

# Migration and HIV: Improving Lives in Britain

An Inquiry into the Impact of the  
UK Nationality and Immigration System  
on People Living with HIV

July 2003

**All-Party Parliamentary Group on AIDS**



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HIV thrives in situations of powerlessness, poverty, exploitation and social exclusion. The factors that drive migration are the same as those behind the AIDS epidemic: social inequalities, economic imbalances and non-respect of rights—factors that push people to migrate also make migrants vulnerable to HIV.

Dr Mary Haour-Knipe,  
International Organisation for Migration



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## *Preface—Neil Gerrard MP*

### *Chair of the All-Party Parliamentary Group on AIDS*

In the last five years we have seen an increasing number of HIV diagnoses in the UK among people who have been infected before coming here. In 2002, of the 4,300 new diagnoses among heterosexuals it is estimated that 90% had been infected overseas, the majority in Sub-Saharan Africa. These are people who have come to the UK for a variety of reasons; as students, tourists, with work permits, or as asylum seekers.

Recently there has been considerable publicity concerning this issue, with claims that the NHS is being overstretched, and calls for mandatory testing for HIV with the implication, sometimes but not always explicitly stated, that those who test positive should be refused entry to the country or denied access to medical treatment.

It was in response to this situation, and in the knowledge that a Cabinet Office inquiry into 'Imported Infections' had been set up, that we decided to hold our inquiry into 'Migration and HIV.' Our intention was to examine the experiences of those people living with HIV who have come to the UK from other countries, to look at how the Government can improve the lives of migrants with HIV living in the UK and how the NHS and other services should respond to the challenges they currently face on this issue.

We recognised that in the UK successive Governments have had considerable success in responding to the HIV epidemic. However, we had serious concerns about the public health impact of neglecting the needs of migrants. We were conscious of the statement in the UNAIDS Best Practice document *Migrants Right To Health* that "As long as any segment of the population (whether or not they are present legally) is neglected in public health terms, then the global response to AIDS will be limited and there will be concomitant cost and suffering."

I hope that the evidence which we have gathered, and the recommendations we make, will lead to a better informed debate on what is undoubtedly a complex and sensitive area, and to changes in policy which will improve the quality of life for people living with HIV.

I would like to thank, first and foremost, all of those who submitted written evidence to this Inquiry or who appeared in front of the panel, for their help in guiding us through these issues and recommendations. I am particularly pleased that at every level in our hearings migrants to the UK were able to



participate and to describe their experiences, especially individuals living with HIV. I would also like to give my thanks to fellow Parliamentarians who gave their time to sit on the panel of this Inquiry, our Advisory Panel of well qualified and committed individuals, the sponsors who made it possible to produce this report and the Policy Adviser of the APPG AIDS, Edwige Fortier.

A handwritten signature in black ink that reads "Neil Gerrard". The signature is written in a cursive style with a large initial 'N'.

Neil Gerrard MP

## *Executive Summary*

In the last five years the annual number of new HIV diagnoses in Britain has more than doubled. At the end of 2001, it was estimated that there were a total of 41,200 people living with HIV in the UK, of which just over a third were undiagnosed. In 2002, there were approximately 4,300 diagnoses acquired through heterosexual sex; 80% of which were likely to have been acquired in Sub-Saharan Africa. The relatively rapid rise in HIV infections in the UK comes at a time when the Government is under increasing public pressure to reduce the number of asylum seekers and migrants coming into the country, on the grounds that they are overburdening the education, health and social welfare infrastructure.

Further to the domestic media and public pressure regarding migrants and asylum seekers, there has been unprecedented international pressure to increase commitments to the Global AIDS pandemic. At present, 42 million people are infected with HIV, over 30 million of whom are living in Sub-Saharan Africa. The majority of the general population in developing countries affected by HIV and AIDS do not have access to anti-retroviral treatments that are widely available in developed countries. This has been condemned by the international development community as trade negotiations, which would allow developing countries to manufacture life-saving generic drugs, have been stalled since December 2002.

The All-Party Parliamentary Group on AIDS was concerned about the growing stigma that surrounds people with HIV in the UK, in particular against migrants and asylum seekers. The APPG AIDS recognised the increasing pitch of the debate and, with the support of the All-Party Parliamentary Group on Refugees, decided to investigate the reality behind the headlines. How significant an impact are migrants with HIV having on UK health and social care services; what reception and treatment do they receive once they are in country; how has government policy responded to the challenges to this point; and, most importantly, what can be done to improve the situation for everyone infected and affected by HIV in the UK? A series of four hearings took evidence from individuals throughout the UK including HIV specialist clinicians, GPs, solicitors, national AIDS organisations, community-based organisations and migrants currently living with HIV.

From the evidence there was a general consensus that NHS services are overstretched due to prolonged underinvestment. Further, under the process of

NHS modernisation, through which 75% of budgetary and planning control has been passed to local Primary Care Trusts (PCTs), clinicians are facing a situation in which HIV services and prevention are being de-prioritised in favour of other serious health problems. In addition, HIV prevention funding is no longer centrally ring-fenced leaving HIV services in the open and subject to the intense pressures that exist across the NHS. This was recognised as a particular concern for HIV because of the continued widespread stigma that affects HIV as a condition and the groups most affected. Migrants and asylum seekers, and services that address their complex needs, fall foul of both.

The Inquiry also noted the concern of clinicians, many of whom are being increasingly asked to serve multiple roles in the clinical setting: as immigration officers, social welfare officers, support liaisons and care workers. They are being continually faced with the ethical issue of whether to treat an individual with HIV in need or deny treatment if the person is not entitled, by virtue of their immigration status, to NHS care. This is leaving many physicians in a situation of having to act out a role for which they are not trained, have no support and are performing in a less than neutral environment.

The Inquiry examined closely the issue of whether or not to test people for HIV prior to or at the point of entry into the UK. This was done for two reasons. The first is that in January 2003 the Cabinet Office announced that it would be holding an inquiry into "imported infections" and that this inquiry would not be taking evidence from outside government. The second was in response to growing media calls to test migrants and asylum seekers for HIV at the point of entry to restrict access into the country and/or to medical services once here. Given the possibility that the government might feel under significant pressure to adopt a policy of testing upon entry, we felt the necessity to examine in more detail the impact of adopting such a move.

We also looked at immigration policy, in particular removal centres, the policy of dispersal and the current benefits system for asylum seekers in the UK. Testimony was taken from asylum seekers living with HIV and from the community-based organisations that work with and support them. We found that such policies can negatively impact upon the physical and mental health of asylum seekers with HIV and increase the risk to public health of HIV transmission. In most cases, we found there to be a lack of communication

between the Home Office, NASS and Social services, which may be putting asylum seekers in situations where they can become more ill or develop resistance to treatment. In particular, the practice of detaining people known to be living with HIV when they require constant access to HIV specialist care or dispersing them to areas where no specialist care is available, damages individual and public health. One of the most striking aspects to the testimonies was the degree to which the current nationality and immigration system forces individuals to live in abject poverty, thereby undermining clinical efforts to maintain good health.

Finally, one of the most interesting conclusions to come out of the Hearings was the intrinsic link between what is happening at the national level and what is happening at the global level. It was recognised that we can no longer consider what is happening in the UK as being separate from the rest of the world, in particular developing countries. As HIV prevalence increases throughout the world, to the extent that in some countries over one-third of the population has HIV or AIDS, we can no longer presume that physical borders can protect one country's population from what is happening in the rest of the world. Population movements have always existed as people seek refuge from political persecution, to resettle with families or to go in search of work or education opportunities. As HIV prevalence rises globally, it is logical that the number of individuals coming to the UK with HIV will also rise.

It was felt that the UK Government cannot look to exclude individuals on the basis of poor health in the UK, while simultaneously working to provide access to health in developing countries. Instead, we should be looking to address the factors which push people to migrate in developing countries: poverty, access to healthcare, conflict, the impact of environmental adversity and social exclusion. We will be dealing with this challenge in the most effective way when we can ensure that those who do come to the UK with HIV are treated in a timely and effective manner while at the same time working in international partnerships to develop sustainable health systems and access to treatment at the global level.

The main conclusions the Members made include:

- That the UK Government should support policies which encourage HIV testing for the purpose of ensuring more effective access to treatment

and care, and it should not adopt a policy of mandatory testing upon entry.

- The UK Government should not detain, solely for immigration purposes, individuals with serious communicable diseases if it cannot provide for their care inside removal centres.
- The Government should develop and implement national best practice guidance on asylum seekers living with HIV that involves both NASS and Social Services responsibilities, including training for senior personnel in both agencies on how to monitor and maintain good practice; this includes a revision of the dispersal and benefits system.
- The Government should work to finalise the Doha trade negotiations with regard to international treatment access, to channel increased resources to health systems development in developing countries and increase long-term support to initiatives like the Global Health Fund.

## Background

1. In 2001, over 80 million people came through the UK ports. Of these, 12.8 million were subject to immigration controls as non-residents of the UK and the EU. In 2002, there were 85,865 applications from individuals seeking asylum in the UK. The main countries from which asylum applications came were Iraq (14,940), Zimbabwe (7,965) and Afghanistan (7,380). These figures serve to demonstrate the sheer number of people coming in and out of the UK. Some of those coming to the UK for various reasons will require the services of the NHS for major or minor emergencies; however some will require longer-term treatment for a serious communicable disease either acquired abroad or after entry.
2. When a person enters the UK seeking asylum he/she may well have come here at great costs to their own personal safety. They may have been trafficked, they may have endured several journeys in unsafe or unhygienic conditions and they may have been abused or exploited at some point in the journey. If the individual is seeking asylum they may have experienced any number of events which could impact on their mental health in the long-term; these include massacres, torture, sexual assault including rape or multiple rape, witnessing of torture of others, forced eviction from home, disappearances of loved ones, forced conscription, political repression, deprivation of human rights, detention, being held under siege or taken hostage or kidnapped.<sup>1</sup>
3. People coming to the UK from higher HIV prevalence countries may come to the NHS in late-stages of HIV requiring complex treatment for opportunistic infections as well as the on-set of AIDS. Some of those diagnosed with HIV may need a significant initial period of assessment and treatment and some will require follow-up care and treatment either for infections or to begin Anti-retroviral (ARV) therapy. For anyone learning that one has HIV can be a life-shattering event, but for an individual coming from a high prevalence country, this news can seem like a "death sentence". They may not know that treatment is now available to people with HIV. Even worse, they may not be able to access it depending on their current immigration status in the UK.
4. In addition to hearing this news, many migrants or asylum seekers will undoubtedly still be in the process of sorting out their immigration

<sup>1</sup> Burnett, A. *Healthcare for Asylum Seekers and Refugees*. Medical Foundation for the Care and Victims of Torture; London, 2003.

- status, a process that can take months and often years to finalise. They may be seeking housing and financial support as well as legal assistance. Asylum seekers will face the possibility of being dispersed to any area of the UK with available accommodation if they have applied for housing from the National Asylum Support Services (NASS). They will be living off approximately £36 a week in the form of vouchers or cash. Some may face suddenly being put in a detention or removal facility without notice or recourse to their legal assistance or healthcare provider. All of these components of the immigration system could cause extreme stress and uncertainty as well as anxiety and depression.
5. People with HIV also face public prejudice that migrants and asylum seekers are putting undue pressure on the limited resources of the UK infrastructure, in particular education, health and social welfare systems. There have been calls by newspapers including the *Sun* and *The Times* to limit the entry of migrants with HIV through a testing upon entry policy at ports of entry into the UK. The Government has responded to this by announcing in January 2003 that it would conduct a closed Cabinet Office Inquiry into the impact of 'imported infections' on the public health. Some people have responded to this claiming it is not a matter of public health but rather an additional measure to protect public resources and costs, and that rather than promoting policies which seek to increase access to appropriate and effective healthcare for all, the Government is examining ways to exclude on the basis of poor health.
  6. At present 42 million people in the world are living with HIV, 95% of which are in developing countries and 30 million in Sub-Saharan Africa alone. In Africa only 50,000 individuals with HIV are currently accessing treatment. These are mainly health workers, military elite, civil servants and the wealthy. In 2001, the Secretary General of the United Nations, Kofi Annan, set up the Global Fund to fight AIDS, Tuberculosis and Malaria, to effectively combat the three diseases most responsible for a reduction in life expectancy in developing countries. After its first year of activity, there is uncertainty as to whether the fund will have the resources to carry through with further grant allocations. Is this a reflection of where the global AIDS pandemic currently sits on the list of governmental global priorities?

7. This Inquiry sets out to address these issues in further detail as well as communicate the actual experience of migrants living with HIV in the UK, through written and verbal testimony. The Government can amend policy to ensure that people who do come to the UK are treated fairly and humanely, with access to healthcare and treatment, stability and compassion regardless of the length of time they are in this country. The Government can also work to ensure that international interventions are designed and sustained for the length of time necessary to effectively combat global HIV and AIDS.



## *HIV in the 21st Century*

2 PHLS Website. HIV and AIDS General Information:  
[www.phls.org.uk/topics\\_az/hiv\\_and\\_sti/hiv/general.htm](http://www.phls.org.uk/topics_az/hiv_and_sti/hiv/general.htm)

8. The human immunodeficiency virus (HIV) is a serious infection which can be transmitted through an infected individual's blood, semen, vaginal fluid or breast milk. When a person acquires HIV he/she may not exhibit symptoms for a significant period of time. However even when asymptomatic, HIV attacks a particular type of white blood cell called CD4 cells which are important in the immune functioning of the body. When a person's CD4 cell count has fallen to a low level they are much more susceptible to other illnesses, such as tuberculosis and pneumonia. In addition they are susceptible to opportunistic infections, many of which are not normally life-threatening to a healthy person. Some of these illnesses at the severe stage of infection constitute acquired immunodeficiency syndrome (AIDS).
9. Transmission of HIV occurs through unprotected sexual intercourse (anal, vaginal or oral) with an infected partner, by injection (eg injecting drug users sharing needles), by transfusion with blood from an infected person (rare in developed countries since screening of blood); or from an infected mother to her baby during birth or through breast feeding.<sup>2</sup> In many areas of the world widespread testing for HIV is not available and even in countries where testing is performed it may not be widely taken up. Most of the estimates of the prevalence of infection in developing countries are based on samples taken from pregnant women. The vast majority of infected individuals even in very high prevalence countries are not aware they have HIV.
10. Recent advances in treatment by combination anti-retroviral therapy (sometimes called Highly Active Anti-Retroviral Therapy or HAART) have enormously improved survival rates in countries which can afford these drugs and have the infrastructure to deliver them safely and effectively. The treatment suppresses the HIV virus and can reverse the damage to the immune system for some time, prolonging the lives of people infected. People can only be prescribed these drugs if they have been tested and know that they have the infection. Drug treatments are complex and are often accompanied by side effects such as weight loss, nausea, diarrhoea, lipodystrophy (fat wasting and accumulation in different parts of the body), new-onset diabetes and neuropathy.

11. Many treatments need to be taken at specific times of the day or with food. HIV drug treatment often requires the individual to maintain a nutritious diet and a healthy lifestyle, including appropriate accommodation and living standards. The individual should ideally try to maintain 95% adherence, meaning that doses should not be missed. For some HIV treatment is unpleasant and difficult to manage. In 2001, scientists in California reported that approximately 50% of treated individuals with HIV had a strain of the virus that was resistant to at least one drug for HIV. When resistance occurs, the drug becomes much less effective, usually resulting in the need for the individual to switch to another drug in what is already a complicated cocktail of drugs.
12. There is general consensus that resistance will continue to be a significant obstacle to controlling the epidemic. Researchers predict that anti-retroviral resistant strains will exceed 40% of HIV infections in San Francisco by 2005. Government statistics in the UK show that the prevalence of treatment resistance among heterosexual HIV sufferers rose from 1.7% in 2000 to 3.4% in 2001.<sup>3</sup> Progress will only be possible with partnerships between clinicians, innovative scientists and politicians. To support these partnerships, there is a clear need for continued funding and investment in HIV/AIDS on the part of both the private and public sectors.

<sup>3</sup> APPG AIDS Meeting Briefing: *Resistance, the Complication in Treating HIV Today*. June 2003.

## Epidemiology and Context: HIV in the UK

- 4 Note: estimated total figures adjusted for late reporting and for initial non-allocation of exposure category.
- 5 Submission by the Health Protection Agency during the APPG AIDS and APPG Refugees Parliamentary Hearings, 6 May 2003; Dr Barry Evans.

