that the developing world is the only location of punitive laws. The United States, notoriously, has always barred entry to people with HIV and this issue became high profile again when the United Nations General Assembly Special Session on AIDS was held in New York.
- 30. The Group recommends that the UK Government should be explicit in its contacts with foreign governments that restrictive public health legislation is inappropriate and is more likely to contribute to the spread of the epidemic rather than reduce it.**

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GUIDELINE 4:

STATES SHOULD REVIEW AND REFORM CRIMINAL LAWS AND CORRECTIONAL SYSTEMS TO ENSURE THAT THEY ARE CONSISTENT WITH INTERNATIONAL HUMAN RIGHTS OBLIGATIONS AND ARE NOT MISUSED IN THE CONTEXT OF HIV/AIDS OR TARGETED AGAINST VULNERABLE GROUPS.

⁸ Setting the Boundaries: Reforming the Law on Sexual Offences, 2000, Home Office.

31. The influences of criminal law on the transmission of HIV are many and varied. John Godwin, Head of Policy at the National AIDS Trust, argued that criminal law must complement public health objectives rather than work against them. At present, sexual offences legislation in England and Wales treats homosexual and heterosexual behaviour differently. John Godwin and Martin Kirk of the UK Gay Men's Health Network argued that the criminal law affects the desire of gay men to protect their health. The Home Office Review Setting the Boundaries⁸ issued recommendations to Ministers that the criminal law "should not treat people differently on the basis of their sexual orientation... Consensual sexual activity between adults in private that causes no harm to themselves and others should not be criminal" and that therefore "the offences of gross indecency and buggery should be repealed" with new proposals to protect vulnerable people without a distinction for sexual orientation.

32. The Group recommends that the Home Office take forward the recommendations made in Setting the Boundaries and ensure that criminal law does not discriminate between homosexual and heterosexual acts.

33. In laws relating to use of illegal drugs, there is a perception that concern about criminal activity now outweighs concern for public health. Erin O'Mara of the National Drug User's Network said: "Current national policy on drug use pays little regard to the threat of HIV transmission and fails to address the transmission, treatment and care needs that have arisen from the recent hepatitis C epidemic". The Group considers that the needle exchange programmes in the United Kingdom are one of our only clear success stories and have contributed to the low rate of new HIV cases among injecting drug users, particularly in comparison with countries in Southern Europe.

34. The Group recommends that "harm reduction" approaches to injecting drug use should be maintained and extended where appropriate.

35. The Group recommends that laws relating to injecting "paraphernalia" should be amended so that additional items which reduce the risk of infection (particularly of Hepatitis C) can be provided and carried.

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36. Temporary repeal of the above laws has already been enacted in Scotland. We further call on the forthcoming Hepatitis C Strategy to consider ways in which "harm reduction" approaches can reduce transmission of blood-borne viruses, especially as the Sexual Health and HIV Strategy is unlikely to consider transmission through drug use.
37. Hilary Kinnell pointed out that prostitution is not illegal per se but many associated activities are and this criminalising of the circumstances of prostitution is unhelpful to public health principles. In particular, she pointed out that British law is in complete contradiction to the Handbook for Legislators which "recommends, very clearly, that current legislation seeks to decriminalise sex work". In particular, laws relating to soliciting, brothels and "living off immoral earnings" were identified as forcing women selling sex into more dangerous situations and, through economic necessity, making them less likely to use condoms. Helen J. Self submitted a written memorandum in which she pointed out that Recommendation 53 in Setting the Boundaries calls for a full review of law relating to prostitution.
- 38. The Group recommends that laws relating to prostitution should be subject to comprehensive review and that the health impact of current legislation is considered and opportunities sought to reduce the harm which prostitution exposes people to, for instance to encourage safer ways of working as well as seeking to reduce pressures to sell sex.**
39. The Guidelines make clear that prisons are important sites of transmission of HIV but witnesses said this field has been neglected in recent years in the UK and there is no coherent strategy. The Prison Reform Trust pointed out in a written submission that Article 2 of the Human Rights Act puts a "positive obligation on public authorities to protect an individual's right to life" which they feel is not always being met. The National AIDS and Prisons Forum pointed out that the shift away from harm reduction approaches to drugs seen outside prison is also having an effect in prisons and thus putting prisoners at risk. They indicated that cleansing tablets, available in Scottish prisons since 1993, are likely to be expanded to England and Wales following a successful pilot. However, they warn that this must be done in a systematic way and does not replace the need for needle exchange. They added that "in countries where needle exchange is available, we note that they are not an inherent risk to the security of the establishment... and that safer use and even reduction of drug use appears to have been an outcome."
- 40. The Group recommends that the evaluation of pilot provision of cleansing tablets in prisons should be published and, if evaluated as successful, expanded throughout England and Wales.**

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- 41. The Group recommends that, in principle, needle exchange schemes should operate inside prisons on the same basis as outside, in parallel to other health promotion measures and work which aims to reduce the incidence of drug use and treat drug addiction, and therefore should be piloted.**
42. The National AIDS and Prisons Forum argued that the method of providing condoms in prisons, adopted in 1995, is inadequate as the “continued lack of a formal instruction leaves the interpretation open and at the same time, reinforces the erroneous notion that HIV prevention is purely a healthcare issue.” Stephanie Sexton, giving evidence, explained how the good intentions of a prison medical officer can be undermined when condoms are later confiscated by other staff.
- 43. The Group recommends that a Prison Service Instruction should be issued to ensure that all prison staff know that they have a duty to provide condoms in an effective and confidential way and not merely through medical officers.**
44. The needs of prisoners with HIV infection do not appear to be co-ordinated, despite the stated principle that standards of healthcare should be the same inside and outside. Leigh Neal of Positively Women told us a little about her experience of being diagnosed with HIV whilst in prison and the lack of support and information she received and the way that the prison put pressure on her to keep her diagnosis secret. Confidentiality is often not respected, even though the principle was believed established a long time ago. Stephanie Sexton said that the new “CARAT” teams are not trained in HIV and in several cases an assessor has broken confidentiality by reporting HIV to the Governor as a “threat to security”. Submissions also highlighted the disproportionate number of people in prison or detention who are asylum seekers from countries with much higher rates of infections.
- 45. The Group recommends that the Home Office in conjunction with the Department of Health develop clear guidelines and implementation mechanisms across the prison service, to ensure that, as far as is possible, the treatment of people with HIV in the prison system reflects practice outside and works towards equivalence.**
46. Confidentiality should be maintained unless there are genuine reasons for disclosure and systems should be flexible enough to adapt to the needs of prisoners with HIV.

