INDEPENDENT ASYLUM COMMISSION

Evidence from the National AIDS Trust

Introduction

1. The National AIDS Trust is the UK's leading independent policy and campaigning charity on HIV and AIDS. The National AIDS Trust develops policies and campaigns to halt the spread of HIV, and improve the quality of life of people affected by HIV and AIDS, both in the UK and internationally. Policy and advocacy related to socially disadvantaged communities, including migrants and asylum seekers, forms an important part of the National AIDS Trust's work.

2. The National AIDS Trust welcomes the opportunity to provide evidence to the Independent Asylum Commission as part of its review of national asylum policies. The National AIDS Trust believes that the asylum process should be more supportive of those asylum seekers living with or at risk from HIV.

3. Managing HIV effectively within the asylum process is relevant to each of the nine categories set out by the Commission in the consultation document. However, this submission will focus on category four: the treatment of vulnerable groups in the asylum process.

Background

4. HIV-positive migrants and asylum seekers are some of the most vulnerable people living with HIV in the UK. The process of migration itself, including high risk of poverty and poor access to safer sex education and health care, can also contribute to the risk of becoming infected.[1]

5. HIV prevalence among migrants from countries with generalised epidemics may be higher than in the general population of the UK. The Health Protection Agency found that almost half of the estimated 7,800 HIV diagnoses in 2006 were in black Africans and 3 per cent were in black Caribbeans.[2] An estimated 4 per cent of the black African population of England, Wales and Northern Ireland were living with diagnosed HIV infection, as were 0.4 per cent of the black Caribbean population, compared with 0.08 per cent of the white population. Of the 73,000 people estimated by the Health Protection Agency to be living with HIV in the UK at the end of 2006, 35%, or roughly 25,550, were born in Africa – and to that number must be added those migrants with HIV from other countries. Of course not all migrants are in the asylum process – many come to work or study or with family ties. But it is clear that a significant number are applying for asylum or leave to remain. It is vital therefore that our immigration system actively consider HIV-related needs in development of both policy and practice (and indeed the disability equality duty as set out in the Disability Discrimination Act 2005 requires the Home Office to do so).

6. Over the past 10 years, the number of black Africans thought to have acquired their infection heterosexually within the UK has risen seven-fold (from 26 reported diagnoses in 1997 to 191 in 2006), and there has been a four-fold

---

[1] National AIDS Trust and Crusaid (2006) *HIV and Poverty*, www.nat.org.uk/document/207.
[2] Health Protection Agency (2007) *Testing Times*, http://www.hpa.org.uk/infections/topics_az/hiv_sti/publications/AnnualReport/2007/HIVSTIs_AR2007.pdf.

increase in black Caribbeans (from 28 to 118 of such diagnoses).[3] In addition, 40 per cent of black African and black Caribbean communities were diagnosed late. Late diagnosis contributes to short term mortality. Those diagnosed late were 13 times more likely to die within a year of their HIV diagnosis than all HIV-infected black African and black Caribbean adults first diagnosed at higher CD4 counts.[4] As the number of black and minority ethnic heterosexuals living with HIV in the UK grows, the likelihood rises of increasing heterosexual HIV transmission.

7. These statistics demonstrate the need for the HIV risk in migrants to be considered earlier. The asylum application process presents an ideal opportunity to do this, but if it is to succeed the process needs to adopt a more joined up and comprehensive approach to addressing the HIV related issues facing asylum seekers.

<u>Treatment of vulnerable groups in the asylum process</u>

Prevention and testing

8. Asylum seekers are amongst the vulnerable communities most seriously affected by HIV in the UK. Many asylum seekers come from countries with high HIV prevalence. The process of migration, including high risk of poverty and poor access to safer sex education and healthcare, can also contribute to the risk of becoming infected. In addition, as asylum seekers are without the right to work and thus have little or no income, some may be driven to seek other means of income that may further increase their risk of HIV infection, such as sex work.[5] For these reasons it is particularly important to ensure effective prevention messages reach asylum seekers and other migrants.