13. During the last five years the annual number of new HIV diagnoses in Britain has more than doubled. At the end of 2001, the Health Protection Agency Communicable Disease Surveillance Centre (formerly part of the Public Health Laboratory Service) estimated that there were a total of 41,200 people living with HIV in the UK, of which just over a third were as yet undiagnosed.
14. There are at present two main reasons for this increase; the first being that although throughout most of the 1990s new HIV diagnoses in men having sex with men had remained constant from the year 2000, the number of new diagnoses began to increase. In 2002, the estimated figure for men having sex with men, when adjusted for reporting delays, was 2000. The second reason for the sharp increase since 1998 has been the additional numbers of individuals becoming infected through heterosexual sex. In the total of 6,600 new diagnoses<sup>4</sup> in 2002, 4,300 were reported in heterosexuals. Of this total, just under 90% were acquired abroad, about 80% of which were likely to have been acquired in Sub-Saharan Africa.<sup>5</sup>
15. The number of new diagnoses of HIV through heterosexual sex can be attributed to a probable country of infection in Sub-Saharan Africa indicating either the political or socio-economic context in which individuals may have migrated to the UK. See table below:

**Table 1.1:**

<b>New UK HIV infections where the probable country of infection was a named country in Africa</b>					
Top 4 countries	1998	1999	2000	2001	2002
Uganda	162	174	207	242	250
Zimbabwe	96	162	409	729	1474
Zambia	63	77	118	110	150
S. Africa	23	37	86	162	243
Other countries	283	402	507	681	962
Not known	116	136	139	138	146
<b>TOTAL</b>	<b>743</b>	<b>988</b>	<b>1466</b>	<b>2062</b>	<b>3225</b>

*\*Health Protection Agency Communicable Disease Surveillance Centre. The 2002 data are estimates based on as yet incomplete data for the full year*

16. This increase has two notable impacts. The first is the immediate impact on healthcare services and the ability of clinics to provide for a doubling or tripling of their patient load in a very short time period. The second is the impact on social and support services outside London. If an individual seeking asylum applies to NASS for accommodation and support, he or she is likely to be dispersed outside London as the Government tries to decrease the burden on infrastructure inside London. The consequence of this policy is that clinics and services with different areas of specialism have to quickly adapt to a multitude of disparate needs, including social, psychological and legal in addition to healthcare needs. In London there are a growing number of asylum seekers with HIV who are receiving support only from NASS, having declined to ask for accommodation as they do not wish to move elsewhere. Many of them depend on friends or relatives for somewhere to live.
17. There are two areas which have been successes of HIV policy in the UK. The first is among pregnant women infected with HIV. Due to the Government policy of universal offer and recommendation of HIV testing in ante-natal clinics, very few infants have been born with HIV and fewer women are ending up at the end of their pregnancy without having their HIV status resolved. At present over 80% of pregnant women who have HIV are diagnosed before or during pregnancy, greatly increasing the chances of their children being born without infection because of the interventions which are possible.
18. The second is that HIV has remained surprisingly low among injecting drug users. The low level of HIV transmission is thought to have been due mainly to successful drug rehabilitation schemes, counselling and most importantly the availability of clean syringes. Overall, with the availability of effective treatment regimes and an increased ability to diagnose early among key cohorts, fewer and fewer people are dying of AIDS, and more people with HIV are able to return to work and live productive lives.

## Continuing Trends of Stigma in Media and Society

*"I don't think you can ever come to terms with it, with HIV. Because in yourself you can come to terms with it but society doesn't allow you to, it's like society is fighting you all the time from all kinds of directions."*<sup>6</sup>

6 Written submission to the APPG AIDS and APPG Refugees: Doyal, L. and Anderson, J. "HIV Positive African Women Surviving in London: Report of a Qualitative Study" 2002.

7 Browne, Anthony. "The Secret Threat to British Lives," *The Spectator*, 25 January 2003, and "No System to Abuse" by Harriet Sergeant, Centre for Policy Studies, May 2003.

8 O'Toole, F. "Racism: the Deadliest Disease," <http://www.metroeireann.com/contents/fintan5.htm>

9 Cogan, J. and Herek, G. "Stigma." *The Encyclopaedia of AIDS*: <http://www.thebody.com/encyclo/stigma/html>

19. With the persistence of anti-immigrant sentiments and recent HIV statistics indicating the extent to which new cases of heterosexually acquired HIV originate overseas or in people of African descent, issues surrounding migration and public health have received increasing attention in 2003. Connections are being made between the reported rise in infections such as TB, Hepatitis B and HIV, and the increasing level of migration to the UK, and between the growing pressure on the NHS and extent to which migrants are able to access healthcare within the UK. These are being accompanied by growing calls for more stringent measures to protect the public health and public purse, such as mandatory health testing of immigrants and greater restrictions on migrants' access to healthcare in the UK.<sup>7</sup>
20. Successive waves of immigration have frequently been accompanied by hostility and prejudice from the host population, and one of the ways in which this has been expressed is through the perception that migrants bring disease and infection to the community. In this way, the typhoid epidemics in New York in the early 20th century were attributed to Irish immigrants<sup>8</sup>, and Commonwealth citizens migrating from the West Indies to the UK in the 1950s were associated with the prevalence of TB.
21. Moreover, certain diseases have been accompanied by stigma throughout history. Stigma is particularly likely to accompany diseases that are highly contagious, visibly identifiable or have serious or fatal consequences for carriers. It also tends to arise when a disease is seen to particularly affect social groups who are already discriminated against, and when transmission is seen to be due to certain actions or behaviour. Since HIV/AIDS conforms to all these categories, it is not surprising that stigma has surrounded it ever since it first came to prominence.<sup>9</sup>

## All-Party Parliamentary Group on AIDS

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- 10 Link, B. and Phelan, J. "On Stigma and its Public Health Implications." <http://www.stigmaconference.nih.gov/LinkPaper.htm>.
- 11 Oral testimony to the APPG AIDS and APPG Refugees, 20 May 2003: Susie Mclean, NAT.
- 12 *Daily Express*, "A wave of asylum-seeker children is seriously disrupting the education of tens of thousands of pupils... schools are facing closure unless exam results improve" in *Asylum: The Final Disaster*, 6 February 2003.
- 13 *The Sun*, "Asylum in Britain is now a Trojan Horse for terrorism," 20 January 2003.
- 14 *The Express*, "Doctors surgery that 'is overrun' by 600 migrants" 27 January 2003.
- 15 *The Sun*, 29 January 2003.
- 16 *The Sun*, 20 January 2003.
22. Two of the most stigmatised groups in today's media and society are immigrants and people living with HIV/AIDS. As Link and Phelan note, stigma arises from "power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination."<sup>10</sup> This can be seen in the way that asylum and immigration issues have been presented in the tabloid press over recent years. The debate over asylum and immigration has become characterised by discussions of perceived problems, such as the numbers of people applying for asylum in the UK, and pressures for increasingly tough solutions, such as tighter border controls. Susie Mclean of the National AIDS Trust said:
- I struggle with it at a personal level because I question how much public support we have got for this issue when already HIV remains so highly stigmatised. Even if it were not associated with race and asylum it would still be associated with sexuality. It is a pre-existing stigmatised illness given another layer of stigma by its link with asylum.<sup>11</sup>
23. Prejudice and discrimination against migrants are being perpetuated by associating them with an increasing range of "problems." Just over the past 6 months an immigration angle has been attached to a wide range of issues, from declining standards in education,<sup>12</sup> fears of terrorist attacks in the UK,<sup>13</sup> and to a lack of capacity within the NHS<sup>14</sup>.
24. Whilst the media portray themselves as taking a responsible stance—for example "We're not racists Mr Blunkett, just terrified for our children's health,"<sup>15</sup> political responses continue to be ridiculed as weak and ineffective in comparison to the implied scale of the problem. Provocative and alarmist articles such as "Read This and Get Angry"<sup>16</sup> directly and indirectly encourage readers to demand an increasingly tough stance on migration issues.
25. Mindful of the electoral consequences for failing to be seen to respond to the public's fears, politicians and policy makers can feel compelled to respond to the groundswell of public opinion by proving their determination to deal with the perceived problem. Thus a self-

perpetuating cycle has been established whereby as the public's perception of the extent of the problem increases, so policy makers respond with increasingly punitive policies. In this way, the proposal within the 2002 Nationality, Immigration and Asylum Act that healthcare and education for asylum seekers be provided within reception centres rather than through mainstream services can be seen as a response to people's fears that public services are "swamped" by asylum seekers. This demonstrates that a dangerous precedent is being set in policy making whereby asylum and immigration policies are made in response to the media's agenda, and led by prejudice and fear rather than factual assessments.

26. The most recent issues to be presented as immigration problems surround non-UK citizens' access to healthcare in the UK and so-called "treatment tourism", the public cost of treating migrants' and non-UK citizens' medical conditions, and the effect that immigration is having on public health in the UK.
27. The stigma that continues to surround HIV/AIDS prevents those affected from getting the treatment and support that they need, and also undermines efforts to prevent HIV from spreading. The effects of HIV/AIDS stigma and discrimination are manifested in different cultures and communities in a variety of ways, but there are some common features.<sup>17</sup>
28. First, there is a considerable amount of fear surrounding HIV/AIDS, since it is primarily seen as an infectious and potentially fatal disease. This can lead to marginalisation and harassment of people who have HIV or who are suspected of having it and deter people from being tested, thereby masking the true extent of numbers affected. A hostile environment can undermine the willingness of people who already know they have HIV to reveal their status to friends, family, and the wider community, and so compound their isolation and potentially prevent them from accessing appropriate treatment and support.
29. A culture of blame also frequently accompanies HIV. People who have HIV/AIDS are sometimes viewed as responsible for their own infection, and therefore less deserving of sympathy and support. Headlines such

<sup>17</sup> Terrence Higgins Trust. "Social Exclusion and HIV" and "Prejudice, Discrimination and HIV," London, 2001.

<sup>18</sup> *The Sun*, 14 February 2003.

as "Where Britain's New Hetero AIDS Cases Began"<sup>18</sup> reinforce the perception that responsibility for the spread of HIV/AIDS lies with particular social groups rather than individuals within society as a whole. They encourage entire groups, in this case, migrants with work permits working within the NHS, to be viewed with suspicion as carriers of HIV. As a result, people may not want to be tested or reveal their status for fear of being associated with these groups. The message of individual responsibility is also undermined, which has serious implications for the prevention of HIV/AIDS.

<sup>19</sup> *The Sun*, "Mr Dolittle," 27 January 2003.

<sup>20</sup> Browne, Anthony, "The Secret Threat to British Lives," *The Spectator*, 25 January 2003.

30. Other articles have used pejorative descriptions for people living with HIV/AIDS such as "polluted with...disease"<sup>19</sup> and a "Threat to British lives."<sup>20</sup> This reinforces people's fear of HIV and contact with HIV positive people, and furthers the marginalisation of people living with HIV or suspected of having it. Calls for mandatory testing compound the fear and stigma associated with migrants and HIV by giving credence to the idea that these groups are a danger which society must be protected from and further, perpetuates the discrimination against them.
31. It is also important to acknowledge that people from high-risk groups or living with HIV/AIDS see the negative media coverage and calls for tough measures such as mandatory testing, and may be deterred from accessing testing, treatment or revealing their HIV positive status due to the prejudice and discrimination which they anticipate receiving. This can be seen in the way that many HIV positive migrants fear that revealing their HIV status may have a negative effect on their immigration status. Thus the current climate of hostility is contributing to HIV/AIDS being driven underground and further isolating people who are HIV positive.
32. As with many previous issues, the alarmist tone of many media reports into the connection between migrants and HIV/AIDS is fuelling the public's fears and pressure for a strong political response. Thus coinciding with the widespread publication of Anthony Browne's article on the impact of immigration on Britain's public health and public purse, in which he asserts that the government "has been importing killer diseases ...and it is trying to hide what is happening from the

<sup>21</sup> *Ibid.*



public,"<sup>21</sup> is the announcement of the Cabinet Office inquiry.

33. There is a danger that current trends in media coverage of migration and HIV issues are simply perpetuating stigma and discrimination, and encouraging ineffective and inappropriate policies. When asked what she thought was driving HIV stigma, Thandi Haruperi explained:

It is mostly the fear. A lot of people still think that you can catch HIV just from sitting on a chair that someone who is HIV positive has sat on. A lot of people think that people who are HIV positive called it upon themselves because they have been sleeping around. I think those are the messages we need to change. If you look at the Africa situation, HIV has not discriminated. It has affected almost each and every person from my part of the world, whether they are a child, whether they are single, whether they are married and have remained faithful to one partner. It does not discriminate.<sup>22</sup>

34. By sustaining a hostile environment for migrants and people affected by HIV/AIDS, and reinforcing misleading messages about HIV/AIDS, affected individuals are becoming increasingly marginalised, HIV is being driven further underground and society is consequently becoming increasingly vulnerable to the spread of HIV.
35. To effectively combat HIV/AIDS stigma and discrimination in the general population there should be a renewed effort aimed at educating the public about these issues, in particular what it means to have HIV in today's society. **In accordance with the recommendations made by the House of Commons Health Select Committee recent report on Sexual Health, the Government should promote comprehensive HIV and sexual health education targeted to the wider public regarding heterosexual transmission.**

<sup>22</sup> Oral Testimony to the APPG AIDS and APPG Refugees, 20 May 2003: Thandi Haruperi, UK Coalition.

## Asylum and Immigration Law in the UK

<sup>23</sup> O'Reilly, J. "HIV and Mobility Roundtable," 23 April 2003.

36. For a number of years issues of asylum and immigration have dominated the headlines and have represented public concerns over stability and the changing identity of Britain. During a roundtable held by the National AIDS Trust it was suggested that the "Control of migration and the 'integration' of migrants into society has become a litmus test for those concerned about the erosion of national sovereignty and identity, crime and quality of life."<sup>23</sup> Debates have arisen over the public threat of migrants with regard to terrorism, crime and the threat of infection. However, migration is an inevitable phenomenon as people search for opportunity and freedom, safety and security in the world.
37. Immigration law is extremely complex and impacts in very different ways on the various categories of migrants both upon entry and throughout their stay in the UK. The legislation can be extremely complicated to interpret, in particular for a new arrival. Different categories of migrants have different rights of access to benefits, housing, education and healthcare, but these rights may not be straightforward. It is important to note that the term 'migrant' implies motion and fluidity and that many individuals may change from one category to another depending upon the course and experience of their stay, for example an individual who may have come as a student may establish residency by marrying a resident of the UK. Those who have entered the country illegally, or have been trafficked into the UK, will have no rights of access to services. They will be undocumented, and will come to the attention of the Immigration Services only if they are found working illegally, are arrested for some reason, or make an application to remain. The following is a list of categories of legal migrants and their entitlements during the time they are in the UK:

### Refugees

38. The Geneva Convention defines a refugee as any person who "owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear is unwilling to return to it." Refugees are now normally granted

24 Weston, H. "Safe Haven? Immigration, Asylum and HIV in the UK," Naz Project London, January 2003.

indefinite leave to remain in the UK at the time they are granted refugee status. Previously they were granted leave to remain in the UK for four years and then could apply for settled status or indefinite leave to remain. They are eligible for family reunion with one spouse and all children under 18.<sup>24</sup> Refugees are entitled to full access to all NHS services and social benefits as any other citizen of the UK.

## ***Asylum Seekers***

39. An asylum seeker is a person seeking refugee status, and who has filed an asylum claim in the UK. The UK is bound by the 1951 Convention Relating to the Status of Refugees. Article 33 of the Convention stipulates that countries that have signed the Convention may not return or expel a refugee. Restricting access to asylum seekers on any grounds, prior to entry into the country, would constitute a breach of the Refugee Convention. Once an asylum seeker has lodged a claim for refugee status, he/she may be entitled to financial support and accommodation. Financial support is usually the equivalent of £36 per week either in the form of vouchers or cash. Asylum seekers may be housed in hostels, hotels or rented properties or dispersed to another area of the UK at anytime while their claim is being processed. They are entitled to all services within the NHS. Significant number of failed asylum seekers remain in the UK after their asylum claim and all appeal rights have been exhausted. Some, who the Home Office accepts cannot be removed to their countries of origin, continue to get some support. Many, however, have all support from NASS or Social Services cut off, and are left totally destitute. A person in this position, with no legal right to remain in the UK, will have no rights to access services.