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⁹ Written submission from Dr Sylvia Casales, CPT President.

47. The Committee for the Prevention of Torture submitted evidence noting that there is great variation in practice and policy relating to people in custody in its 41 member countries. "The increasing migrations of people across Europe, many passing, as they go, through custodial settings... makes this an urgent public health issue for the whole of Europe." ⁹ The Group recommends that there should be a pan-European strategy to address the spread of communicable diseases in custody.
48. There were various submissions about the laws relating to the intentional and unintentional transmission of HIV. The George House Trust said "The use of the criminal law neither protects from infection, nor empowers the infected. Pushing HIV underground undermines health promotion campaigns, marginalises those living with HIV, and will ultimately lead to more infections than the existence of such a law may prevent." The BMA Foundation for AIDS raised concerns about proposals for involuntary manslaughter where they expressed concerns that health care workers involved in accidental transmission could be criminalised. The Group does not consider that there is any reason to criminalise HIV transmission and that, as with the conviction of Stephen Kelly in Scotland, existing laws can already be used in the rare event that they might be considered necessary.
- 49. The Group recommends that any change to the law on transmission of disease should not refer to HIV in isolation and the public health impact of any law should be considered carefully.**
50. Martin Foreman of the UK NGO AIDS Consortium discussed the criminalisation of HIV transmission and other laws which have been used against people with HIV. In Cuba, for many years, all people with HIV were confined to sanatoria. Julian Hows pointed out that one Indian state forbids marriage for people with HIV. Martin Foreman said that a similar law is about to come into force in the Chinese city of Changwu. In Florida, to have sex without informing a partner of HIV status is a third degree felony which could lead to charges for attempted murder. In July 2001, it was reported that Kenyan President Daniel arap Moi has 'demanded' that people who 'knowingly transmit' HIV to others receive the death penalty.¹⁰
- 51. The Group recommends that the British Government, through any and all appropriate routes, raise human rights abuses with international bodies and the governments concerned, especially drawing attention to situations where inappropriate criminalisation is likely to encourage HIV transmission.**

¹⁰ Reported through IPPF International News Highlights, 3 July 2001.

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GUIDELINE 5:

STATES SHOULD ENACT OR STRENGTHEN ANTI-DISCRIMINATION AND OTHER PROTECTIVE LAWS THAT PROTECT VULNERABLE GROUPS, PEOPLE LIVING WITH HIV/AIDS AND PEOPLE WITH DISABILITIES FROM DISCRIMINATION IN BOTH THE PUBLIC AND PRIVATE SECTORS, ENSURE PRIVACY AND CONFIDENTIALITY AND ETHICS IN RESEARCH INVOLVING HUMAN SUBJECTS, EMPHASIZE EDUCATION AND CONCILIATION, AND PROVIDE FOR SPEEDY AND EFFECTIVE ADMINISTRATIVE AND CIVIL REMEDIES.

52. The UK's Disability Discrimination Act (1995) was cited as a very positive step for including, as it does, people with HIV under the definition of disability. However, as Andrew Little pointed out in evidence: "any such legislation should operate from the assumption that HIV infection in most circumstances is not a disability - it only becomes such because of discrimination by others... But the Disability Discrimination Act has no mechanism for doing this - it is based on a medical rather than a social model of disability." It was argued in several submissions to the Inquiry that the DDA needs to be extended to cover HIV from the point of diagnosis, including from the Disability Rights Commission, Terrence Higgins Trust Lighthouse, National AIDS Trust and the UK Coalition of People with HIV/AIDS.

¹¹ Government response to Towards Inclusion, Disability Rights Task Force.

53. Subsequent to the Inquiry, the Government has announced its intention to carry out such an extension.¹¹ Furthermore, Paul Ward pointed out that the DDA does not cover the police or the armed forces but that the Government has also signalled its intention to extend this. John Godwin also argued that that it should be extended to "carers and associates of people living with HIV."

54. The Group recommends that in considering review of the Disability Discrimination Act, the Disability Rights Commission should investigate how anti-HIV discrimination affects people who are presumed to be infected or discriminated against because of their association with HIV.

55. The Guidelines also call for protection from discrimination for vulnerable groups. In the UK, gay men, drug users and sex workers are not currently protected from discrimination by any legislation.

56. The Group recommends that a cross-departmental HIV/AIDS Strategy should consider where further anti-discrimination legislation would help address the social exclusion of vulnerable groups and the subsequent contribution to HIV transmission.

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57. Martin Foreman discussed the way that development aid support for vulnerable and marginalised communities does not usually have an explicit human rights element to it but “they are providing opportunities for these groups to educate themselves and educate their communities. Through this process there is greater recognition, both within the group and outside it, that these people are worthy of attention and worthy of support.” He said that the UK Government’s approach was “quite good implicitly... less explicit than the Dutch or Norwegians, when the Governments and a number of NGOs do make human rights and integral and upfront part of their policies.”

58. The Group recommends that human rights elements of aid programmes to address HIV/AIDS are vital and cannot be seen as an optional extra or something which it is hoped will implicitly occur. Instead the promotion of the human rights of vulnerable groups and people with HIV should be an explicit aim of HIV/AIDS programmes.