9. Throughout the asylum pathway, there are opportunities to promote voluntary HIV testing for those most at risk, either upon request or clinical indication, and to highlight HIV and sexual health issues. There is also an opportunity to look at what health information is available at each stage in the process and provide asylum seekers with specific HIV and sexual health resources in key languages. This is particularly relevant during the induction process and health assessment as well as at post-dispersal locations.

10. **<u>Recommendations</u>: The National AIDS Trust recommends that information about HIV testing as well as HIV-prevention and sexual health promotion messages should be made available to asylum seekers at each point of the asylum process. This should include:**

    - **information about the opportunity to have an HIV test;**
    - **information on the circumstances in which a test is advisable;**
    - **implications of being HIV positive in the UK compared with other countries (such as access to treatment);**
    - **information about the effectiveness of HIV treatment, how to access healthcare and the provisions for confidentiality; and**
    - **HIV-prevention and sexual health promotion messages in initial accommodation, dispersal accommodation, immigration removal centres**

[3] Ibid.
[4] Ibid.
[5] Burnett and Peel, *Asylum Seekers and Refugees in Britain*, British Medical Journal, 2001.

This information should be provided in an appropriate and confidential way at all points along the asylum pathway.

11. **The Independent Asylum Commission should work with the Home Office Border and Immigration Agency and Department of Health to continue to gather examples of best practice in both pre- and post-dispersal settings of measures taken to prevent and treat HIV and should facilitate more detailed discussions with key stakeholders, including clinicians.**

Treatment

12. The development of antiretroviral (ARV) therapy has changed, fundamentally, the health prospects of those living with HIV in the UK. As long as diagnosis does not take place too late, ARV therapy usually means that an individual can live a long and healthy life. Once commenced, ARV therapy cannot be interrupted. For optimum effectiveness it must be taken for the remainder of the person's life and strict adherence to the, often demanding, drug regimen is essential if drug resistance is not to develop. This has particular implications for asylum seekers going through the stressful and increasingly rapid asylum process.

13. Continuity of care at all points during the asylum process, in particular during dispersal and removal, is essential. Moving from one part of the country to another inevitably disrupts day to day life, and can interrupt clinical care and drug adherence. Treating clinicians need to be assured that appropriate arrangements are in place to ensure continuity of care before dispersal can occur. In addition, accommodation providers in dispersal locations must ensure that asylum seekers with serious health conditions, such as HIV, are registered with a GP upon arrival. As recommended in the Home Office Border and Immigration Agency policy bulletin on dispersing asylum seekers with healthcare needs, it is imperative that dispersal is done in a way which does not harm a person's health or endanger their life. There are particular concerns about the dispersal of HIV positive asylum seekers including short notice of a sudden move to another area. The National AIDS Trust has been made aware of a number of related cases and some examples are set out below, followed by NAT's recommendations to improve the process in the future.

14. **Case study 1**
    A woman living with HIV in Berkshire was moved to Plymouth in early 2007. Her clinician had advised the Border and Immigration Agency that the woman should not be moved for medical reasons, and raised concerns that the woman would not be able to access a similar support structure in the new area. The Border and Immigration Agency was aware of this woman's HIV-positive status, but the National AIDS Trust was informed that she received a letter giving one day's notice of her dispersal to Plymouth. This did not allow an appropriate amount of time to prepare adequately for the journey and, being on treatment for HIV, she did not have the opportunity to organise sufficient medication for the move.

15. This woman's clinician and support worker both contacted the Border and Immigration Agency to query the case. The support worker was told that the policy bulletin on the dispersal of asylum seeker with healthcare needs was 'a

guideline only' and that the Border and Immigration Agency is not required to carry out dispersal as outlined by the bulletin.