## ***Applicants for Exceptional Leave to Remain (ELR) Under Article 3 of the European Convention on Human Rights***

40. Article 3 states "No one shall be subjected to torture or to inhuman or degrading treatment or punishment." The European Court on Human Rights found that returning someone who is HIV positive to a country

25 O'Reilly, J. "HIV and Mobility Roundtable: Background Paper," National AIDS Trust, April 2003.

26 Written Submission to the APPG AIDS and APPG Refugees: Immigration Law Practitioners Association.

where there is a complete absence of treatment, facilities or social support, and which could result in an imminent and/or lingering death and cause physical suffering, can give rise to the UK's obligations under Article 3 which prohibits inhumane treatment.<sup>25</sup> Applications concerning HIV and AIDS cases are dealt with for the most part by a unit in the Home Office. Decisions can take four months or more, however the Home Office is currently making a concerted effort to make these decision times shorter. During this time an applicant may be entitled to support from the National Asylum Support Services (NASS) or social services. Such claims are not always successful and may result in an appeal to the original decision by the Home Office. If the application is successful, the applicant is likely to be given a year's permission to stay, with the ability to work and claim public funds. This means that an Article 3 claimant has the right to the same support for all purposes as an asylum seeker. This is renewable on an annual basis and after 6 years an application can be made for indefinite leave to remain.<sup>26</sup> At present, the largest challenge for individuals applying for leave to remain under Article 3 is the interpretation of a 'complete absence of treatment' in the individual's country of origin. In most developing countries, although some individuals (healthcare professionals, civil servants, government and high-ranking military officials) may have access to treatment and care for HIV and AIDS, the average person will not be able to afford or access sustainable treatment and follow-up.

## Visitors

41. A Visitor to the UK is defined for the purposes of this report as a person seeking to come to the UK for a temporary purpose. This includes students, work-permit holders, long-stay family visitors and tourists. During a visitor's stay he/she may fall ill and require care. If the individual has been in the UK longer than 12 months, they are entitled to free treatment under the NHS for themselves, their spouse and their children. However, individuals who are entitled to immediate free treatment from the NHS are people with permanent residency permits, permanent immigrants for employment purposes and people who have come to marry someone in the UK. If the individual falls out of these

27 Terrence Higgins Trust, "Asylum, Article Three and Long Stay Visitors," London, 2003.

categories, they are not entitled to free treatment under the NHS.<sup>27</sup> However, in some cases the waiting period may be inappropriate, in particular for pregnant women who may be infected with HIV and for people who are significantly ill with HIV or an AIDS-defining illness, and may require immediate life-saving treatment. At present, clinicians are left to determine whether or not a condition is life-threatening and whether it requires 'emergency' treatment, care and follow-up (this issue will be revisited further in the document). A visitor may claim under Article 3 of the ECHR.

## *Refusals and Appeal*

28 Written Submission to the APPG AIDS and APPG Refugees: Immigration Law Practitioners' Association

42. The majority of individuals making an application for the first time based on ill health will have a right of appeal against any decision of refusal. Such an appeal would be heard by an independent adjudicator.<sup>28</sup> The Immigration Directorates' Instructions (IDIs) concerning AIDS and HIV cases sets out that:

...the fact that an applicant has AIDS, is HIV positive or is suffering from any other serious illness in not in itself sufficient grounds to justify the exercise of discretion where the requirements of the Rules are not met. AIDS cases requiring the exercise of discretion should be evaluated in the same way as any other case where the applicant has a serious illness.

## *Recent Amendments to Asylum Legislation*

43. On 8 January 2003 the Government brought in new regulations to limit the number of asylum claims and refugees seeking support in the UK. Sections 55 and 57 of the Immigration and Asylum Act stipulate that people who do not apply for asylum "as soon as reasonably practicable" after arriving in the UK will be denied support from NASS. This amendment to Section 55 denies housing to childless people who do not claim asylum with the immigration service at port, young people under 18 whose age is disputed, people awaiting confirmation from NASS that they are entitled and people challenging the decision to refuse support. Already the adoption of this policy has left many

29 For more information see: "Blunkett's Asylum Appeal Rejected," BBC News, 18 March 2003.

30 Letter from the Home Office Immigration and Nationality Directorate re: Ending of Exceptional Leave Policy, February 2003.

people coming to the UK in search of asylum destitute. A group of asylum seekers brought their case to the High Court with regard to the refusal of support under Section 55. The High Court ruled in favour of these individuals in March 2003, specifying that denying support and housing amounts to degrading treatment under the ECHR, however the Government has yet to make adjustments to this policy.<sup>29</sup>

44. On 7 October 2002 the Home Office announced the abolition of Exceptional Leave to Remain with the aim of "focusing the existing system and granting protection only to those who really need it."<sup>30</sup> The Home Office replaced exceptional leave with the system of 'Humanitarian Protection' effective as of April 2003. Alongside Humanitarian Protection procedures, the exceptional leave system would be replaced by 'Discretionary Leave' procedures which would be used more sparingly than under the Exceptional Leave system. Humanitarian Protection would be given to anyone who, if removed, face in the country of return a serious risk to life or person arising from the death penalty, unlawful killing or torture, inhuman or degrading treatment or punishment. The current policy is that a person with a serious medical condition claiming Article 3 under the ECHR would not be in need of international protection and would therefore not qualify for Humanitarian Protection. Individuals in this category would then possibly qualify for Discretionary leave. Under Discretionary Leave the initial grant of leave will be no longer than three years and may be less. A person under this policy would not be eligible for settlement until they have completed 6 years of Discretionary Leave. The Home Office stipulates that anyone who has been refused asylum and Humanitarian Protection but granted Discretionary Leave will have full access to mainstream benefits, access to the NHS and the right to employment.

## Chapter 1: Entering the UK: Arrival and Application

<sup>31</sup> As reported in *The Independent*, "Asylum. The Facts," 23 May 2003. Sources include UNHCR, the Home Office, the Refugee Council, The Institute for Public Policy Research and Mori.

<sup>32</sup> Hughes, S. *Who Goes Where? Asylum-Opportunity Not Crisis*. Centre for Reform, London, 2002.

45. In 2002, there were 85,865 applications for asylum. Of asylum claimants who had decisions made during the year (many of whom would be people who had arrived in previous years), 8,100 (10%) were granted asylum, 19,965 (24%) exceptional leave to remain and 54,650 (66%) were refused.<sup>31</sup> The main countries from which asylum applications came in 2002 were Iraq, Zimbabwe and Afghanistan. During this year, the UK was 8th in Europe in terms of the number of asylum applications per 1,000 of the population; Austria is number one. Across the world there are approximately 20 million refugees; the UK currently hosts 1.98%. In 2001, it was estimated that there were over 380,000 asylum applications across the European Union, a figure which, contrary to public opinion, is a 50% **decrease** from ten years before.<sup>32</sup>
46. The reasons that individuals migrate are as diverse as the countries they are coming from and the cultures in which they were brought up. People migrate to change their current life situation; either to move away from a situation which is politically precarious or unstable in which the life of the individual or their family may be at risk; to escape an internal or external country conflict in which the individual may have lost loved ones, experienced torture, physical violence or sexual assault; or to migrate in search of new opportunities for learning or skills development. Individuals may migrate to study, to carry back to their country of origin new methods of healthcare, education or agricultural development; they may come to work temporarily to support financially their families back home; and individuals may come here to join a spouse who is already settled.
47. It is important to reiterate in the midst of negative tabloid press and opinion against migrants, the positive contribution migrants have made and continue to make to the UK. Whether this is economic, scientific, educational or religious, migrants have shaped the identity of Britain for centuries. In the document *Who Goes Where*, Simon Hughes MP writes:

<sup>33</sup> *Ibid.*

...many benefits such as cultural ones cannot be given any cost value, but also among past refugees are some of the most famous names ever to have lived in Britain, from Sigmund Freud to Karl Marx and from Michael Marks of Marks and Spencer to Sir George Solti, the conductor.<sup>33</sup>

48. We will examine the process of arrival for various categories of migrants and how under the current Nationality and Immigration system their first experience in the UK is likely to be shaped. Throughout the remainder of this document we will be referring specifically to migrants who are living with HIV. We will look at the implications of adopting the policy of testing for HIV upon entry, the impact of detention or removal facilities upon an individual with HIV, the consequences of dispersal on a person who is living with HIV and the process and experience of accessing benefits in the UK for an asylum seeker or person applying for Article 3 status. All of the material in the remainder of the document is based upon written and oral evidence submitted to members of the inquiry panel.



## Testing Upon Entry

*Despite the inclination of governments to treat access to medical treatment as a privilege rather than a right, it is no less a right than other rights such as the right to life, human dignity and freedom which are unambiguously inscribed in national constitutions.<sup>34</sup>*

34 Ngwena, C. *AIDS and Right of Access to Treatment: The Scope and Limits*, Paper presented at the Xith International Conference on AIDS and STDs in Africa, Lusaka, 12-16 September 1999; as referenced in UNAIDS, *Migrants' Right to Health*, March 2001.

49. When HIV and AIDS first appeared in the public and political eye, a number of countries were quick to adopt exclusionary measures, for at the time it was unknown how quickly HIV/AIDS could spread throughout the general population and what impact it would have on public services and infrastructure. Some countries adopted policies of confinement through quarantine and others adopted measures to ensure that individuals with HIV were not able to remain in a country on a long-term basis, such as through policies of testing upon entry. The United States, which adopted such a policy, now has one of the highest prevalence levels of HIV of any developed/Western country in the world.
50. Although HIV and AIDS have not penetrated the general population in Western countries, it has quickly spread throughout developing/low-income countries in Sub-Saharan Africa and is currently expected to experience similar growth patterns in Asia over the next five to ten years. This is largely due to poverty, poorly developed and sustained health infrastructure, conflict, the prevalence of additional immune suppressing illnesses such as tuberculosis and malaria and a lack of ARV treatment.
51. At the time of writing of this report the results of the Cabinet Office Inquiry had yet to be announced, but concerns had permeated through both statutory and voluntary organisations as to how the adoption of a policy of testing upon entry could impact individuals currently living with HIV, many of whom may be unaware of their HIV status.
52. Countries which have adopted the policy of testing upon entry with the aim of exclusion have done so for various reasons. They include the belief that testing would prevent HIV from entering and spreading into

pockets of the general population, to protect public health. Reasons also include the necessity to minimise the costs to healthcare systems of treating individuals with a long-term illness requiring medicine, care and follow-up throughout the life of the individual. There are many issues to consider when determining whether or not testing upon entry could have the positive impact a government is seeking.

53. The UNHCR is strictly against mandatory testing and the exclusion of those infected with HIV from countries purely on the grounds of their HIV status. In addition, guidance from the UNHCR and UNAIDS in 1998 stipulates that "There is no public health rationale for restricting liberty of movement or choice of residence on the grounds of HIV status." Not only are the restrictions of movement based on HIV status unfounded but they are also considerably resource-intensive, providing a multitude of logistical and financial costs from funds which could be used instead for prevention and education initiatives.

35 Oral Evidence presented in the APPG AIDS and APPG Refugees Parliamentary Hearings, 6 May 2003.

54. It is necessary to consider what message a policy of testing upon entry for reasons of exclusion would send out to other countries. Simon Taylor of the UNHCR explains, "We are concerned,... given, frankly, the small number of refugees and asylum seekers in this country in the great scheme of things—there are more refugees in Tanzania than in the whole of Europe put together—the message that this would send out to other countries, particularly developing countries, is that, if this UK can do this, so can we, and that is something about which there is concern."<sup>35</sup>

36 Presentation given to the APPG AIDS in January 2003, Dr Kevin Fenton, "Recent Trends in Sexually Transmitted Infections and Sexual Behaviour in Britain," Health Protection Agency.

55. Testing migrants for HIV upon entry into the UK sends out a false sense of security to the general public that they are not at risk of acquiring HIV and that only immigrants and asylum seekers carry this risk. In 2001, chlamydia and gonorrhoea cases in Britain doubled and tripled compared to rates of infection from 1996. At present, England has one of the highest teenage pregnancy rates in Europe. Individuals, particularly young people, are continuing to engage in unsafe sex and are putting themselves at more and more risk of acquiring HIV as the age at first intercourse decreases and the number of sexual partners per person shows an overall increase.<sup>36</sup>

56. Many stakeholders, from HIV specialist clinicians to individuals working in the voluntary sector, question the singling out of HIV among other diseases which may not only be contagious but which are also extremely costly to treat. Dr Adé Fakoya, an HIV consultant at Newham General Hospital in London explains:

37 Oral Evidence presented in the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003.

...from an ethical point of view why single out HIV to test for, as opposed to any other health condition? If we are looking at global viruses, you could test for hepatitis B, which is more prevalent and more costly to treat, or hepatitis C. Or if you are going to do it purely on economic terms, you can take an illness which is more prevalent like cardio-vascular disease, and decide that you are going to screen immigrants...for smoking because actually later on down the line they are going to be a bigger health burden than people who do not smoke. Clearly, whatever argument I see for testing migrants, for me it falls down as a non-starter.<sup>37</sup>

57. Mandatory testing for HIV upon entry could also have negative implications for HIV prevention. If we actively single out HIV as an illness which we would like to keep out of the UK, we risk discouraging individuals who are already in the UK to test. The Health Protection Agency in Britain reports that almost one-third of the cases of HIV in the UK are undiagnosed. If some of those undiagnosed are migrants already in the UK, this will dissuade them from seeking a test. The consequence is that they may continue to engage in unprotected sex and hence put the public health at greater risk for HIV infection. A large component of HIV prevention rests on individuals feeling comfortable enough to seek out testing. We should instead be concentrating our efforts and resources to ensure that those who are HIV negative stay negative.
58. There are also logistical challenges and costs of activating a policy of testing upon entry. Asylum seekers, under the European Convention on Human Rights, cannot legally be denied the right to seek asylum based on an HIV positive test result. There is no evidence in any case that it is only asylum seekers entering the country that may have HIV, as opposed to other migrants. The countries which at present are the

source of the largest numbers of asylum seekers are often not high prevalence countries although some, such as Zimbabwe, are. There are many people entering the UK from high prevalence countries through other categories of immigration. Logically this means that some visitors, at least, would be the target for testing. Given that over 12 million visitors passed through immigration controls in the UK in 2001, testing every visitor entering the UK would be impossible, therefore decisions on who to test may be arbitrary and discriminatory in nature.

38 Oral Evidence presented in the APPG AIDS and APPG Refugees Parliamentary Hearings, 6 May 2003.

59. When the challenge of HIV was first recognised in the UK in the early 1980s the issue of mandatory testing arose. It was decided then that testing had to be on the basis of a fully informed and voluntary decision of understanding the consequences and the implications of the test. Simon Taylor of the UNHCR said that, "We do not believe that a border crossing or an immigration holding centre...is an appropriate or safe place for such decision making to take place and for those individuals to be able to make those decisions...we think that is virtually impossible."<sup>38</sup> Ensuring a welcoming environment for pre and post-test counselling in the context of mandatory testing upon entry would be a serious challenge and could risk infringing upon the rights of individuals.
60. What about the allegations of 'health tourism' which suggest that individuals come to the UK from developing countries purely on the basis of seeking HIV/AIDS treatment and care? Recently the press has claimed that many migrants with HIV are "NHS Cheats" who only come here with the full knowledge that they will be able to access free healthcare to treat their HIV. In most developing countries, particularly in Sub-Saharan Africa, health systems are under-developed due to decades of under-funding, conflict, policies of user-fees and lack of adequately trained health workers. HIV prevalence is still largely measured through anonymous ante-natal testing in clinics and hospitals therefore only limited numbers of the population may actually know they have been infected with HIV. In addition, the decision of where to migrate, or to seek asylum, is largely influenced according to where the individual may have family or friends, work, language ties or support networks. It is unlikely that this decision is

dictated by preferences for health systems. Max Sesay, Executive Director of the African HIV Policy Network clarifies:

My experience over the last 10 or 14 years suggests that the UK health system is an incredibly complex system to navigate for those who wish to spend time in the United Kingdom. I would be very surprised if someone in, say, Sierra Leone and who has never been to the United Kingdom has any idea as to how the UK health system operates and for people to say that people are getting the money to buy a ticket and are boarding the plane with the intention of setting off specifically to access medical treatment when in fact they have no idea whether, firstly, they will be admitted to the country and secondly, that they would have entitlement to HIV is a very bad sign.<sup>39</sup>

39 Oral Evidence presented in the APPG AIDS and APPG Refugees Parliamentary Hearings, 6 May 2003.

40 Haour-Knipe, M. Social Enquiry and HIV/AIDS, Background paper prepared for the XIV International Conference on Social Sciences and Medicine, Scotland, 2-6 September 1996 as cited in: UNAIDS. *Migrants' Right to Health*, 2001.