GUIDELINE 6:

STATES SHOULD ENACT LEGISLATION TO PROVIDE FOR THE REGULATION OF HIV-RELATED GOODS, SERVICES AND INFORMATION, SO AS TO ENSURE WIDESPREAD AVAILABILITY OF QUALITATIVE PREVENTION MEASURES AND SERVICES, ADEQUATE HIV PREVENTION AND CARE INFORMATION AND SAFE AND EFFECTIVE MEDICATION AT AN AFFORDABLE PRICE.

59. The African HIV Policy Network argued that “For a variety of reasons, HIV primary prevention for African communities living in England is grossly under-funded, yet the epidemic amongst this group is increasing dramatically.” They point out that much HIV prevention funding is diverted by health authorities to other areas of spend. Similarly, the National AIDS Trust report *Are Health Authorities Failing Gay Men?* showed that the amounts of money being spent on prevention work with gay men are disproportionate to the epidemiology and that money is diverted to a wide range of other areas of work, despite national instructions to target the groups most at risk of transmission.

60. The Group recommends that spending priorities should be clearly directed by epidemiological evidence of transmission and not by historical tradition, prejudice or scarcity of funding.

61. Ken Bluestone of VSO and Jon Pender of GlaxoSmithKline debated the issue of access to patented medicines under the World Trade Organisation’s Trade-Related Intellectual Property Rights Agreement (TRIPS). Although medical care has generally not been within the remit of this Inquiry, the panel wished to look briefly at the human rights aspects of the particular dispute between the South African Government and the pharmaceutical industry.

62. While noting that the issue of access to patented medicines is currently under discussion in various fora, as part of its Human Rights Inquiry, the Group recommends that DFID’s Commission on TRIPS seeks to balance the needs of the Northern-based pharmaceutical industry with the needs of developing countries experiencing devastating national emergencies. In particular, the Group believes that the British Government must make greater efforts to avoid appearing to side with its pharmaceutical industry in disputes.

63. The Group recommends that the pharmaceutical industry should make much faster and more meaningful progress towards differential pricing for medicines used to treat HIV and opportunistic infections than is currently being achieved.

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64. The Group also recognises that international efforts to address HIV/ AIDS in Africa require a partnership between governments of the North and South, multi-national businesses, people with HIV and affected communities, charitable NGOs and multinational bodies. In particular, we believe that the failure to ensure that adequate supplies of condoms are available is a shocking omission.

65. The Group recommends that all future discussions about preventative tools, medicines and treatments need to be based on principles of equality of access and respect for the human rights of all people.

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GUIDELINE 7:

STATES SHOULD IMPLEMENT AND SUPPORT LEGAL SUPPORT SERVICES THAT WILL EDUCATE PEOPLE AFFECTED BY HIV/AIDS ABOUT THEIR RIGHTS, PROVIDE FREE LEGAL SERVICES TO ENFORCE THOSE RIGHTS, DEVELOP EXPERTISE ON HIV-RELATED LEGAL ISSUES AND UTILIZE MEANS OF PROTECTION IN ADDITION TO THE COURTS, SUCH AS OFFICES OF MINISTRIES OF JUSTICE, OMBUDSPERSONS, HEALTH COMPLAINT UNITS AND HUMAN RIGHTS COMMISSIONS.

66. People need support if they are able to challenge instances where their rights have been violated through individual rulings or wider policies. In many examples, it is case law which establishes a right or interprets how that right should be applied. As Britain has a low-level concentrated HIV epidemic, it is not possible to assume that all legal agencies are well-informed about HIV/AIDS or capable of approaching it in an unbiased way. The high level of stigma that remains attached to HIV will be apparent here too. Therefore HIV specific legal advice is necessary to support both individuals and legal professionals.
67. The UK's HIV-specific legal advice service, Immunity, was incorporated within the Terrence Higgins Trust Lighthouse's legal advice team. Nick Partridge said: "We see a large number of problems related to discrimination, prejudice or individual rights and that ranges from dismissal from employment or unfair treatment within employment, loss of housing, domestic disputes, occasionally still refusal of treatment... We also see many of the problems relating from prejudice or, more broadly, from social exclusion." In their submission, they point out that their legal advice service is only available to people resident in areas where they have a presence. Other HIV charities offer legal advice to people with HIV but there is no systematic national coverage.
- 68. The Group recommends that people with HIV, their families or communities should be able to access specialist legal advice in order to enforce their rights or challenge violations.**
69. This should not necessarily be funded from health budgets and not restricted to areas where health authorities have been willing to fund legal services. Use should be made of information technology to provide a national service.
70. The Group notes that British Government funding has occasionally supported legal advice and human rights projects addressing HIV such as the Mexican Human Rights Centre Miguel Augustin Pro Juarez.¹² This has the capacity to develop the voices of people with HIV, to challenge discrimination and to encourage legal and structural changes which are beneficial to the fight against HIV.

¹² p.83, Foreign and Commonwealth Office Human Rights Annual Report 2000.

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71. The Group recommends that developing and strengthening the capacity for in-country legal advocacy for HIV-related human rights is an appropriate use of development funding and may be an extremely effective and cost-effective intervention.

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GUIDELINE 8:

STATES, IN COLLABORATION WITH AND THROUGH THE COMMUNITY, SHOULD PROMOTE A SUPPORTIVE AND ENABLING ENVIRONMENT FOR WOMEN, CHILDREN AND OTHER VULNERABLE GROUPS BY ADDRESSING UNDERLYING PREJUDICES AND INEQUALITIES THROUGH COMMUNITY DIALOGUE, SPECIALLY DESIGNED SOCIAL AND HEALTH SERVICES AND SUPPORT TO COMMUNITY GROUPS.