41 Oral Evidence presented in the APPG AIDS and APPG Refugees Parliamentary Hearings, 6 May 2003; Dr Mary Haour-Knipe, IOM.

42 Oral Evidence presented in the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003.

61. The alternatives to exclusionary policies which seek to keep vulnerable and marginalised people out of the country are to examine policies based on inclusion. This would involve harm reduction, persuasion in modifying lifestyles linked to disease, education, voluntary testing and counselling and protecting privacy and social interests.<sup>40</sup> Inclusive border controls can be helpful for improving diagnosis, links with healthcare services and immigration services, facilitating access and reinforcing partnerships between sending and receiving countries.<sup>41</sup> Instead of using a positive HIV test as a means to exclude and to return an individual to a country where he/she may not be able to access treatment, we should be looking to improve the timely diagnosis of HIV and ensuring that health providers can plan for individuals who will require more care. Dr Adé Fakoya explains, "I spend most of my time looking after people who I should have seen two or three years ago and the cost of treating them is much more than it would be if they were asymptomatic and I could get them on a very simple anti-retroviral regimen..."
62. **The Government should reaffirm its commitment to the UNAIDS guidelines against mandatory testing upon entry for HIV. It would be in breach of international obligations and human rights to give mandatory HIV tests to asylum seekers upon entry and in addition there is no evidence to support that such a policy would be effective at**

43 Oral Evidence presented in the APPG AIDS and APPG Refugees Parliamentary Hearings, 6 May 2003: Dr Haour-Knipe, IOM.

**protecting the public health. The consequence of testing upon entry would be worse as people with HIV avoid presenting for testing and HIV would risk becoming further stigmatised. Instead the Government should encourage policies of inclusion which support testing based on informed consent with the aim of reaching individuals in need so that they can receive timely access to care and treatment.** Dr Mary Haour-Knipe of the International Organisation of Migration explains "Let me say that investing in improving health structures in developing countries would be a far more effective means of addressing the epidemic than border controls when the border controls are understood in a context of exclusion."<sup>43</sup>

44 Gilmore, N. Human Right Issues and Migration, presentation at the 12th World AIDS Conference, Geneva, July 1998, as cited in: UNAIDS. Migrants' Right to Health. 2001.

63. The UK Government should be working in partnership with the international community to increase access to treatment for people living with HIV/AIDS in developing countries rather than examining policies which would restrict access to care and treatment in the UK. Gilmore notes "When non-nationals are deprived of opportunities to be healthy this not only endangers their own health, but also promotes denial and discrimination. It jeopardises public health efforts, in particular prevention efforts, thereby threatening the public's health."<sup>44</sup>

## Detention and Removal Centres

*One lady, who is an Ugandan national, was suffering from AIDS and her CD4 count had gone below 200, she was being treated for that. She had an eight month old baby. She was signing on as required with the local police station and the day after she was signing on immigration staff came to detain her at her home. She was not at home but her neighbours reported this to her. She went, herself, to immigration and handed herself in. When I talked to her about this later and asked "Why did you do that? Why did you turn yourself in?" she said "With the amount of drugs I am on, there is no way I could be on the run."<sup>45</sup>*

45 Oral Testimony to the APPG AIDS and APPG Refugees, 08 May 2003; Nicola Rogers, ILPA.

64. When an individual comes to the UK to apply for asylum their application is dealt with by the Immigration and Nationality Directorate of the Home Office. Throughout the course of the application process, which may take several months and in some cases years, the individual may be detained in a detention or removal centre. They may be detained immediately upon entry or they may be sought for detainment at a later stage in their asylum application.

46 House of Commons, Home Affairs Committee: Asylum Removals. Fourth Report of Session 2002-2003, Volume 1.

65. The Home Office policy is that only those asylum seekers who are destitute should be supported from public expenditure. In the future the government hopes to ensure that the basic needs of asylum seekers are met whilst considering their claim for asylum through the use of accommodation centres. The Home Office website explains that "accommodation centres will make it easier to stay in close contact with asylum seekers while we consider their applications." The process of detention is based on the Immigration Act 1971 and the Immigration and Asylum Act 1999. However, the criteria for detention are not stated in the legislation, and have, according to the Home Affairs Committee report on Asylum Removals, therefore been "a matter of policy."<sup>46</sup>

66. An individual may be detained immediately upon entry at port while authorities are making the decision as to whether or not to admit them into the country or while their application is processed; they may be

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47 For more information see: "Asylum Claims will be Halved—Blair," BBC News, 10 February 2003.

detained at a later point if it is thought they are likely to be removed based upon an unsuccessful application. The issue of removal centres has been highly polarised in the media as the Government has been criticised for allowing too many rejected asylum seekers to remain in the country. The Government has been under recent pressure to increase the number of removals, which now appears to be happening. In February 2003, the Prime Minister, addressing the House of Commons, stated that asylum claims would effectively be halved by September 2003.<sup>47</sup> Therefore the number of rejections and successful removals is the key to the Government meeting those targets.

***"Every ring of the door bell, they've come to deport me, that's what it feels like, the sight of a police car, are they looking for me, you know; that's the kind of life you have to live and definitely with the virus you don't need that."—HIV Positive Ugandan National***

48 House of Commons, Home Affairs Committee: Asylum Removals. Fourth Report of Session 2002-2003, Volume 1.

67. In 2002, 795 asylum seekers were in detention at the end of December; 32% of this total had been in a detention/removal facility for more than 4 months.<sup>48</sup> In the Home Affairs Committee report, Bail for Immigration Detainees explained:

The use of immigration detention is arbitrary and lacking in vital safeguards. Liberty is deprived for long periods for administrative reasons based on arbitrary decisions and apparently without consideration of more humane alternatives.<sup>49</sup>

49 *Ibid.*

68. Being placed in a removal facility severely impacts upon access to services such as legal support and access to one's healthcare provider. If the asylum seeker being detained is HIV positive, the impact upon their physical and mental health could have immediate as well as long-term negative consequences. Nicola Rogers, a member of the Immigration Law Practitioners' Association, pointed out that removal centres, rather than being centres where applications are put on a fast track for decisions, are centres where the claimant has little if any contact with their legal support. In fact, once they are in such centres they can easily be forgotten, hence being cut off from support and advice. Nicola Rogers states "I actually think that the problem of



<sup>50</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 8 May 2003: Nicola Rogers, ILPA.

representation...is that one-fifth of detainees are not represented at all. They are very easily forgotten in the system actually and what our members find is that they get contacted by detainees who have been in detention for considerable periods of time and the system seems to have completely forgotten them."<sup>50</sup> This can have devastating consequences for an individual trying to make an appeal for bail.

69. In addition, if the individual is detained after their arrival and short-term settlement in the UK it is not unusual that their medical notes will not follow them into detention. This can be serious for a person living with HIV. Not only will they lose contact with their healthcare provider, they will be forced to report to the medical staff in the detention centre who will probably not have any HIV specialist care experience. Detained individuals will have their medication taken from them upon entry into a facility and will not be given any medical exam until 24 hours have elapsed. This can mean that a person with HIV can spend an entire 24 hours without access to their anti-retroviral medicines, hence increasing the likelihood of future drug resistance.

*"Then there are mornings when I wake up and think 'can the Home Office not just let me know if I can or cannot stay so I can go and spend my last remaining days with my child.' These are times when I wonder what someone like myself has done to deserve this kind of mental degradation."—Anonymous Submission from an HIV Positive Woman*

<sup>51</sup> HM Inspectorate of Prisons. *Inspection of Five Immigration Service Custodial Establishments*. April 2003.

70. Conditions inside removal centres may be inappropriate for people suffering from a serious illness such as HIV. In Her Majesty's Chief Inspectorate of Prisons Report which reviewed five immigration establishments, it was pointed out that healthcare and in particular mental healthcare, was an issue in most centres, stressing poor communication between the centres and community healthcare services.<sup>51</sup> A person living with HIV will experience difficulty in coordinating the time they are required to take their medication and the set meal times in the centres. Nicola Rogers describes the experience of one of her clients:

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52 Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 8 May 2003: Nicola Rogers, ILPA.

...When you are taking the drugs that she is required to take you need to take them with food. Drugs are not administered until after breakfast at Harmondsworth so she could not take her morning dose until lunchtime which meant she was already behind in the day with her medical treatment...In other words, she is unable to manage her own medical treatment because of detention.<sup>52</sup>

53 Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 8 May 2003: Sarah Cutler, BID.

71. Individuals also experience difficulty in making their appointments with healthcare providers on the outside as often the centre may cancel the appointment, either for logistical or practical reasons, for example no one being on hand to drive the individual. In one case a person living with HIV was taken to his medical appointment in handcuffs and his blood test was consequently carried out while he was wearing the handcuffs. Sarah Cutler of Bail for Immigration Detainees states "We would argue that if someone is ill enough to need hospital treatment they are also too ill to be in detention and are very unlikely to abscond if they are that ill..."<sup>53</sup>

54 Statutory Instrument 2001 No. 238, p.15.

55 Documents submitted during the oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 8 May 2003: Sarah Cutler, BID.

72. How appropriate is it to detain people living with HIV in removal centres? According to detention policy in the Operational Enforcement Manual which is issued to the Immigration Service, paragraph 38 describes which categories of people the Immigration Service considers are not normally suitable for detention other than in "very exceptional circumstances." Among these categories are pregnant women, people suffering from medical conditions or the mentally ill and those where there is evidence that they have been tortured. In addition, Detention Centre Rules<sup>54</sup> cite under paragraph 35 that "the medical practitioner shall report to the manager on the case of any detained person whose health is likely to be injuriously affected by continued detention or any conditions of detention."<sup>55</sup> A representative from Bail for Immigration Detainees explained that the guidelines on who should and should not be contained are not followed because detention criteria are not statutory, rather are simply guidelines. Therefore, although the Government has guidelines on people with serious illnesses being detained, these guidelines are not necessarily being followed.

*"I take your point about the medical service, I do not expect them to be specialists, but then do not put people in their care who need specialist care. If you find out somebody is HIV positive or has a mental health problem, a pregnant woman, do not detain them. If you cannot look after them, do not detain them"—Diana Mills, Asylum Aid*

73. Being detained in a removal facility can severely impact upon a person living with HIV. A person with HIV is compromised as he/she may be detained in confined quarters which may perpetuate the spread of communicable diseases like tuberculosis, leaving someone whose immune system is already greatly compromised, more susceptible to infection. There are no counselling or psychiatric services available in detention, and in detention centres where HIV tests are done on-site, this could entail that individuals are not receiving adequate pre and post-test counselling relating to their HIV status. Diana Mills of Asylum Aid pointed out her concerns regarding HIV testing in removal centres:

My other worry about actual testing is informed consent. Can you get informed consent for an HIV test from somebody who is actually in a detention centre when you have got that kind of power balance? They have been detained on arrival, they have run away from their country, they have made long journeys after being persecuted, and having gone through horrendous drama, they come to a detention centre and they are not feeling well, they are offered an HIV test, can they give informed consent?<sup>56</sup>

74. **The Government should not place people with serious communicable diseases, such as HIV, in detention or removal centres for immigration purposes where it is not possible to provide suitable medical care for them. All evidence received during the inquiry suggests that removal centres are unsuitable places for people living with HIV. Detention can undermine efforts to maintain good health.**

<sup>56</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 8 May 2003: Diana Mills, Asylum Aid.

## The Impact of Dispersal Policies

*We had one client who was HIV positive and had given birth to her child by caesarean. She had developed a small number of bacterial infections so she could not be released from hospital at that time. She was sent a letter from NASS demanding that she was released from hospital. We had quite a farcical situation of the ward sisters and staff nurses almost linking arms on the ward to prevent NASS from getting to the woman because there was no physical way that woman could move, she was so desperately unwell.<sup>57</sup>*

57 Oral Testimony to the APPG AIDS and APPG Refugees, 8 May 2003: Sid Sheehan, Terrence Higgins Trust.

75. The 1999 Immigration and Asylum Act and the 2002 Nationality and Asylum Act stipulate that if an individual who has applied for asylum in the UK seeks support and housing, he/she may be dispersed anywhere throughout the UK as soon as accommodation becomes available. Under these regulations, NASS is not permitted to take into account an individual's preference to reside in a specific area of the UK. Individuals seeking asylum and individuals who have made a claim under Article 3 and who seek accommodation are likely to be dispersed. Once a decision of dispersal is made it is very difficult to appeal and any decision must be appealed within a limited amount of time.
76. Often decisions of dispersal are made very suddenly whereby people have little notice that they will be dispersed—sometimes less than 24 hours, and in many cases are given unclear information as to where they are going. Evidence was presented to the inquiry of asylum seekers being told their dispersal destination as they were in the process of boarding the bus. Ayob, an HIV positive service user explains:

On 11 March I received a letter from NASS that I would be dispersed within the Birmingham area so I said that was okay...Then on the 14th in the morning the people collected me and took me to Coventry. While boarding the bus I was given another letter which said I had been dispersed to Manchester. Before boarding I explained to the NASS officer who was distributing letters that I had not collected my drugs and I have to take these drugs. The officer told me he had nothing to do with it because instructions came from NASS headquarters.<sup>58</sup>

58 Oral Testimony to the APPG AIDS and APPG Refugees, 8 May 2003: Ayob, HIV Positive Service User.

59 Oral Testimony to the APPG AIDS and APPG Refugees, 8 May 2003: Nadine Finch, ILPA

60 Article 3 stipulates that the individual would be sent to an area where there is no treatment and that it would be degrading and inhumane.

61 Article 8 sets out the right to private life argument indicating that the individual would not have proper support networks.

77. For a person living with HIV, the NASS assessment of the appropriateness of dispersal will usually focus simply on the availability of a hospital which can prescribe medication. It rarely takes into account the availability of specialist HIV services which are also able to address the needs of asylum seekers, including adequate legal support, mental health services and the prevalence of support services and networks, not to mention the current health of the individual. If a person living with HIV is suddenly dispersed and seeks to appeal, he/she is required to appeal to the asylum support adjudicator within two days. From that point the Home Office/NASS is obliged to hear the individual within the next seven days.<sup>59</sup> At the appeal, human right grounds can be used in reference to Article 3<sup>60</sup> and Article 8<sup>61</sup> of the European Convention on Human Rights.

*"They always come at midnight, at 5am when you can't get a hold of anyone to help. They always time Friday and Saturday. I don't have anyone. I don't know where they want to take me"—Anonymous Submission by a Person Living with HIV*

78. If the person living with HIV is dispersed this creates a multitude of challenges at many levels. Given that there is often little notice of dispersal, individuals are not able to contact their healthcare provider in time to ensure that their medical notes follow them immediately to an appropriate provider, if available in the dispersal area. It is not uncommon for a physician to experience a 'disappearance' of their patients formerly seeking care. The lack of adequate notice also puts the individual with HIV at risk as they may not be aware of when they are going and so may not take enough ARV treatment with them. This can be exacerbated if they are unable to find HIV specialist services which prescribe the same treatment regimens as the former clinician at the dispersal destination. The danger of this is that current anti-retroviral therapy requires approximately 95% adherence, which means that individuals are required to be extremely cautious not to miss timed doses. If several doses are not taken on time, with adequate food and drink or missed altogether, this can lead to resistance, thereby reducing HIV treatment options of the individual for the long-term and

in some cases increasing the cost to the NHS to treat them with more expensive drugs.

79. HIV clinicians often express frustration as the time and effort it takes to build up a particular relationship with the individual and to respond to the variety of their needs is invalidated by the policy of dispersal. HIV clinicians who gave evidence to the Inquiry indicated that there was a strong lack of communication and respect on the part of NASS for the arduous nature of the work of the clinician and the relationship he/she may have built up over time with the individual living with HIV. One HIV clinician stated:

The lack of flexibility and responsiveness to these individual cases makes it (the system) appear brutally indifferent to the plight of many of these individuals. The dispersal process frequently completely, and recklessly, disregards the opinions, expertise and professional medical reports by specialist HIV professionals, including doctors, psychiatrists and psychologists, by ignoring recommendations made in formal, medical, and other, professional reports.<sup>62</sup>

80. Some physicians feel that many of the services which have been developed in London over the years to address the needs of migrants and asylum seekers cannot be replicated. These include translation services, a variety of community-based organisations targeting specific cultural and individual need and larger voluntary organisations providing complementary therapy. Many have referred to the policy of dispersal as completely disruptive to the quality and consistency of care at needless cost to the physician and person living with HIV.

81. HIV clinicians from dispersal areas indicated during the Inquiry that their workloads are dramatically and quickly increasing due to large numbers of asylum seekers being dispersed into areas where previously no HIV specialist services existed. One clinician in Glasgow explained, "The quality of the work has changed because of the complexity of care. We have people with different languages. It takes much longer to see somebody with an interpreter. We have people with different health beliefs who in some areas are very suspicious of Western medicine and do not subscribe to an allopathic method of treatment."<sup>63</sup>

62 Oral Testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 8 May 2003; Dr Chris Wood.

63 Oral Testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 8 May 2003; Dr Andy Winter.

82. The clinicians also indicate that because of dispersal individuals with HIV suddenly arrive without any details of their treatment history or care making it difficult for the clinicians to know how to treat them. It is common that medical notes do not follow the individual when he/she is dispersed to a new area. This has become a constant frustration for clinicians caring for dispersed people with HIV. There has also been a sharp increase in the level of administrative responsibilities which may accompany asylum seekers as clinicians are required to write numerous reports and letters to physicians outside the dispersed area, to legal advisers, support networks and to NASS officials. Clinicians from dispersed areas also point out that there has been an increase in the need for services in the past few years for which previously there was little need, in particular for mental health services. Many clinicians have not received training in areas of mental trauma and are finding it difficult to cope with accounts of individuals' personal trauma, including rape and persecution.

***"Many of our patients who are dispersed we have never been notified officially about. We have never had a single letter from NASS"—Dr Chris Wood, HIV Clinician, North London***

83. Clinicians report concern regarding HIV positive mothers who are pregnant and require constant care and follow-up to ensure that their child is not born HIV positive. In some cases women who were several months pregnant have been dispersed to areas where they have no contact with their healthcare provider and who take weeks to be either tracked down or to find ways to contact their physicians. In some instances, the effect of dispersing a pregnant woman has led to the child being born HIV positive, an avoidable consequence had physician and patient advice been taken into account by the dispersing agent.
84. There are concerns that the policy of dispersal is actually having the impact of worsening public health as people with HIV are consigned to areas of sub-standard care, threatening their own health and possibly the health of others. In the written submission by Terrence Higgins Trust, they explain "THT further believes that indiscriminately

64 Written submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: THT.

65 Oral Testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003: Nick Partridge, THT.

dispersing people with HIV is potentially damaging to public health...in particular, health promotion work for migrants and appropriate interventions to maintain sexual health and reduce onward transmission of HIV barely exist outside a few metropolitan areas."<sup>64</sup> Nick Partridge said, "...If we can sort dispersal out, in many respects we will be able to sort out many of the other issues around HIV migration and immigration. It is one of those key things that actually create many of the other difficulties."<sup>65</sup>

85. **The Government should make extra funding available to deal with decisions resulting directly from dispersal policies. Current methods of funding leave PCTs with no flexibility or reserves to be able to deal with sudden and unexpected demands on clinics and GUM services resulting from dispersal.**
86. **When a decision of dispersal is made by NASS regarding a person known to be living with HIV, all such decisions should necessarily take into account expert medical and professional advice. Any decision by NASS to overrule specialist advice should be justified. The Government should require NASS to provide satisfactory evidence that dispersing an HIV positive asylum seeker will not jeopardise their ongoing medical and psychosocial care.**
87. **NASS should only continue to disperse people living with HIV to areas where HIV clinical expertise and capacity is available to treat the complex and manifold needs of migrants and asylum seekers, in particular to places with a multiplicity of cultural and language services, mental healthcare services for trauma victims and HIV support services and networks. A person with HIV should not be dispersed if dispersal is going to severely impact upon their health.**
88. **When an asylum seeker with HIV is dispersed they should be given sufficient notice—at least seven working days. The Government should ensure that an organised process of referral and handover of care is in place. Particular consideration should be given to the treating physician in order to ensure that required notes and materials can be duly forwarded in time onto the awaiting physician in the dispersal area and to the person known to be living with HIV to ensure they have an adequate amount of medication to take with them.**



## Accessing Benefits

*...All of a sudden she gets a letter from the Home Office saying: "You are due for deportation." She brings all these letters in for us to interpret. Where have we gone wrong? We are not humane anymore. This woman is sleeping on the streets. She has been put out of NASS accommodation. Honestly, the challenges are just too great.* <sup>66</sup>

<sup>66</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Inquiry, 8 May 2003: Daisy Byaruhanga, Innovative Vision Organisation.

89. When an asylum seeker comes to the UK they may have left their homes suddenly, leaving most of their belongings behind. To make the journey they may have had to pay a considerable amount of money pooled together from family and friends. Upon arrival many asylum seekers will be desperately impoverished. Arriving in the UK can be an extremely confusing time for most asylum seekers, particularly if they do not speak English. They will immediately want to find accommodation for the first few nights they are here, either with friends, family or acquaintances. As mentioned in the chapter on Asylum and Immigration law, Section 55, adopted in January 2003, stipulates that if the individual does not apply for asylum "as soon as reasonably practical" he/she can be denied housing and income benefits. Already some individuals have been denied support after applying only days after arrival, leaving them utterly destitute.
90. If the individual is able to claim asylum during the time period necessary, they will be eligible for housing and financial support. Depending upon their current situation support will either be provided through NASS or Social Services. If the individual is applying for support due to their needs as aged, ill or disabled then the duty falls upon the relevant Local Authority's Social Services Department to provide services to meet those needs. For a person living with HIV who, in particular, is currently ill and being treated for opportunistic infections, AIDS-related illnesses or who has been placed on long-term ARV treatment, they would be required to seek support from Social Services.
91. If the individual living with HIV has had an HIV diagnosis and is not receiving treatment, then it may be that Social Services are not obliged

67 Written submission to the APPG  
AIDS and APPG Refugees  
Parliamentary Inquiry: ILPA.

to provide support. However, if the individual has needs relating to their diagnosis, beyond their needs as destitute, then they are the responsibility of Social Services. If they do not, then the duty would fall on NASS if they are asylum seekers.<sup>67</sup> In either case, the support given by Social Services or by NASS is between £28 and £36 per week; this income can be in the form of vouchers or cash. An individual seeking the support of Social Services would normally be given a Community Care Assessment to further determine individual need. However, not all assessments look closely at the particular needs of the individual at that time. A person living with HIV will probably need a refrigerator to store anti-retroviral medication, cooking facilities to set their own meal times and they may need accommodation which is easy to access. The Immigration Law Practitioners Association explains:

68 Written submission to the APPG  
AIDS and APPG Refugees  
Parliamentary Inquiry: ILPA.

...We can say that, despite the numbers of persons to whom Social Services have a duty, there is an appalling unevenness in service delivery, a patent lack of training as to the inter-relationship between a person's community care needs, their HIV diagnosis/treatment regimes and their immigration status.<sup>68</sup>

92. Often the accommodation which is provided either by Social Services or by NASS to an asylum seeker living with HIV is entirely inappropriate. Usually the accommodation will be shared with several people, sometimes 8 or 10 to one flat sharing toilet and bathing facilities, as well as a kitchen and fridge. A person receiving treatment for HIV will in most cases need to store their medication in the fridge. This could risk breaching the confidentiality of the individual regarding their HIV status. In addition, anti-retroviral treatment can cause extreme diarrhoea and nausea, making it incredibly difficult and uncomfortable for someone who is required to share bathroom facilities. Many asylum seekers have also described feeling unsafe in such shared accommodation, complaining that the conditions are "filthy and grimy, with damp and inadequate heating." All of these factors can serve to exacerbate a serious illness, in particular HIV.
93. The financial support asylum seekers receive forces them to live in a continual state of poverty and deprivation whereby individuals struggle to purchase food, toiletries and travel fares. Representatives from

69 Written submission to the APPG  
AIDS and APPG Refugees  
Parliamentary Inquiry: Sexual Health  
Department at Homerton University  
Hospital in Hackney.

Homerton University Hospital in Hackney report that "Asylum seekers frequently experience discrimination and are expected to live on an amount which is well below what people who receive benefits live on. They thus live a very poor quality of life, without the support of a local community, dislocated from friends and family."<sup>69</sup> People living with HIV often are not able to buy the foods they are accustomed to eating either due to only being given vouchers or because they cannot afford it with the income they are given. Individuals living with HIV have difficulties managing their illness due to the inadequate level of income they receive.

*"I want to try and do whatever I can to get my life back. I want to put my knowledge, the things I've studied and my skills into practice. I don't want to just sit there and be on benefits, I want to be useful."—HIV Positive  
Zambian National*

94. Finally, individuals awaiting their asylum claim decision are not able to work until their status has been resolved. Individuals find this very disempowering as they are forced to rely on sub-standard benefits and to be dependent upon Social Services or NASS. This contributes to low self-esteem and feelings of worthlessness. For a person living with HIV this greatly impacts upon their ability to adhere to their HIV treatment, as they are depressed, living in an uncomfortable and sometimes unsafe environment, with inadequate finances to cover not only their own basic needs, but in some cases the needs of their dependants. All of these elements severely impact on the physical and mental health of the individual.
95. **The Government should develop and implement national best practice guidance on asylum seekers living with HIV that involves both NASS and Social Services responsibilities, including training for senior personnel in both agencies on how to monitor and maintain good practice. In addition, Social Services should be required to undertake regular and comprehensive reviews of the needs of individual asylum seekers with regard to the suitability of their accommodation and benefits package.**

96. **The Government should ensure that people known to be living with HIV are given appropriate financial support and accommodation. Poor accommodation and inadequate financial support greatly impacts upon treatment adherence making the process more difficult and costly to treat in the long-run.**
97. **The Government should review current levels of essential living allowance provided by NASS. Benefits should be enough to maintain good health and a good diet. In addition, housing should be of sufficient standard to maintain privacy, dignity and hygiene for all asylum seekers, particularly those with HIV.**
98. There is a desperate need to have more joined up services between healthcare providers, Social Services and NASS to ensure that the core needs of these individuals are met. In 1999-2000, immigrants contributed £31.2 billion in taxes and consumed £28.8 billion in benefits—a net contribution of approximately £2.5 billion to the economy.<sup>70</sup> Migrants and asylum seekers have continued to bring financial as well as cultural gains to the British economy, yet they continue to be treated like "criminals" and "scroungers." These are individuals who desperately want to work and contribute to their society; some of these individuals are also living with HIV.

<sup>70</sup> *The Independent*. "Asylum the Facts." 23 May 2003.

## Chapter 2: Access to Healthcare and Treatment

*I spoke to one physician and said, "If you are not supposed to treat, what are you supposed to do?" He said, "I treat syndromically; we treat the illnesses. If someone comes with an opportunistic infection, I treat the infection, but I am told not to treat the HIV." That is what happens in Africa. This is not Africa, and we ought to really set the bar a little bit higher than that.<sup>71</sup>*

<sup>71</sup> Oral Testimony to the APPG AIDS and APPG Refugees, 13 May 2003: Yasmin Halima, Naz Project London.

99. When a person decides to migrate to the UK, either to claim asylum or to work or study, they are often unaware of how bureaucratic systems such as healthcare, legal advice, immigration support or education systems operate. To understand how to access various services under these systems, individuals usually look to family or friends for advice and support. If they do not know anyone in the UK, then they are likely to look to external support networks which either offer a common language or which are targeted to specific cultures.
100. Accessing healthcare and treatment in the UK can be a daunting challenge for many recent arrivals, especially if they do not speak English. Different hospitals may apply different regulations regarding a migrant's ability to access treatment and care. At present, the NHS is in the process of modernisation, whereby commissioning responsibilities are being devolved to the local level through Primary Care Trusts. Primary Care Trusts are therefore the main decision-making bodies regarding spending priorities. For HIV, this has had serious consequences.
101. Before the *National HIV and Sexual Health Strategy* was published in July 2001, HIV prevention funding was ring-fenced to protect services from being sidelined or reprioritised. This ring-fence was removed in April 2001, since then decisions rest with local PCTs as to how much funding HIV will receive. In the face of mounting treatment budgets and the need for more specialised HIV services outside London, in large part due to dispersal, HIV services are under greater cost pressures than ever before at a time of record demand.

102. An individual who is newly arrived in the UK will require time to access information on their entitlements to NHS care. They may not have to make this decision until faced with an acute health problem. In addition, they will have to face cultural and language barriers, often being unable to understand the complex information which is being conveyed to them or be forced to use translation services, repeating personal information in front of strangers. Finally, these individuals will require support at every level which can take the form of faith-based groups, community-involvement groups or larger non-profit institutions to ensure their rights are respected and that they are able to access the services and care they need.

## Access and Entitlement to the NHS

*The way in which asylum seekers access and experience treatment for sexual health problems, including HIV, plays an important part in their ability to receive and respond to health related information. The building of a successful working rapport is critical to this process, as it is through the relationship with healthcare professionals that patients come to understand the importance of adhering to treatment as well as the need to disclose factors that may adversely be affecting their health.<sup>72</sup>*

72 Written Submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: Homerton University Hospital in Hackney.

73 Written Submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: ILPA.

103. Section 1(1) of the National Health Service Act 1977 imposes a duty on the Secretary of State for Health to provide a comprehensive health service designed to secure an improvement in the prevention, diagnosis, and treatment of illness within the UK. Section 1(2) stipulates that charges will not be made for such services unless provided for by statute.<sup>73</sup> The ability to charge foreign visitors—non-EU residents—is contained in regulations made under Section 121 of the Act. The Act specifies that the National Health Services (Charges to Overseas Visitors) Regulations 1989 authorising charges in some cases came into force in April 1989. Paragraph 4 limits charging to individuals who have not been "ordinarily resident" in the UK for more than 12 months. Individuals who are in prison, detention/removal centres, work permit holders, self-employed, students or fiancées of residents are eligible for free treatment under the NHS.
104. However, for visitors who have been in the UK for less than a 12 month period, they are only responsible for charges in certain cases. Paragraph 3 of the National Health Service (Charges to Overseas Visitors) Regulations 1989 indicate that if the individual presents at the Accident and Emergency services for an emergency, he/she is not responsible for payment and all treatment is free at the point of delivery irrespective of nationality or immigration status. This regulation also enables people to receive pre and post-test counselling for an HIV test. General Practitioners however, are not subject to the 1989 regulations as most are self-employed. This means that GPs are not obliged to charge anyone for their services and therefore have the discretion to treat

anyone free of charge, irregardless of their immigration status. In their submission to the Inquiry, Immigration Law Practitioners' Association writes:

74 Written Submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: ILPA.

Given the serious nature of both HIV positive or AIDS status any attempt to deny access to treatment and especially access to anti-retroviral treatment whilst the patient is in the UK is likely to give rise to a serious risk of them being subjected to inhuman and degrading treatment.<sup>74</sup>

75 Written Submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: Terrence Higgins Trust.

105. At present, a person may present to Accident and Emergency with a serious AIDS-related illness or with complications resulting from opportunistic infections associated with HIV. If their immigration status is unclear or undecided, or if they have been in the UK for less than 12 months, they are only entitled to be treated for the infections but not for the underlying cause of their illness, HIV. This entails that individuals will only be treated to become well enough until they acquire another opportunistic infection caused by HIV. This not only makes HIV/AIDS in the long-run more expensive to treat but it also creates a great risk to the individual as he/she presents at later and later stages of HIV/AIDS. In a written submission from the Terrence Higgins Trust, they explain "This creates a 'cat and mouse' situation whereby someone is constantly in a state of crisis about their severe ill-health and where, inevitably, their immune system is fatally weakened and their longevity shortened."<sup>75</sup>

76 Written submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: MedFASH.

106. This situation is particularly acute for pregnant women who, under the government's universal offer and recommendation programme are being offered an HIV test as a routine part of their ante-natal care. They can therefore test positive for HIV and then be denied the treatment required to prevent HIV being transmitted to their child. Several parties giving evidence to the Inquiry thought that this constituted cruel and inhuman treatment. In a submission from the Medical Foundation for AIDS and Sexual Health (MedFASH) they explain "MedFASH does not believe that any (pregnant) woman should be denied this treatment in the UK, regardless of her immigration status."<sup>76</sup> Dr Angela Robinson explains:



77 Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Inquiry: Dr Angela Robinson, President of MSSVD.