72. Sue Lucas of the International HIV/AIDS Alliance said: "Probably the most important element of prevention among vulnerable people is their participation... But parallel with promoting participatory work such as this, it is also essential to develop a supportive legal and political environment." In the UK, Nick Partridge said that "We also see many of the problems relating from prejudice or, more broadly, social exclusion. I think this is quite a helpful term... issues like depression, poor mental health, poverty, isolation, broken families, violence, poor ability to manage treatments, poor general health and, indeed, poor social interactions."
73. The Group believes that it is an appropriate and important task for work addressing HIV to address the cultural context within which vulnerable groups live, in particular prejudice and inequalities. We do not regard this as a diversion from what is classically regarded as health promotion but instead an essential task if the social factors behind HIV transmission are to be addressed. Many of these areas are addressed through broader political campaigning but the rationale for addressing these in order to address HIV should add both impetus and understanding to this work.
74. World Vision submitted a report "Children and HIV/AIDS: A Millennium Time Bomb" in which they argue that children worldwide are especially vulnerable to infection and the impact of HIV/AIDS when their rights are not respected. They pointed out that the principles set out in the UN Convention on the Rights of the Child would "help protect the health and development of children and when they are not respected and promoted, they become vulnerable and have little or no control over HIV/AIDS related risks." Susan Crane of International Family Health pointed out that education is a right but that many young people, especially the 13 million orphans that AIDS has created, are denied this right.
75. Francesca Simms, in written evidence, said that there was a need for UK aid to support traditional family structures in Africa: "Such action is urgently required on a large scale to prevent the destruction of traditional social care systems resulting in millions of destitute children and elderly and disabled people requiring care at a cost quite out of the question for a developing country." She pointed out that the Universal Declaration of Human Rights in 1948 as well as the UN Convention of the Rights of the Child asserted that adequate standards of care are a right and that mothers and children are entitled to special care.

76. The Group recommends that, internationally, increased efforts to respect the UN Convention on the Rights of the Child are key to decreasing the vulnerability of children to HIV infection and its impact.

77. Maria Dickson told the Inquiry about the experiences her daughter had had when her mother's HIV status became known. The isolation experienced by members of a family with HIV/AIDS in Scotland affirmed the fact identified by the National Children's Bureau that HIV "remains a hidden issue, shrouded with mystery, prejudice and taboo." They pointed out that Department of Education guidance to schools in the 1980s has not been updated or promoted recently and that "In the HIV sector the needs of children are not understood and in the Children's Sector the HIV needs of these children are not understood either."

78. The Group recommends that the Department for Education and Skills should review and update its guidelines for children with HIV as a matter of priority and make support available from national and regional educational sources.

79. It is the view of the Group that widespread training for all teachers across the country is not likely to be practical as, for most schools, a child directly affected by HIV will be encountered rarely, however in areas where regular instances of a child directly affected by HIV are more likely, i.e. London and areas with asylum seekers from high-prevalence countries, more proactive training should be carried out. In other areas, systems of support and training should be implemented quickly when needed.

80. Women are clearly particularly vulnerable to HIV due to the social context which denies them rights and control over sexuality in many parts of the world. Programmes aiming to promote condom use can only have success if they are changing the lack of control women usually have over their use. Karen Newman of IPPF said that "If you look at issues around marginalised groups, those groups who traditionally have less access to services, it is almost always women within those groups who have even less and who are even more discriminated against." She said that the British Government need to encourage countries to look more holistically at HIV prevention within sexual and reproductive health rights.

81. Susan Crane pointed out "People will often blame sex workers for their transmission of HIV without recognising that they are clients who also have wives and also have children." Hilary Kinnell pointed out that the more repressive law enforcement against prostitution "the more likely the people who engage in it will be those who have the least choice and the least self-esteem and the least incentive to worry about whether they are using condoms or not."

82. The Group recommends that work to address the HIV epidemic must take account of the social context in which vulnerable groups live their lives – not merely to promote their access to “services”. In particular in developing countries, where high level epidemics are mainly transmitted through heterosexual sex, the realities of women’s lives, their ability to control their reproductive health and their social and economic circumstances must be addressed.

83. Neil Wooding talked about the importance of addressing the environment within which gay men live in order to address continued high HIV rates among this population: “there are higher levels of homophobia in Wales that are often attached to very traditional or very rural communities... This has a consequence for gay men within those communities that is significant and severe in terms of their access to health, and they impact upon health as well.”

¹³ p.27, Vital Statistics: Findings from the National Gay Men’s Sex Survey 1999, Weatherburn et al, Sigma Research.

84. Martin Kirk pointed out that the term “social exclusion” is not used often in relation to gay men, however, “their social exclusion is not only exclusion from society as a whole but they can often be socially excluded from within their family networks and their immediate social support network... This has an effect throughout their life, obviously, so once they progress from social exclusion which they suffer from there, they have to face legislative inequalities and continued social exclusion from society as a whole. It is a well accepted fact, the link between feelings of inclusiveness, feelings of self-esteem and your propensity to behave in a way that will be detrimental to your health.” The National Gay Men’s Sex Survey 1999 showed “a clear association” between low educational qualification and testing positive for HIV among gay men.¹³ Similar surveys have suggested a link between HIV and ethnicity among gay men with those from ethnic minority groups perhaps more likely to have HIV. Promotion of a supportive and enabling environment would be a legitimate area of HIV prevention activity but needs action across a range of government departments.

85. The Group recommends that the environment in which gay men grow up and live is addressed in order to affect the impact it has on self-esteem, assertiveness and, ultimately, health.

86. Sue Lucas discussed the reasons why sex workers, men who have sex with men, injecting drug users, vulnerable children and prisoners are vulnerable groups in developing countries and the importance of addressing the environment within which they live: “The problem is that their rights have already been compromised and they become compromised more because of the risk of HIV that they face.” Beyond altruism, the logic for addressing this is that “in many countries who are nowadays on the frontiers of the epidemic where it is just starting, this epidemic is often concentrated now, in particular communities among people with particular behaviours, if we can stop it there, we can stop a major epidemic growing in countries and that is why it is important.”

87. The Group recommends that the Department for International Development should continue to fund innovative work with vulnerable and stigmatised communities in developing countries in order to reduce emerging epidemics in vulnerable communities before they develop into more generalised ones.

88. The African HIV Policy Network argued powerfully that the HIV epidemic among Africans living in the UK could not be addressed without tackling the context within which many Africans live in the UK, particularly the experience of asylum seekers. In written evidence, they pointed out that "African communities affected by HIV are so overwhelmed with social exclusion issues such as housing, unemployment, poverty, isolation, anxiety about family reunion and deprivation that they are not always able to prioritise HIV and AIDS." As well as the issue of poverty within this community, Winnie Ssanyu Sseruma said that "for a lot of people when they come in, especially newly arrived asylum seekers, their priority is not health. Their priority is to get some place secure where they can live without hearing guns or whatever, unless they get ill and are forced to go to hospital."

89. Winnie Ssanyu Sseruma said that "HIV thrives in situations of powerlessness, poverty and social exclusion. Further marginalising especially asylum seekers and specifically from the African community can have a very real effect on HIV in the United Kingdom". In particular the dispersal and voucher systems for asylum seekers were singled out: "There are people who have disclosed [their HIV status] who are being dispersed to places where there is no social support, where they cannot access services, especially for children." The system where vouchers are provided instead of income support cash for people awaiting decisions was described as "incredibly limiting". Blackliners, in a written submission, pointed out that many banks refuse asylum seekers a bank account and this frustrates any attempts to work and increases social exclusion. The Group believes that the concerns expressed about African people with HIV, for instance their late presentation and generally worse health than other groups, are directly related to the social realities for African people in the UK.

90. The Group recommends that the Home Office should specifically investigate the impact that the asylum system, in particular dispersal and vouchers, is having on asylum-seekers with HIV.

91. Furthermore, a Strategy for HIV which takes into account the social factors should consider the impact that social exclusion and discrimination will have on this community in the future and whether these may result in increasing transmission of HIV within these communities and from them to the wider UK society.

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¹⁴ "When will drug users be given their human rights?", submitted by Andria Efthimiou-Mordaunt, Beryl Poole and Anonymous.

92. A submission from Mainliners discussed the social context in which people inject drugs: "Drug users remain a strongly marginalised, socially excluded group. HIV positive drug users in many ways face a double oppression in that they are often excluded from society in general and are not party to decisions which have a direct impact on their lives." Giving evidence, Basil Williams said: "We have discrimination within the sector itself and we already know about the public attitude towards drug users in the community, and injecting drug users particularly are further discriminated against because of the attitude that they do self-harm and therefore the attitude towards injecting drug users is even worse than, say, towards those who are taking recreational drugs." Andria Efthimiou-Mordaunt of the John Mordaunt Trust submitted evidence in which she pointed out that there is "some research-based evidence to suggest that folk who are vulnerable to drug dependence are psychologically vulnerable, and therefore predisposed to drug dependence in order to cope with life and its hardships."¹⁴
93. The Group reiterates its concern that there has been a shift away from harm reduction approaches to drug use and with it a move away from looking at the social environment and other factors involved in drug users' lives. An HIV, Hepatitis C or blood-borne viruses strategy needs to consider these factors rather than expect to deal with drug use in isolation.
- 94. The Group recommends that reviews of the UK Anti-Drugs Strategy should ensure that the health impact of drug use and blood-borne viruses are accorded specific attention, reinforcing a "harm reduction" approach alongside other action.**
95. HelpAge International argued in a written submission that older people should be clearly identified as a vulnerable population due to the impact that HIV is having on them in some of the worst affected countries. They also pointed out that HIV data collection internationally focusses on 15-49 age groups, thus obscuring the epidemic among the over 50s.
- 96. The Group recommends that the UK government, through its international influence, should support work directed towards alleviating the impact of HIV on older populations and to attempt to understand the levels of infections in the over 50s.**

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GUIDELINE 9:

STATES SHOULD PROMOTE THE WIDE AND ONGOING DISTRIBUTION OF CREATIVE EDUCATION, TRAINING AND MEDIA PROGRAMMES EXPLICITLY DESIGNED TO CHANGE ATTITUDES OF DISCRIMINATION AND STIGMATIZATION ASSOCIATED WITH HIV/AIDS TO UNDERSTANDING AND ACCEPTANCE.

97. There was clear evidence throughout the Inquiry that attitudes to HIV remain highly discriminatory and prejudiced. The stigma attached to HIV, both internationally and in the UK, hampers efforts to fight the disease and greatly increases the problems faced by people infected. In Britain, Maria Dickson told us how her house was graffiti-ed by her neighbours when they learnt the reason for her husband's death. Evidence that these attitudes have not changed was provided by an NAT survey which Nick Partridge told us about: "people were asked whether they would give time or money to cancer charities or leukaemia charities and, thankfully, 74% said yes they would give time or money. The same people were then asked whether they would give time or money to AIDS charities and 86% said no, they would not." It was also pointed out that, as HIV becomes more of a fluctuating chronic condition in industrialised countries, sympathy and public support are likely to erode further.
98. In order to address HIV/AIDS it is obviously necessary to confront, challenge and work to eradicate this stigma. Furthermore, discriminatory attitudes to HIV are deeply connected with attitudes towards sex, drug use, homosexuality, women, ethnic minorities and, increasingly, immigration. It is not possible for attitudes to HIV to be changed without also engaging with these issues. Work to address the stigma attached to HIV must also address the stigma attached to groups and communities vulnerable to it, as discussed earlier.
99. The National Children's Bureau submitted evidence about the need for schools to change discriminatory attitudes both to HIV and to communities vulnerable to HIV in the UK. They pointed out that there is no legal requirement to deal with HIV at primary school level although "For some children HIV will already be part of their world, whether infected themselves or with family and friends infected or having died." They argued that HIV education "must involve not just information about infection and routes of transmission, but also provide an opportunity to develop personal and social skills as well as form positive attitudes and beliefs." Giving evidence, Simon Blake said that "we have to look at it in the broader context of how well we are doing on the whole range of discriminatory attitudes. We are not doing very well on racism, sexism or gender issues in a lot of cases as well... what we do not have is widespread uniformity and a strong government lead for all of this."