Unlike when we deal with the gay population when somebody has HIV through heterosexual transmission, if you see a pregnant woman you have not got one patient, you have at least three. You have got the baby, and the partner and the rest of the family so it more than triples the workload when you see one person with an HIV problem.<sup>77</sup>

78 Written Submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: British HIV Association.

107. The job of a clinician is, first and foremost, to treat those in need. However with rising costs, many reported being cautioned by managers from treating every individual who presents or who may require treatment for HIV. This requires many clinicians to face an ethical dilemma: to treat the individual in line with the basic tenets of their profession, or to exercise immigration powers for which they are not trained and in situations that are less than neutral, and decide who should and should not receive treatment. The British HIV Association (BHIVA) exclaims "once a person is admitted to hospital for emergency care, the UK has assumed responsibility for their welfare."<sup>78</sup>

79 Individuals may present late to health services for various reasons including: a lack of knowledge on where to access care, cultural and language barriers, fear of disclosing immigration status or fear of having asylum application rejected.

108. Clinicians report that individual cases are becoming more and more complex as individuals may present with co-infection requiring care which is more complex and costly. In addition, asylum seekers and migrants, many of whom may already be experiencing AIDS-related complications, may present late to health services.<sup>79</sup> The length of time for consultations also increases as many individuals require interpreters due to language barriers who translate either in person or through the use of telephone interpreting services like Language Line. In addition, extensive discussions and explanations may be needed over a series of consultations to explain the complex nature of HIV treatments, terminology, disease-progression and complete adherence issues.

109. There are anxieties around treatment budgets as the ring-fence around HIV prevention funding has been removed and local priority setting has transferred to the PCT level. Because decisions at this level are relatively new, there is concern that PCTs are overlooking the true costs of treating people with HIV and consequently not prioritising the necessary funds. In an effort to highlight this particular concern George House Trust explained:

## All-Party Parliamentary Group on AIDS

### Migration and HIV: Improving Lives in Britain

80 Written submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: George House Trust.

81 Written Submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: AHPN; see Brooks, L. "Five Tough Questions about Asylum," *The Guardian*, 1st May 2003.

82 *The Guardian*, 12 April 2000.

83 *The Guardian*, 28 February 2002.

84 *BBC*, 27 June 2000.

85 Written Parliamentary Question to Minister of State for Health, 25 March 2003.

...In a healthcare economy where there are significant budgetary pressures, and where paying for HIV drugs is at the frontline of those budgetary pressures, we must continue to be vigilant to ensure that HIV positive immigrants and asylum seekers have access to life saving treatments in this country.<sup>80</sup>

110. As mentioned earlier, there are the widespread concerns that the NHS is being over-stretched, in part due to increasing numbers of individuals with HIV and rising costs of treating a long-term chronic illness such as HIV. However, Vivienne Nathenson, head of the science and ethics committee at the BMA argues that the cost of asylum seekers to the NHS is marginal, "The system is very stretched, and we have a shortage of GPs. It (HIV) adds to the strain but it didn't create it."<sup>81</sup> In fact, Diabetes and complications arising from it cost the NHS £4.9 billion per year;<sup>82</sup> illnesses caused by alcohol abuse cost the NHS £3 billion per year;<sup>83</sup> and treating smoking-related diseases cost the NHS £1.7 billion per year.<sup>84</sup> In 2001 the NHS spent £279 million on HIV and AIDS in the UK;<sup>85</sup> of the total NHS budget, approximately 1% is reported to be spent on HIV.

111. Clinicians continue to face an ethical dilemma over who is entitled to NHS care and who is able to access it. There is an understanding that even if individuals were refused free care they would be entirely unable to pay in most cases, amounting to the prohibition of access to treatment. This not only places the clinician in an unfair situation, it also has serious implications for public health. If more and more people are denied access to treatment and care, the more individuals are at risk of engaging in high risk behaviour. Daisy Byaruhanga of Innovative Vision Organisation explains:

You are a visitor, you are a student. All sorts of scenarios are happening in different hospitals. Different hospitals are telling different stories. That is a challenge. Some doctors will treat without questions but some doctors are turning into immigration officers they are so concerned about the public purse. What do we do? It is a challenge to our efforts in encouraging others to test.<sup>86</sup>

86 Oral Testimony to the APPG AIDS and APPG Refugees, 8 May 2003: Daisy Byaruhanga, Innovative Vision Organisation.

112. Effective control of HIV demands timely access to treatment, care and prevention services. The national standards under the British HIV Association treatment guidelines should be followed and implemented for all people known to have HIV in the UK regardless of immigration status.
113. The Government should ensure that healthcare professionals, including GPs and clinicians based in areas where people with HIV are being dispersed, are offered training in the complex clinical, psychological experiences, cultural and mental health needs of migrants and asylum seekers.

## Information Access

*Social integration and then acculturation is a complicated process involving linguistic, social, cultural, and conceptual transference processes that can denude migrants of everything they have previously been used to and which may have provided the basis of their identity.<sup>87</sup>*

87 Carballo and Siem as cited in: Haour-Knipe M and Rector R. *Crossing Borders: Migration, Ethnicity and AIDS*. London, Taylor and Francis, 1996; UNAIDS. *Migrants' Right to Health*. Geneva, March 2001.

88 Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 13 May 2003.

114. When an individual arrives in the UK, much of their time will be spent on accessing information. Information regarding one's ability to access services and networks throughout the UK is usually passed on through friends and relatives. People who do not have relatives and friends may access information at the nearest hospital, at religious or social functions or universities if students. Walter Gillgower of Terrence Higgins Trust points out "Word of mouth is a very powerful method of communicating information, hence the importance of going back to where people access that information,...to continually update and ensure that the information that is given is correct."<sup>88</sup>
115. To ensure that information is available and disseminated throughout the groups of individuals who most need it, statutory and voluntary organisations need to develop innovative methods of transmitting information. This entails working through community-based groups and providing information in places where people socialise, such as barber shops, music shops and food shops. It is also necessary to take into account that people may prioritise other needs over their health needs, in particular their immigration status, therefore information needs to be compatible with other issues besides health.
116. Information also needs to be culturally appropriate. The provision of information in English only means that vulnerable individuals may fall through the cracks and risk not receiving essential information about where they can go in a healthcare emergency. Richard Senwewo of the African Community Involvement Association explains:

There may be certain people from one culture in a particular area who do not understand English, and the information should be translated into languages which can be easily understood by

89 Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 13 May 2003.

these respective communities. The information also has to be simplified to suit the needs of the communities we are dealing with. Most of the information available at the moment is quite complex, especially to newly arrived asylum seekers.<sup>89</sup>

117. However, most of the services which provide comprehensive, targeted information in a culturally appropriate manner are still concentrated in larger metropolitan areas such as London and Manchester. When asylum seekers are dispersed they can find themselves in regions where there is a lack of vital information in languages other than English. In addition to belonging to the highly stigmatised group of asylum seekers, they may also have HIV. The stigma surrounding these issues may make it extremely difficult for an individual to come forward and actively search vital information.
118. **The Government should ensure that health information is targeted in a more effective manner to marginalised individuals newly arrived to the UK. There needs to be more health/HIV-related information provided outside London which target a range of needs.**

## Support Networks

*...She came and she was I think more empowered. I must say I take my hat off to them, asylum seekers...in most cases are very resilient, they will persevere, she came and said: 'You know what it is that I really need, it is not about all of this that has been provided, what I need is to stress what has happened. From a very early age I have been pushed from one country to another, I do not know where my parents are and it has taken me this long journey to know what my need is.' I think it is realising that central to this is the whole issue of psychological trauma.<sup>90</sup>*

<sup>90</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 8 May 2003: Spiwe Takura, Terrence Higgins Trust.

119. One of the most crucial elements in developing feelings of security and certainty is the individual's ability to develop support networks within their environment. These networks allow individuals to learn which services are available and suitable to their needs, what interventions are in place to address their concerns and anxieties, give them a forum to discuss their experiences and find a common understanding among individuals in similar circumstances.

*"It's a totally different picture I saw when I went there, people are putting on music, dancing; some of them are dancing; and they are talking about their difficulties." –HIV Positive Ugandan Woman*

120. Certainty and security can be achieved when an individual finds housing in which they feel safe and comfortable, when they have an income which allows them to fulfil their needs beyond core necessities, when they have friends and networks upon whom they can depend and finally, when they are in stable health. When any of these elements is missing, which can occur through being suddenly dispersed or threatened with removal, the individual's physical as well as mental state may suffer. Dr Oliver Davidson, a clinical psychologist working in North Central London in HIV explains:

91 Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 13 May 2003.

...The degree of social networking and social support structures around a person is the key issue in determining their level of risk. So as soon as you hear of a person, regardless of their background, who is in significant psychological distress for whatever reason, and you learn that they have next to no social support, alarms bells ring, and it really is a stepwise increase in the concerns that you have in responding to that person, because all the evidence suggests that that person has a much greater likelihood not to function socially and to be a risk to themselves and at times to other people.<sup>91</sup>

92 Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 13 May 2003: Justine Sserwadda, Positively Women.

93 Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 13 May 2003: Dr Wondwosen Eshtu, Ethiopian Health Support Association.

121. The role community-based organisations in the UK play are a key component in providing the necessary support that migrants with HIV require throughout the time they are here. Many voluntary organisations provide courses on anti-retroviral therapy, understanding complex medical terminology, HIV prevention as well as counselling services and discussion forums. Many of these organisations also provide extra resources to individuals such as further allowances for transport, cash for food in specialised markets catering to different cultures and tastes, as well as resources for furniture, day-care and alternative therapies. Community-based organisations are in many ways filling the gaps in support that the Government does not provide for. Justine Sserwadda of Positively Women points out "When it comes to social workers, they do not always access these users, just because of their immigration status. This has always led to community organisations that always meet and pick up the pieces."<sup>92</sup> Dr Wondwosen Eshtu adds, "Our main aim is just to make the client feel that they are still human beings and to build up their confidence so that they do not lose their identity."<sup>93</sup>

*"These organisations, apart from giving me a carer they have also made sure that my children are comfortable and they have also made sure I am comfortable by coming to visit me in hospital, and even talking to me on the phone, and that is very good, it just made me very happy." –HIV Positive Kenyan National*

122. It is in the best interest of the individual and public health for there to be a concentrated effort geared towards ensuring individuals can access and maintain valuable support networks. This means we should avoid as much as possible sudden changes in the surroundings of the individual. It is key that the individual be allowed to develop networks and trust among healthcare providers, immigration services and community-based organisations. People living with HIV need a multitude of services to ensure their needs are met. If these services have to be continually rebuilt due to dispersal or the constant threat of removals, this puts unnecessary stress on the individual leading him/her to delay accessing services and support.



## Cultural and Language Barriers

123. Not being able to speak and understand the language of the country in which one is residing can create numerous barriers to access, in particular one's ability to interact with formal structures like health or immigration services. If a person is offered a test for HIV and given pre and post-test counselling, then there is the question of whether or not that individual fully understands the consequences of such a test or result. For individuals from developing countries, particularly from Sub-Saharan Africa, an HIV positive test result is literally a 'death sentence' as treatment for HIV and AIDS is unavailable to the majority of the general population. For an individual who migrates to the UK and is given a positive test result, this can be extremely traumatic if not explained in the correct language or with trained interpreting services.

94 HM Inspectorate of Prisons.  
*Inspection of Five Immigration Service  
Custodial Establishments.* April 2003.

124. However, there are challenges to using interpreting services. In most cases they are expensive to use and so not all services which require interpreting facilities use them. In Her Majesty's Inspectorate Report on Prisons, it is reported that interpreting services are under-utilised in detention and removal centres either because staff are unaware such services exist or feel they are too resource-intensive to use.<sup>94</sup> Clinicians report that interpreting services, which often are conducted by telephone, have the effect of tying up the surgery's line to receive other calls. In addition, people with HIV are hesitant to trust such services as it requires them to convey very personal information through strangers and worry about confidentiality. A representative from Homerton University Hospital in Hackney points out:

Our understanding of this is based on difficulties in people working with interpreters that cannot be seen, which seems to interfere with patients being able to sufficiently trust that the information they disclose will be treated as confidential.<sup>95</sup>

95 Written Submission to the APPG  
AIDS and APPG Refugees  
Parliamentary Inquiry: Homerton  
University Hospital in Hackney.

125. Some migrants may bring their children with them to doctor's appointments to translate for them. In most cases this is inappropriate as an individual should not have to report such personal information in front of young people. Kate Mavor, the Executive Director of Language Line, explains:

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96 Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 13 May 2003.

The other impediment that we hear about from GPs is that someone will turn up with their child, and the child acts as the interpreter; and this is highly inappropriate, particularly with sexually transmitted diseases, where a GP makes a diagnosis and asks perhaps an 8-year old boy to tell his mother she has got an STD. These things happen, and the situation needs to be dealt with very vigorously because it is obviously totally unacceptable.<sup>96</sup>

97 Written Submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: George House Trust.

126. Community-based organisations are having to recognise this need and to provide information in several languages as well as different cultural settings. George House Trust writes "As an agency, we are starting to have basic information about what we do in other key languages and have engaged volunteers, particularly French speakers, to help in informal translation in social settings."<sup>97</sup>

127. The challenge of cultural and language barriers is not just ensuring that information is provided in a language which can be comprehended but ensuring that the information itself is understood by the individual. This means that clinicians have to spend more time with patients explaining complex terminology, such as the definition of CD4 counts, drug-resistance and total drug adherence. We need to provide comprehensive language services outside of London in areas where people are being dispersed. Yasmin Halima of Naz Project London said:

98 Oral Testimony to the APPG AIDS and APPG Refugees, 13 May 2003: Yasmin Halima, Naz Project London.

We have talked a lot about language, but the key thing to me is that I would make a real distinction between language and understanding and communication. There has been a piece of research that has proved that of this cohort of BME patients, 20 percent of patients were literally told by their physician, 'you have a drug-resistant virus' and thought that meant they could not transmit. There is a real need to be able to explain some of these things.<sup>98</sup>

128. **The Government should ensure that wherever possible the use of family and friends as interpreters in healthcare settings should be avoided and children should never be used. Face-to-face interpreting should be a preference over telephone interpreting where this is**

possible. Services such as NASS need to consistently link up with qualified language interpreters in all settings which involve migrants. In particular, the Government should provide comprehensive language services outside of London in areas where people are being dispersed.

## Chapter 3: Integration into UK Society

*Even when they are granted leave to remain, what actually happens is they cannot probably transfer their skills. They maybe left their families behind and are desperate for work, and then someone who may have the qualifications that I did will actually end up as a cleaner, or juggling two, three, four jobs, which is actually not very good for the health, and then the children are left in the house because childcare is very expensive. So it brings up many things and actually increases the stress. From my experience, the one thing I have learned is that HIV and stress are at parallels...<sup>99</sup>*

<sup>99</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003: Beatrice Nabulya, HIV Positive Service User.

129. Previous chapters have illustrated the challenges an individual may face when newly arrived to the UK, specifically challenges for someone who is diagnosed with HIV. Certainty in one's immigration status can take up to several years until someone is given the right to settle in the UK. During this time, an individual may have moved several times, and have spent time in accommodation which was unsuitable for them and any dependants. The individual may change healthcare providers a number of times, especially if they have been dispersed or held in a removal centre.
130. After a person living with HIV is given the right to remain or settle in the UK, one would expect that levels of stress and anxiety would subside but integration into UK society can be equally as challenging. A person is likely to encounter difficulties finding work not only due to the problem of proper skills transfer, but also because living with HIV may mean they require more flexible working schedules to cope with the sometimes erratic nature of the illness and also to be able to make hospital appointments and any other services they are receiving.
131. Individuals may also encounter housing difficulties, sometimes because of delays in issuing status letters by the Home Office, which creates problems in accessing benefits, but also due to stigma and discrimination against asylum seekers and people living with HIV. Some landlords may openly discriminate against someone with HIV by

denying them housing. There may also be continuing problems regarding dependants. If the Home Office is still in the process of deciding the immigration status of dependants, they may be ineligible to reside with the family members in social housing.