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100. NCB also argued that “Homosexuality is often completely invisible within Sex and Relationships Education and young gay men leave schools without the skills or knowledge to protect themselves against infection.” Furthermore, “bullying is damaging to self-esteem and low levels of self-esteem are associated with sexual risk taking.” Nick Partridge mentioned Section 28 as a inhibition against schools addressing HIV openly. The UK Gay Men’s Health Network pointed out that “Recent research findings clearly show that the majority of gay men receive little or no sex education that is relevant to them.” We note the long-standing concerns expressed by the HIV sector about the signal that Section 28 of the Local Government Act 1988 continues to send in England and Wales.
- 101. The Group recommends that HIV education in schools should prioritise addressing stigma and discrimination, both towards HIV itself and vulnerable groups, and that this should be encouraged through Department of Education and Skills guidance, Ofsted inspections and National Healthy Schools Standard assessments.**
102. Throughout the Inquiry, the issue of how to use the media or national campaigns in order to promote the human rights of people with HIV or communities vulnerable to it was discussed. Paul Ward said: “we have an expert reference group of people [with HIV] that works with the organisation, and they say ‘the single biggest thing that THT and the Government could do is reduce the stigma we face in our everyday lives.’” Bernard Forbes of the UK Coalition said: “It is the stigma and the ostracisation, the further separating people with HIV from the whole of society that is probably causing more problems than anything else.”
103. Winne Ssanyu-Sseruma said: “It would be good to have a national HIV awareness programme because it is long overdue. I, as a positive woman, go to schools and places where people think HIV has disappeared, HIV has been cured, people who have never interacted with a positive person knowingly.” Ruth Webb, Chairman of the UK Coalition of People Living with HIV/AIDS, agreed with a campaign if it were properly evaluated: “We need the national media campaign but that is going to be a fairly general campaign, providing information, perhaps having images of people who are prepared to be open, showing that they are like you and me, perfectly ordinary, living every day.”
104. However, concerns were expressed about the impact of such a campaign, particularly on vulnerable groups. Dorothy Mukasa of the African HIV Policy Network said: “For a lot of people, it will be yet another stick with which to beat these immigrants...What is more important is to raise awareness amongst the 220,000 strong African communities in the United Kingdom so that the awareness is raised amongst the group affected so they do more for themselves to try and avoid infection or seek treatment.” Martin Kirk of the UK Gay Men’s Health Network said: “I think you are going to have to be very careful about what awareness you are raising and among which groups.”

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105. Campaigns to change discriminatory attitudes against vulnerable communities were felt important. Basil Williams said: "In many cases there are good social reasons why someone might have become a drug user or a commercial sex worker. Those images are never shown within the media and the only image that you get is of burglary, robbery, criminality and crime and therefore that does not help public attitude in terms of meaningful support to drug users." Martin Kirk discussed the Terence Higgins Trust Lighthouse campaign It's Prejudice that's Queer - "an HIV campaign but it is a campaign targeted at prejudice against, in this case, gay men". Simon Blake summed up this dual approach: "Yes, we have to mainstream but we also have to work out how to target, how to address exclusion, how to make sure that we are raising awareness around discriminatory approaches."
- 106. The Group recommends that any media campaigns targeting the general public in the UK should have, as their first objective, challenging the stigma and discrimination associated with HIV and those groups who are most vulnerable to it.**
107. This should be co-ordinated with the Disability Rights Commission's remit for public education. Whilst messages about HIV transmission are relevant to the general population, these need to be integrated into wider sexual health promotion rather than addressed in isolation.
108. In countries where higher level HIV epidemics are being seen, the extreme stigma associated with the virus remains. Perhaps the most extreme and well-known example was the stoning to death of South African activist Gugu Dlamini by her neighbours after she talked publicly about having HIV. Only a small number of people are open about living with the virus. Julian Hous talks of the "brave and courageous individuals" who form the Network of African People Living with HIV and AIDS.
109. The "shame" associated with HIV and the lengths to which people go to disguise a cause of death have been well-documented. Susan Crane pointed out that, even when a child in a family affected by AIDS does not have to withdraw from school for economic reasons, "There have been a number of quite disappointing cases of young people who have been rejected from schools because of their HIV positive status." She discussed the way that HIV work in developing countries must address stigma: "People will often blame sex workers for the transmission of HIV without recognising that there are clients who also have wives and also have children. People mistakenly believe that they can identify particular groups of people and say they are to blame, like injecting drug users or sex workers or whatever groups without recognising that you cannot say, "This is the only group of society which is vulnerable". Everybody has access to these groups and if you think about how these different groups interact you recognise quite quickly that in fact everybody is vulnerable and it is as true in Africa as it is in Eastern Europe and other parts of the world where the epidemic is spreading rapidly."

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110. Susan Crane also discussed the anti-stigma work that must be part of HIV interventions in the former Soviet Union: “the project that we are working on is the first project that DFID has ever funded anywhere in the world with injecting drug users, but that is quite a step in itself, to be able to explain to people about the fact that HIV is going to affect everyone and being able to help them to educate the young people, educate society about the impact of HIV and not to stigmatise those who they think are the vectors of the disease.”
111. Martin Foreman argued that human rights alone is not the answer in places where social factors drive the epidemic. For instance, in Eastern Europe, he pointed out that economic and cultural factors driving the epidemic are much wider than the lack of respect for the human rights of those who inject drugs. In particular he highlighted the need to change the cultural environment and relationships between men and women.
- 112. The Group recommends that action to reduce discrimination and stigma in developing countries through education and campaigns, particularly with the involvement of national leaders and politicians is essential and should be a very high priority.**

GUIDELINE 10:

STATES SHOULD ENSURE THAT GOVERNMENT AND THE PRIVATE SECTOR DEVELOP CODES OF CONDUCT REGARDING HIV/AIDS ISSUES THAT TRANSLATE HUMAN RIGHTS PRINCIPLES INTO CODES OF PROFESSIONAL RESPONSIBILITY AND PRACTICE, WITH ACCOMPANYING MECHANISMS TO IMPLEMENT AND ENFORCE THESE CODES.

113. A particular area of concern about the private sector raised during the Inquiry was the employment issues faced by people with HIV. Andrew Little said that discrimination law should be “educative not punitive” and this is clearly one area where codes of practice could prevent problems from arising. A further reason is to avoid unnecessary reliance on welfare amongst people with HIV: “People are being forced into a category of ‘disabled person on benefit’ when there is no reason for them to be.” The written submission from the UK Coalition said that “It is the experience of the UK Coalition and Positive Futures that the real or anticipated reaction of employers to HIV positive job seekers is the single biggest barrier to people with HIV going back into employment”.
114. Paul Ward of Terrence Higgins Trust Lighthouse said that research they had carried out showed that “positive people are far less likely to disclose their HIV status to their employer than they are to other groups of people” and that “many employers are still quite ignorant about HIV” and “a small proportion who are overtly hostile”. He said that their work suggested that a disproportionate number of people had had problems with private sector employers, rather than public sector ones and that they were quite surprised to encounter problems with large household names rather than small companies. However, Maria Dickson related the discrimination her daughter had faced working for a small company.
115. The Coalition argued that “the Government needs to send a clear message to employers and the community at large that it is unnecessary and potentially discriminatory specifically to ask about HIV status at job interviews or on application forms, and should explicitly exclude HIV from the category of “contagious diseases” which employers are entitled to ask about, except with a few exceptions.” Paul Ward said that consideration of employment of people with HIV must look at “the needs of people who want to stay well on treatment, having to take treatment in the work place and having to take relatively large numbers of tablets; secondly, having to manage the side effects of combination treatment when they are in an office environment; thirdly, the need to be able to take trips to hospital for out-patient treatment”.
116. Andrew Little pointed out that employers would think about HIV policies only after an incident had occurred and that “good practice is having a good policy in place before you need it”.

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117. The Group recommends that joint codes of practice relating to employment of people with HIV should be developed by the Department for Work and Pensions in partnership with the private sector, positive organisations, NGOs and the Disability Rights Commission.

¹⁵ International Labour Office, Geneva, 2001.

118. This work should look at how prejudice and myths are driving people with HIV out of the workforce unnecessarily. We welcome the International Labour Organisation Code of Practice on HIV/AIDS and the World of Work and recommend its use as a guide to HIV and employment.¹⁵

119. It has also been pointed out that the lack of flexibility of the benefits system may be a barrier to people with a fluctuating or chronic condition attempting to contribute to society through working. Many people with HIV no longer leave work automatically after being diagnosed and many people who did so are able, thanks to the treatments, to consider returning to work in some form.

120. The Group recommends that the Department for Work and Pensions should look into the means of enabling people with HIV to go back into or remain in the workplace, considering HIV alongside other fluctuating and/or chronic conditions, whilst acknowledging the especial nature of the stigma and discrimination directed towards HIV.

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GUIDELINE 11:

STATES SHOULD ENSURE MONITORING AND ENFORCEMENT MECHANISMS TO GUARANTEE THE PROTECTION OF HIV-RELATED HUMAN RIGHTS, INCLUDING THOSE OF PEOPLE LIVING WITH HIV/AIDS, THEIR FAMILIES AND COMMUNITIES.

121. Within the UK, there has been little systematic monitoring of HIV-related human rights. HIV service organisations, pressure groups, organisations of positive people and others have highlighted particular instances of discrimination or societal vulnerabilities, and campaigned when necessary. This has sometimes had significant influence over government policy, for instance the extension of the Disability Discrimination Bill in 1995, partly aided by the close links between the All-Party Parliamentary Group on AIDS and NGOs. However, there is a clear lack of any systematic method of collection or report. This Inquiry has not gone into the Human Rights Act 2000 in any detail but the European Convention on Human Rights has many aspects relevant to HIV/AIDS, e.g., privacy, freedom from cruel or degrading treatment, right to non-discrimination in enjoyment of rights, etc.

122. The Group recommends that the Joint Select Committee on Human Rights ensure that HIV issues are incorporated into audits of compliance with the Human Rights Act.

123. The main reporting system for action to address HIV/AIDS is the AIDS (Control) Act Reports compiled by Health Authorities, discussed earlier. These reports have concentrated on spending of health budgets and reports of health sector activity with no remit to look any wider. There were also concern that these reports, once received by the Department of Health are not compiled, monitored or acted upon. The All-Party Parliamentary Group on AIDS would like to see the AIDS Control Act reports further strengthened by a requirement to report on activity wider than the health sector to consider what social factors are relevant to the local HIV situation, what discrimination exists against people with HIV and what action is being taken by other sectors to address these problems. This could encourage staff with HIV/AIDS responsibilities to think outside of the health paradigm.

124. Similarly, an expanded Expert Advisory Group on HIV/AIDS, as recommended earlier, should develop its role in monitoring the human rights of people with HIV and strengthen its role in advising the government on the need to address structural vulnerabilities in ways other than health promotion campaigns.

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125. In the following section we discuss how Britain should report to international bodies. We commend the Foreign and Commonwealth Office for the inclusion of HIV/AIDS as a distinct section in its 2000 Human Rights Annual Report. However, we note that this section does not look at human rights problems or actions to address them, as is seen in other parts of the report. Instead, they report on FCO funding to agencies, most of which, with one exception, appear to be purely health education projects.