132. Finally, parents have expressed having difficulty in finding places for their children to attend formal education. At present, in some areas there is a shortage of school places; for children coming in the middle of term this can be increasingly problematic. In addition to this, children may be discriminated against institutionally if it is discovered that a child has HIV. Although there is very clear guidance to schools issued by DfES, it is not always understood in schools and some schools have been found to discriminate against children on the basis of their HIV status.
133. When commencing integration into UK society migrants with HIV are faced with a two-fold challenge. The first is being discriminated against because they are asylum seekers or migrants and the second is being stigmatised against because they have HIV. Both challenges can make integration unpleasant as well as troublesome for the individual and their family. Many will continue to experience depression and anxiety for many years after their entry into the UK.

## Access to Work

*It's so difficult because I would like to go back to work but all days are not the same, sometimes you can work, sometimes you can't work,...I would like to be working, because as well as I need my freedom and I want to work freely.<sup>100</sup>*

<sup>100</sup> Written submission to the APPG AIDS and APPG Refugees : Doyal, L. and Anderson, J. "HIV Positive African Women Surviving in London : Report of a Qualitative Study." 2002.

134. Migrants with HIV who are given the right to settle in the UK will then have the right to work. This allows them to move away from the benefits system, and most importantly it restores their sense of self-worth and empowerment. Individuals living with HIV who are looking to start work in the UK face three main challenges: their health, skills transfer and the challenge of disclosure of status.
135. Simply because a person is on a treatment regimen for HIV does not mean that they will experience optimal health for the rest of their life. The person will still have days or weeks when their immune systems are less resistant and they fall ill. They will still be more prone to acquiring opportunistic infections than the average individual and they may still encounter life long problems with treatment, including severe weight loss and weight gain, weakness, nausea, diarrhoea and experience flu-like symptoms to name a few. This can make returning to a full-time work schedule challenging in most cases. In addition, work stress can complicate HIV. Some people remain symptom free for several years and only when they return to a normal work routine with normal work stress, do they re-experience physical ailments associated with HIV. Some cannot tolerate a 9.00 to 5.00 job and are better suited for part-time work or flexible hours to accommodate medical appointments, childcare and sudden physical manifestations of HIV. Edith Kaggwa of Positive Futures explains:

Of course being HIV positive itself is unpredictable because people do not know when they will be falling ill. Today they might be up and running and tomorrow they will be down with pneumonia, and treatment itself is unpredictable. Today it will be working and tomorrow they will get all the side effects and will go down.<sup>101</sup>

<sup>101</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003: Edith Kaggwa, Positive Futures.

136. Migrants also experience challenges when they try to transfer skills acquired in their home country and apply them to finding work in the UK. Many individuals who are able to make the journey over to the UK may have been of relatively high stature in their home country. They may be well-qualified academically and some may have served as high-ranking officials in their home governments. It is very expensive to travel to the UK, and it is often only the better-off who are able to make the journey over. However, an individual with a post-graduate degree in science in his home country may have to be a taxi driver in the UK if his skills are not recognisable. Many people have to alter their entire career path just to find work in the UK as they have families back home to support and provide for.

*"I'm supporting, I'm paying my son here and I'm paying for them in Africa, I'm paying the house they stay in, I'm paying for the food they eat"—HIV Positive Service User, Ugandan National*

137. Many organisations offer skills upgrading and computer courses to give migrants the skills that a UK employer would find a necessity. Many of these programmes are offered by organisations providing for people living with HIV. In fact, some migrants with HIV decide to work in the voluntary sector for organisations providing services for people with HIV, because the employers may be positive themselves, work hours are more flexible and the problem of disclosure is not such an issue. Edith Kaggwa points out:

I have found HIV organisations being very supportive, and you find so many HIV organisations are employing HIV positive people. For instance, Positive Futures, Positively Women, Terrence Higgins Trust—all of them employ a lot of HIV positive people because this is the place where they feel more comfortable and they can disclose their status without being discriminated.<sup>102</sup>

138. Finally, there is the issue of disclosure of one's HIV status. Although the Disability and Discrimination Act is in place to ensure people with symptomatic HIV who are openly discriminated against are protected

<sup>102</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003; Edith Kaggwa, Positive Futures.

<sup>103</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003: Julian Hows, Strutton Housing.

under the law, people with HIV may still have their HIV status disclosed "by default."<sup>103</sup> They may be on a placement and be receiving treatment, they may have to explain to their employer reasons for illness or leaving for medical appointments, or they may simply be 'suspected' of having HIV. This can be very difficult for a person living with HIV as they may be treated differently as a result of their positive status. Voluntary organisations are actively working with some employers to sensitise them on HIV/AIDS discrimination concerning disclosure and confidentiality.

139. The sooner individuals are able to get back to work the quicker they are able to rebuild their physical and mental well-being. They are also able to begin rebuilding their life after having experienced extreme levels of instability and uncertainty caused by migrating to the UK and learning they have HIV.
140. More training needs to be done with employers at the national level regarding the issue of disclosure and confidentiality in the work place. In addition, more awareness-raising at the general level of the population needs to be done in order that people know more about living with HIV. This means explaining to employers what it means to be on treatment and re-emphasising how HIV is transmitted from person to person. The Disability and Discrimination Act should be extended to cover HIV from the point of diagnosis.
141. **The Government should provide more support to migrants with HIV in getting back into the work force as soon as possible. It has been proven that the ability to work improves the physical and mental health of migrants with HIV. This entails a revision of the reaccreditation process, more availability of skills training such as IT, and that more flexible hours are introduced so that individuals have choice in terms of how they cope with HIV in the work place.**



## Access to Housing

*...Most of the people who come to us when I see them...are showing shock, denial, grief, isolation. They are fearful, suicidal and totally overwhelmed by the situation they are in. They might well have a total and absolute fear about confidentiality. Many of those clients have families, and are migrants who are usually at the lower end of the socio-economic scale in this country at any rate and are struggling anyway.<sup>104</sup>*

<sup>104</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003: Julian Hows, Strutton Housing.

<sup>105</sup> Written submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: Terrence Higgins Trust.

142. After being given the right to settle in the UK, individuals will change from receiving benefits from NASS or Social Services to earning their own wages and paying their own expenses. One of the principle things an individual will have to do is to find housing for themselves and any dependants. However, there are numerous barriers to accessing housing once the person is no longer receiving benefits. Terrence Higgins Trust indicate that the challenges may be the result of several factors such as delays in receiving National Insurance numbers, delays in processing applications, clients failing to qualify as 'in priority need' under Local Authority homelessness provisions, the provision of unsuitable accommodation and the refusal by housing departments to whole families where one or more members have not been granted leave to remain.<sup>105</sup>
143. One of the first things an individual needs to apply for once they are given the right to settle in the UK is a National Insurance number. Depending upon the area where the individual resides, this can be a problem. Benefits Agency offices may be reluctant to issue a National Insurance number to someone who cannot show they have the offer of a job. Employers may be reluctant to offer a job to someone who cannot show they have a National Insurance number. During this waiting period individuals may be forced to rely on family members and acquaintances for loans and support.

*"I just pray I get a small place to myself, maybe when I sit there alone and put my HIV in perspective, when I am alone I will be able to plan the future."—HIV Positive Ugandan National*

144. It is not uncommon for individuals to be given housing which does not meet their needs as people living with HIV. Medical Assessment Officers (MAO) might think because a person is on an HIV treatment regimen that they are not prone to infections or in need of special arrangements as people with special needs. Again, however, individuals are placed in hostel-like accommodation with shared bathroom and kitchen facilities; it can be difficult to get people living with HIV individual facilities.
145. Finally, to qualify at all for consideration for housing under special needs the individual would have to disclose his/her HIV status. Some people may fear that authorities would breach confidentiality and that disclosure could hurt their chances of getting adequate housing. Many individuals continue to go for months without housing, homeless or squatting or in accommodation which is unacceptable and places them at risk of worsening their HIV illness.

## Access to Education

146. Many people come to the UK with dependants or during the time their applications for immigration or asylum are being processed they may have children. Some of these children may have HIV. Parents of children who are either infected or affected by HIV face some key challenges in accessing education in the UK. The first is access to schools which may be over-stretched or under-funded with limited spaces throughout the year. The second is the issue of disclosure.

<sup>106</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003; Dr Lyall, CHIVA.

147. At present there are less than 1,000 children or young people in the UK with HIV and approximately three-quarters of these are in London. Also, HIV in children is different from the illness in adults. It is more complicated in that it affects the nervous system in some children, therefore many will require a multitude of different needs throughout their lives.<sup>106</sup> Dr Lyall from the Children's HIV Association (CHIVA) points out that these young people will have been exposed to a considerable amount of drugs in their development and they may go on to experience complicated side effects of their treatment.

148. Schools where there may be places available may be in areas which are harder to get to, beset by problems due to under-funding or because they are the least popular. Many of these schools may not be suitable for a young person with HIV. Different schools have different policies regarding mid-term admission, procedures for dealing with healthcare and the management of medication.

149. Policies which are in place for managing medication may mean that the child's status may be disclosed depending upon what is done with that information. In addition, infection control policies differ from school to school. Sheryl Burton from the National Children's Bureau explains:

Whether or not there is a supportive environment which is going to help integration and whether there are policies around infection control are not in themselves stigmatising, because if the school has an appropriate infection control policy which applies to all children then you will not have the latex gloves out for dealing with any minor accidents.<sup>107</sup>

<sup>107</sup> Oral testimony to the APPG AIDS and APPG Refugees Parliamentary Hearings, 20 May 2003.

150. A supportive environment which applies universal precaution policies to the whole school will create an environment for children and families in which they feel they are able to disclose the HIV status of the child. This will in turn impact upon how quickly and effectively they are integrated into the system. All schools should adopt such policies and universal precautions regarding blood-borne illnesses should be taught to young people at all level from within the education system. Teachers and managers should be given more in-depth training regarding the Disability and Discrimination Act as well as more information on the experiences of children and young people living with HIV today.

## Our Global Responsibility

151. At present, over 42 million people are living with HIV throughout the world, 95% in developing countries. Over 30 million people living with HIV are from Sub-Saharan Africa. Some countries in Southern Africa have HIV prevalence levels above 30%, in particular Botswana—38% and Zimbabwe 33%. In one decade average life expectancy has gone from 60 or more to under 40 in many countries in Africa.
152. Rates of HIV and AIDS infections have vastly exceeded predictions and have led to double-disasters causing famine and food insecurity in countries like Malawi and Ethiopia. There is simply not a healthy workforce able to produce and cultivate food. HIV and AIDS have also been reported to be the reason for prolonged internal and external conflict in part of Sub-Saharan Africa, mainly in Northern Uganda and the Congo. Peace arrangements can lead to HIV positive soldiers and military returning home and increasing infection in the general population. Some military units, like ECOMOG in Sierra Leone, are experiencing 85% HIV prevalence.
153. Millions of children and young people are losing one or both parents to AIDS throughout the developing world. In 2010 orphans will account for 15-25% of all children in Sub-Saharan Africa, who will be left entirely destitute.<sup>108</sup> Many of these children will form a new generation of young people who have had almost no access to education, who have been abused and exploited, who have grown up without any social support or family networks and without a cultural identity of who they are or where they have come from.
154. At present, approximately 58% of all AIDS cases in Sub-Saharan Africa are women. Not only are women more physiologically susceptible to HIV but they are also more socially vulnerable. They are often deprived of their rights in predominantly patriarchal cultures, with little say in the sexual lives of their spouses. Many have husbands who migrate seasonally, either internally or externally, in search of work, leaving their families behind. When their husbands return they may become infected with HIV. Some women are also forced to engage in commercial or transactional sex to provide for themselves or their families. Finally, some women will also be the victims of war experiencing kidnapping and rape by soldiers or military from the opposing forces.

<sup>108</sup> Presentation by Dr Alan Whiteside to the APPG AIDS and APPG Africa in May 2003: "HIV/AIDS: A Long-Wave Disaster for Africa."

155. In September 2002, the National Intelligence Council of the US released a report predicting that by 2010 there will be between 50 million and 75 million cases of HIV/AIDS in five of the world's most populous countries, possibly dwarfing the current epidemic in Sub-Saharan Africa and exceeding worst-case scenarios for the global burden of the disease. The five countries that will be affected are Nigeria, Ethiopia, Russia, India and China. In addition, 10 new countries will be joining the EU, some of which have higher prevalence levels in injecting drug users and among commercial sex workers. The combination of these two factors could impact upon the HIV epidemic in Europe including the UK.
156. In February 2003, President George Bush announced during his Presidential State of the Union address that only 50,000 people in Africa were receiving treatment for HIV. Many of these individuals are high-ranking government officials, doctors, civil servants or military. The general population in developing countries affected by HIV has no access to treatment. In December 2002, governments met to finalise agreement on the Doha Trade Negotiations established through the World Trade Organisation regarding Intellectual Property Rights on drugs manufacturing. This agreement would allow developing countries to generically manufacture their own anti-retroviral drugs currently patented by several pharmaceutical companies. All countries but the United States agreed to the commitments. At the time of the writing of this document, agreements were still not finalised.
157. There are several initiatives in place throughout developing countries to help countries design National AIDS Programmes and to support civil society organisations in developing community-led and based interventions. However, health systems, due to decades of under-investment, conflict and environmental disaster, have been decimated in most countries, with few services operating outside urban and semi-urban areas.
158. In 2001, the Secretary General of the United Nations, Kofi Annan, announced that to prevent and treat HIV and AIDS the world would need between \$8 and \$10 billion per annum. To mobilise this commitment into action he set up the Global Fund for AIDS, Tuberculosis and Malaria. The Global Health Fund has been operating

fully since March 2002 and has gone forward with two rounds of grant allocations, providing \$1.5 billion in support and resources over the period of two years to over 150 programmes in 93 countries. However, Western countries are hesitant to continue to support the Global Fund until it can show 'results.'

159. The US President also announced a commitment of \$15 billion over 5 years to AIDS in several countries in Africa and the Caribbean. Although the West is coming to realise that HIV in developing countries will have a 'long-wave impact' on global trade, stability and the environment, it is still not making the total commitment necessary to eradicate HIV and AIDS in world.
160. In the UK we are experiencing a local manifestation of what is happening on a global scale. The epidemic is becoming increasingly heterosexual in many places and migrant or immigrant communities are becoming the most at-risk communities for acquiring HIV. Many of these individuals are coming from the most highly-affected countries in the world: countries experiencing years of conflict, countries where treatment is simply not available. The National AIDS Trust explains:

The most just, practical, effective and sustainable response to the entirely natural human inclination to move in the search for a better life is to reduce the factors that make population movement desirable and to enhance the factors and conditions which will improve the quality of life in the countries from which people are migrating.<sup>109</sup>

161. We cannot promote human rights and access throughout the world yet deny it in our own country. The British Association for HIV writes:

The United Kingdom is an affluent nation with a comparatively low prevalence of HIV infection in global terms. Our moral obligation is to show solidarity by providing international development support and assistance to the severely affected, resource-poor countries of Africa, the Caribbean and elsewhere. While the UK cannot be expected to solve the global crisis of lack of access to HIV/AIDS treatments single-handed, to focus our efforts on discrimination and exclusion seems petty and distasteful when many more constructive avenues are available.<sup>110</sup>

<sup>109</sup> Written submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: NAT.

<sup>110</sup> Written submission to the APPG AIDS and APPG Refugees Parliamentary Inquiry: BHIVA.

162. We have the resources and the technology to treat every individual with HIV in the UK. To deny such treatment under any condition once the individual has learned they have HIV is cruel and inhumane. **The Government should work to finalise the Doha trade negotiations with regard to international treatment access, to channel increased resources to health systems development in developing countries and to increase long-term support to initiatives like the Global Health Fund.**
163. The Government should reconsider its understanding of Article 3 of the ECHR. At present, individuals being treated for HIV cannot be returned to their home country in the "complete absence of treatment"; this should be amended to consider instead the "practical availability" of treatment. The Government should regularly review treatment availability in developing countries as this is susceptible to constant change.



## *Policy and Practice Recommendations and Conclusions*

It is necessary to point out the commendable efforts of the UK government in responding to HIV/AIDS since the beginning of the epidemic. A concerted response at all levels has meant that the UK has one of the lowest levels of HIV prevalence in the West. We have successfully kept infection rates among injecting drug users down and worked to ensure that fewer and fewer people are dying of AIDS-related illnesses through ongoing treatment and care. Through the Government policy of universal offer and recommendation of HIV testing in ante-natal clinics we have been able to identify much earlier pregnant mothers with HIV to ensure they are treated in a timely manner. We were one of the first developed countries to actively support the development of an AIDS vaccine and we were one of the key countries in helping to set up and support the Global Fund for AIDS, Tuberculosis and Malaria.