126. The Group recommends that the Foreign and Commonwealth Office Human Rights Annual Report should identify HIV-related human rights abuses and report action that the British Government has taken or intends to take to help address it.

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GUIDELINE 12:

STATES SHOULD COOPERATE THROUGH ALL RELEVANT PROGRAMMES AND AGENCIES OF THE UNITED NATIONS SYSTEM, INCLUDING UNAIDS, TO SHARE KNOWLEDGE AND EXPERIENCE CONCERNING HIV-RELATED HUMAN RIGHTS ISSUES AND SHOULD ENSURE EFFECTIVE MECHANISMS TO PROTECT HUMAN RIGHTS IN THE CONTEXT OF HIV/AIDS AT INTERNATIONAL LEVEL.

127. International bodies have developed mechanisms to monitor the human rights aspects of HIV/AIDS. The UN Commission on Human Rights requests a report every two years from the UN Secretary-General on progress towards implementing the International Guidelines on HIV/AIDS and Human Rights. Information is solicited by requests to all national governments as well as NGOs. It was noted that the United Kingdom Government did not respond to the 1998 request. In answer to a Parliamentary Question in November 2000, the Foreign Office reported that they planned to respond to the 2000 request "in the near future" but again no report was sent for inclusion in the Secretary-General's report to the 57th Session of the United Nations Commission on Human Rights in 2001. The All-Party Parliamentary Group on AIDS believes that the UK Government should prioritise co-operation with international bodies on HIV/AIDS and human rights much higher than it has done so far. The next request from the Secretary-General will be received in 2002 for a report to the 59th Session of the UN Human Rights Commission in 2003.

128. The Group recommends that the UK Government should now begin to prepare a substantial response to the UN Secretary-General's 2002 request on the UK's actions to implement and promote the Guidelines.

129. This is important not only for its own sake but to encourage those countries which do not prioritise human rights to begin to follow. The All-Party Parliamentary Group on AIDS offers this Report and its co-operation to help develop a meaningful submission.

130. Karen Newman of International Planned Parenthood Federation argued that NGOs are well-placed to promote awareness of human rights among vulnerable communities in developing countries and that the Department for International Development could make more use of NGOs to address this area. "A lot of DFID literature does focus on different elements within civil society. I think they do talk about that, but they do not necessarily follow through by recognising that often it is the groups outside government, it is the non-governmental groups, that are better at identifying the more effective language."

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131. Susan Crane reiterated a point also made by Martin Foreman – that the human rights elements of DFID’s HIV/AIDS programmes are implicit rather than explicit: “There is a target strategy paper on human rights which looks very much at human rights development in general but does not make it so explicit about how human rights will be promoted within DFID’s health policy. I think there is a lot of implicit work, and what a lot of NGOs do, by working with vulnerable groups and groups that most people think should be thrown on the rubbish heap, is implicitly promote the human rights of these vulnerable groups, but it is not explicit and I think that that could be done much better.”
132. Rights-based approaches may appear meaningless to people in situations where basic living necessities are difficult. Concern for “human rights” may be seen as a luxury. However, Karen Newman pointed out that it is possible to achieve gradual cultural change that respects local cultural values and traditions whilst working towards change. “Sometimes you cannot talk about human rights because people think that means you are going to challenge the government; oh, that is a bit dangerous, but you might be able to talk to elements within the culture which speak to equity”. She argued that development work should also be building an awareness of human rights such as entitlement to services: “People think, ‘Oh, but when we talk about human rights, the right to life, that is capital punishment, is it not?’ Well, yes, it is, but it is also maternal mortality, it is also women dying of causes related to pregnancy and childbirth and those deaths are preventable. People think of liberty and security of the person. That is unlawful imprisonment, is it not? Well, yes, it is, but look at female genital mutilation, look at those issues as well.”
133. Julian Hows described how the UK’s promotion of HIV and Human Rights needs to move beyond the health or aid programmes. In particular, he called for UK missions and political officers to be engaged in this area rather than marginalised as an “aid” or even “health” issue alone: “That is especially true if it is not only the British Embassy (or High Commission) Aid Officer that is kept in the loop, but if we go outside of the DFID thing and we actually keep the political officer in the loop, once again if we are talking about joined up thinking, then it is an important thing to do. The political officers often provide a fresh perspective, a new dimension for such exchanges and visits for both sides of the equation. It actually means that the visit is taken more seriously rather than it being just a bit of foreign aid.”
134. The United National General Assembly Special Session on HIV/AIDS in June 200 issued, in its final Declaration, a call for the realisation of human rights as essential to reduce vulnerability to HIV/AIDS, calling on states to “enact, strengthen or enforce as appropriate legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups”.¹⁶

¹⁶ Section 58 of final declaration.

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135. The Group recommends that the Department for International Development should develop and strengthen its linking of human rights and health, particularly HIV, and make efforts to bring together its work in these areas.

¹⁷ October 1999, Working with the OHCHR – the United Nations Office of the High Commissioner for Human Rights: Institutional Strategy Paper.

136. The Group believes that the UK Government could, through its influence in international bodies and the multinational sector, through its aid programme, through its international links especially the Commonwealth, do more to build awareness of the International Guidelines on HIV/AIDS and Human Rights and to encourage their implementation in all countries, especially those facing real or potential high-level epidemics. There should be more cross-referencing of DFID's Strategy Papers on HIV/AIDS and those on Human Rights, such as Working with the Office of the High Commissioner for Human Rights.¹⁷ We do not believe that the human rights approach to HIV/AIDS should be seen as an "add-on" but should be an essential pre-requisite to all action to address HIV/AIDS. Information-giving, behaviour change, impact mitigation and treatment and care programmes will be undermined unless the human rights implications are carefully considered and the promotion of human rights built into programmes from the beginning.

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