The UK has done a considerable amount with regard to HIV/AIDS prevention and treatment, however at present we are taking our eyes off some of the most vulnerable groups in the UK. Although infection rates in gay men had subsided since the beginning of the epidemic, rates among younger men have been increasing during the last few years. In addition, we are facing a situation in which the HIV virus is constantly changing making it more complex to treat with current anti-retroviral therapies. It will be necessary for the Government to continue to support initiatives to develop a successful AIDS vaccine and to carry on supporting the development of new drug therapies. Although the UK Government has a lot to be proud of it is important that we do not give the impression that this local and global challenge is solved.

We believe we must continue to respond to HIV in a compassionate and humane way. The following is a list of recommendations we would like to make to the Home Office, the Cabinet Office, the Department of Health and the Department for International Development:

1. In accordance with the recommendations made by the House of Commons Health Select Committee recent report on Sexual Health, the Government should promote comprehensive HIV and sexual health education targeted to the wider public regarding heterosexual transmission. (Paragraph 35)

## *Testing Upon Entry*

2. The Government should reaffirm its commitment to the UNAIDS guidelines against mandatory testing upon entry for HIV. It would be in breach of international obligations and human rights to give mandatory HIV tests to asylum seekers upon entry and in addition there is no evidence to support that such a policy would be effective at protecting public health. The consequence of testing upon entry would be worse as people with HIV would avoid presenting for testing and furthermore, HIV would risk becoming further stigmatised. Instead the Government should encourage policies of inclusion which support testing based on informed consent with the aim of reaching individuals in need so that they can receive timely access to care and treatment. (Paragraph 62)

## *Asylum Seekers and Individuals Claiming Article 3 Status*

3. The Government should not place people with serious communicable diseases, such as HIV, in detention or removal centres for immigration purposes where it is not possible to provide suitable medical care for them. All evidence received during the inquiry suggests that removal centres are unsuitable places for people living with HIV. Detention can undermine efforts to maintain good health. (Paragraph 74)
4. Social Services should be required to undertake regular and comprehensive reviews of the needs of individual asylum seekers with regard to the suitability of their accommodation and benefits package. (Paragraph 95)
5. The Government should develop and implement national best practice guidance on asylum seekers living with HIV that involves both NASS and Social Services responsibilities, including training for senior personnel in both agencies on how to monitor and maintain good practice (Paragraph 95), specifically:

- *The Government should make extra funding available to deal with decisions resulting directly from dispersal policies. Current methods of funding leave PCTs with no flexibility or reserves to be able to deal with sudden and unexpected demands on clinics and GUM services resulting from dispersal. (Paragraph 85)*
- *When a decision of dispersal is made by NASS regarding a person known to be living with HIV, all such decisions should necessarily take into account expert medical and professional advice. Any decision by NASS to overrule specialist advice should be justified. (Paragraph 86)*
- *The Government should require NASS to provide satisfactory evidence that dispersing an HIV positive asylum seeker will not jeopardise their ongoing medical and psychosocial care. (Paragraph 86)*
- *A person with HIV should not be dispersed if dispersal is going to severely impact upon their health. (Paragraph 87)*
- *NASS should only continue to disperse people living with HIV to areas where HIV clinical expertise and capacity is available to treat the complex and manifold needs of migrants and asylum seekers, in particular to places with a multiplicity of cultural and language services, mental healthcare services for trauma victims and HIV support services and networks. (Paragraph 87)*
- *When an asylum seeker with HIV is dispersed they should be given sufficient notice—at least seven working days. The Government should ensure that an organised process of referral and handover of care is in place. (Paragraph 88)*
- *Particular consideration should be given to the treating physician in order to ensure that required notes and materials can be duly forwarded in time onto the awaiting physician in the dispersal area and to the person known to be living with HIV to ensure they have an adequate amount of medication to take with them. (Paragraph 88)*

6. The Government should ensure that healthcare professionals, including GPs and clinicians based in areas where people with HIV are being dispersed, are offered training in the complex clinical, psychological experiences, cultural and mental health needs of migrants and asylum seekers. (Paragraph 113)
7. The Government should ensure that people known to be living with HIV are given appropriate financial support and accommodation. Poor accommodation and inadequate financial support greatly impacts upon treatment adherence making the process more difficult and costly to treat in the long-run. (Paragraph 96)
  - *Housing should be of sufficient standard to maintain privacy, dignity and hygiene for all asylum seekers, particularly people living with HIV. (Paragraph 97)*
  - *The Government should review current levels of essential living allowance provided by NASS. Benefits should be enough to maintain good health and a good diet. (Paragraph 97)*

## ***Meeting the Complex Needs of Migrants with HIV***

8. Effective control of HIV demands timely access to treatment, care and prevention services. The national standards under the British HIV Association treatment guidelines should be followed and implemented for all people known to have HIV in the UK regardless of immigration status. (Paragraph 112)
9. The Government should ensure that health information is targeted in a more effective manner to marginalised individuals newly arrived to the UK (Paragraph 118):
  - *There needs to be more health/HIV-related information provided outside London which target a range of needs. (Paragraph 118)*
  - *The Government should ensure that wherever possible the use of family and friends as interpreters in healthcare settings should be avoided and children should never be used. Face-to-face interpreting should be a*

*preference over telephone interpreting where this is possible. Services such as NASS need to consistently link up with qualified language interpreters in all settings which involve migrants. (Paragraph 128)*

- *The Government should provide comprehensive language services outside of London in areas where people are being dispersed. (Paragraph 128)*
10. The Government should provide more support to migrants with HIV in getting back into the work force as soon as possible. It has been proven that the ability to work improves the physical and mental health of migrants with HIV. This entails a revision of the reaccreditation process, more availability of skills training such as IT, and that more flexible hours are introduced so that individuals have choice in terms of how they cope with HIV in the work place. (Paragraph 141)
  11. The Government should support social and policy research on migrants and HIV, in particular on undocumented migrants who may be completely removed from care and support.

## **Global**

12. The Government should work to finalise the Doha trade negotiations with regard to international treatment access, to channel increased resources to health systems development in developing countries and to increase long-term support to initiatives like the Global Health Fund. (Paragraph 162)
13. The Government should reconsider its understanding of Article 3 of the ECHR. At present, individuals being treated for HIV cannot be returned to their home country in the "complete absence of treatment"; this should be amended to consider instead the "practical availability" of treatment. The Government should regularly review treatment availability in developing countries as this is susceptible to constant change. (Paragraph 163)

## *Annex 1: The All-Party Parliamentary Group on AIDS and the All-Party Parliamentary Group on Refugees*

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. In order to be recognised a Group must demonstrate that it has cross Party membership.

The All-Party Parliamentary Group on AIDS 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 people living with or working with HIV/AIDS. The Group has 175 MPs and Peers in membership.

The All Party Group on Refugees concentrates its work on policy issues concerning asylum seekers and refugees in the UK. It has 194 MPs and Peers in membership.

### **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  
Rt Hon Francis Maude MP (Conservative), 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 current Officers of the All-Party Parliamentary Group on Refugees are:**

Neil Gerrard MP (Labour, Walthamstow), Chair  
Karen Buck MP (Labour, Regent's Park & Kensington North), Vice-Chair  
Earl Russell (Liberal Democrat), Vice-Chair  
Peter Bottomley (Conservative, Worthing West), Vice-Chair

**The Following Members and Peers took part in this Inquiry:**

Neil Gerrard MP (Labour, Walthamstow)

David Borrow MP (Labour, South Ribble)

Sandra Gidley MP (Liberal Democrat, Romsey)

Baroness Masham of Ilton (Crossbench Peer)

Laura Moffatt MP (Labour, Crawley)

Russell Brown MP (Labour, Dumfries)

Dr Evan Harris MP (Liberal Democrat, Oxford West and Abingdon)

Rt Hon Francis Maude MP (Conservative, Horsham)

Dr Desmond Turner MP (Labour, Brighton Kemptown)

Iain Coleman MP (Labour, Hammersmith and Fulham)

Dr Ian Gibson MP (Labour, Norwich North)

## Annex 2: The Inquiry

The inquiry was established following discussion by the Officers of the All Party Group on AIDS, who suggested that the Refugee Group might also wish to be associated. MPs and Peers from both Groups were then invited to take part in the inquiry. In March 2003, a wide range of interested parties were invited to submit written evidence with regard to:

*How the UK Government can improve the lives of migrants with HIV?*

Over 50 items of written evidence were received. From this evidence a range of individuals and organisations were invited to give oral evidence during four Parliamentary Hearings held in May 2003.

The following individuals were members of **the Advisory Panel** which guided the terms of reference for the written submissions, panel participant choices and the final draft and recommendations of the report:

Martin Kirk and Lisa Power, Terrence Higgins Trust

Susie Mclean and Joseph O'Reilly, National AIDS Trust

Elisabeth Crafer, Positively Women

Bryan Teixeira, Naz Project London

Dr Kevin Fenton, Health Protection Agency

Dr Barry Evans, Health Protection Agency

Max Sesay, African HIV Policy Network

Dr Adé Fakoya, Newham General Hospital

Dr Jane Anderson, British HIV Association and Department of Immunology, Barts

Ruth Lowbury, Medical Foundation for AIDS & Sexual Health (MedFASH)

Peter Nieuwets, HIV Commissioning Manager for West Sussex

Simon Taylor, UNHCR

Rhon Reynolds, Black Londoners



## **Tuesday 6 May 2003: Introduction and Review of Current Issues Regarding Migration and HIV**

### ***Witnesses:***

Dr Barry Evans, Health Protection Agency  
Peter Nieuwets, HIV Commissioning Manager for West Sussex  
Dr Jane Anderson, Department of Immunology, Barts and the London School of Medicine and Dentistry, Honorary Secretary of the British HIV Association (BHIVA)  
Dr David Goldberg, Scottish Centre for Infection and Environmental Health (SCIEH) and University of Glasgow  
Dr Mary Haour-Knipe, International Organization for Migration (IOM)  
Simon Taylor, United Nations High Commission on Refugees (UNHCR)  
Joseph O'Reilly, National AIDS Trust (NAT)  
Max Sesay, African HIV Policy Network (AHPN)  
Dr Angela Robinson, Mortimer Market Centre, University College London, MSSVD  
Dr Sally Nelson, British Medical Association (BMA)  
Dr Angela Burnett, Sanctuary Practice and the Medical Foundation for the Care of Victims of Torture  
Ruth Lowbury, Medical Foundation for AIDS & Sexual Health (MedFASH)

## **Thursday, 8 May 2003: How Current Government Policy Affects Asylum Seekers**

### ***Witnesses :***

Dr Andy Winter, Sandyford Initiative and Brownlee Centre, Glasgow  
Colin Armstead, George House Trust, Manchester  
Sid Sheehan, Terrence Higgins Trust  
Dr Chris Wood, North Middlesex University Hospital (NMUH)  
Nadine Finch, Immigration Law Practitioners Association (ILPA)  
Ayob, Service User  
Nicola Rogers, Immigration Law Practitioners Association (ILPA)  
Sarah Cutler, Bail for Immigration Detainees (BID)  
Diana Mills, Asylum Aid  
Theonest Ingusi Mbabazi, National Institute for African Studies  
Nadeem Ahmad, North East Consortium for Asylum Support Services (NECASS)  
Sarah Zetler, Department of Sexual Health, Homerton University Hospital  
Spiwe Takura, Terrence Higgins Trust Midlands  
Daisy Byaruhanga Bamaturaki, Innovative Vision Organisation (IVO)

## **Tuesday, 13 May 2003: Access to Healthcare and Treatment**

### ***Witnesses :***

Walter Gillgower, Terrence Higgins Trust  
Richard Patrick Senvewo, African Community Involvement Association (ACIA)  
Dr E.G.Hermione Lyall, Children's HIV Association of the UK and Ireland (CHIVA)  
Liz Kawonza, Terrence Higgins Trust  
Dr Oliver Davidson, Camden & Islington NHS Trusts and the Department of Psychiatry & Behavioural Sciences, Royal Free & University College Medical School  
Justine Sserwadda, Positively Women  
Dr Jenny Miah, Sun Clinic, Newham General Hospital, East London  
Kate Mavor, Language Line  
Yasmin Halima, Naz Project London  
Dr Wondwosen Eshtu, Ethiopian Health Support Association

## **Tuesday, 20 May 2003: Integration into UK Society and Recommendations**

### ***Witnesses :***

Edith Kaggwa, Positive Futures  
Julian V Hows, Strutton Housing  
Sheryl Burton, National Children's Bureau  
Beatrice Nabulya, Service User  
Nick Partridge, Terrence Higgins Trust  
Susie Mclean, National AIDS Trust (NAT)  
Dr Ade Fakoya, Newham General Hospital, East London  
Thandi Haruperi, UK Coalition of People Living with HIV (UKC) and AIDS and Raintrust

The full transcripts of these sessions are available separately and on the APPG AIDS website. The Report was approved by the Members' Panel. Members will draw the attention of 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. However, the recommendations are a summary of a number of priorities that the members who took part in the inquiry wish to take forward. The recommendations do not necessarily reflect the views of the members of the two Groups as a whole. Rather they reflect where there was agreement amongst the Panel, on behalf of the All-Party Parliamentary Group on AIDS and the All-Party Parliamentary Group on Refugees, that a recommendation was appropriate, realistic and practical.

**Written evidence was submitted by the following individuals/organisations:**

African Community Involvement Association  
African HIV Policy Network  
Anonymous Testimonies from people living with HIV  
Bail for Immigration Detainees  
Barts and the Royal London Medical School  
Beatrice Nabulya, Service User  
Black Health Agency  
Black & Minority Ethnic Health Forum in Kensington  
Body Positive  
British Federation against Sexually Transmitted Diseases  
British HIV Association  
British Medical Association  
British Psychological Society  
Central Middlesex Hospital, Patrick Clements Clinic  
Children's HIV Association of the UK and Ireland (CHIVA)  
City and Hackney Primary Care Trust  
George House Trust  
Guy's, King's and St Thomas' School of Medicine  
Hampshire County Council, Social Services Department  
Health Protection Agency  
Homerton University Hospital NHS Trust, Department of Sexual Health  
Immigration Law Practitioners Association  
Innovative Vision Organisation  
Leeds City Council, HIV, Sexual Health and Substance Use Team  
Leicestershire AIDS Support Services

Medical Foundation for AIDS & Sexual Health (MedFASH)  
Medical Foundation for the Care of Victims of Torture  
Migration Watch  
Mildmay Hospital  
Mortimer Market Centre  
North Middlesex University Hospital (NNUH), Dr Chris Wood  
National AIDS Trust  
Naz Project London  
Newham Healthcare Trust  
The Peace Hospice  
Positively Women  
School for Policy Studies, University of Bristol  
Southend Primary Care Trust  
South East Sheffield Primary Care Trust, Anthony Bains  
Sun Clinic Services for Families Living with HIV  
Terrence Higgins Trust  
UK Coalition of People Living with HIV  
United Nations High Commission on Refugees

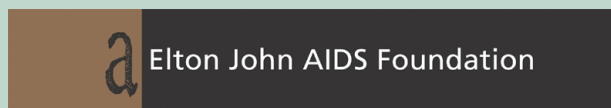
## *Annex 3: Acronyms and Abbreviations*

ACIA	African Community Involvement Association
AHPN	African HIV Policy Network
AIDS	Acquired Immune Deficiency Syndrome
APPG	All-Party Parliamentary Group
ARV	Anti-retroviral
BHIVA	British HIV Association
BID	Bail for Immigration Detainees
BMA	British Medical Association
CHIVA	Children's HIV Association
DfES	Department for Education and Skills
DfID	Department for International Development
ECHR	European Convention on Human Rights
ELR	Exceptional Leave to Remain
GP	General Practitioner
GUM	Genito-Urinary Medicine
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
IDI	Immigration Directorate Instructions
ILPA	Immigration Law Practitioners Association
IOM	International Organisation for Migration
IVO	Innovation Vision Organisation
MEDFASH	Medical Foundation for AIDS and Sexual Health
MSSVD	Medical Society for the Study of Venereal Diseases
NASS	National Asylum Support Services
NAT	National AIDS Trust
NHS	National Health Service
PCT	Primary Care Trust
PHLS	Public Health Laboratory Service (Now the Health Protection Agency)
STI	Sexually Transmitted Infection
THT	Terrence Higgins Trust
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNHCR	United Nations High Commission on Refugees
WHO	World Health Organisation





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