16. **Recommendations: The National AIDS Trust believes the Independent Asylum Commission should urge the Home Office Border and Immigration Agency to do more to ensure its staff implement and abide by procedures set out in the Home Office's policy bulletin on the dispersal of asylum seekers with healthcare needs.**

17. **The National AIDS Trust recommends the Independent Asylum Commission also urge the Home Office Border and Immigration Agency to ensure all case owners understand fully the requirements of the Home Office's policy bulletin in relation to dispersal of asylum seekers living with HIV and that it monitors case owners' actions regularly to make sure procedures are being followed. This will ensure the guidance is consistently and effectively implemented.**

18. **In addition, the National AIDS Trust recommends that case owners are trained in the HIV- and sexual-health related needs of asylum seekers as a critical element of the 55-day Foundation Training Programme.**

19. **Case study 2**
    A second case study involved a woman living with HIV in Essex, who was scheduled to be dispersed to Birmingham in mid 2007. The woman was 26 weeks pregnant, diagnosed with tuberculosis and on daily treatment injections for a variety of illnesses. The woman's clinician provided a letter to the Border and Immigration Agency requesting she not be dispersed due to her complex health situation. The Border and Immigration Agency confirmed receipt of the letter via telephone with the woman's support worker. However, the National AIDS Trust was later informed that the Border and Immigration Agency denied receiving the letter when the woman's support worker followed up. The Border and Immigration Agency discontinued Section 4 support for the woman because of her supposed refusal to be dispersed, and as a result, the woman became homeless. The National AIDS Trust was also informed that the woman had not been transferred to the Complex Casework Team (CCT) at any point during the asylum process. The National AIDS Trust contacted the Border and Immigration Agency to query why this happened but received no response.

20. **Recommendations: The Independent Asylum Commission should urge the Home Office Border and Immigration Agency to make it a requirement that complex cases needing additional care, such as those involving pregnant asylum seekers living with HIV, are transferred to the Complex Casework Team. This will ensure clarity and consistency during the asylum process.**

21. **The National AIDS Trust also recommends that letters from clinicians, whether sent directly or through an asylum seeker's representative, must be acknowledged by the Home Office Border and Immigration Agency and receipt confirmed in writing, for example via e-mail. In the case above, this woman should not have been denied continuation of Section 4 support.**

22. **Case study 3**
    A woman living with HIV who had given birth by caesarean section six weeks previously was moved from Luton to Dover. This was against the advice of her

clinician because, in addition to being HIV positive with a newborn baby, her caesarean operation scars had not yet healed. Following enquiries by the National AIDS Trust, it appears that the woman had just claimed asylum and was required to travel to Dover to begin the dispersal process.

23. **Recommendation: The National AIDS Trust recommends that the Independent Asylum Commission encourage the Home Office Border and Immigration Agency to respond flexibly, sensitively and appropriately to clinical advice regarding the health needs of asylum seekers living with HIV. In the example above, this woman should not have been required to travel immediately to the Dover initial accommodation centre to begin accessing support given the clinical advice that any move should be delayed.**

24. It is also important to consider access to NHS treatment more generally. New UK Government regulations, from 2004, mean that some vulnerable communities, including refused asylum seekers and other undocumented migrants, may be charged for some forms of care.

25. In detail, asylum seekers living with HIV with a current application ongoing (including appeals) are entitled to free NHS care for HIV or any other condition. If an asylum seeker is already receiving free NHS care and their right to residence in the UK comes to an end or their application is refused, they still have a right while in the UK to continue to get treatment for that condition free of charge. However, if an asylum seeker accesses NHS care only after their application is refused then they may be charged for treatment. In addition, anyone who has overstayed their visa or is otherwise resident in the UK without legal status may be charged.

26. There is increasing evidence of people living with HIV who have not been provided with HIV treatment because of misunderstandings over entitlement, or who disappear from care for fear of HIV-related bills.[6]

27. **Case study 1**
A was a Somalian national who claimed asylum in 1999 and was supported under the Immigration and Asylum Act 1999 Interim Regulations. After five years, the Home Office was unable to clarify her status in the country. Following requests to provide clarification of her status, the Home Office replied stating their file did not have sufficient information to establish how she entered the UK. Due to this administrative confusion, *A* was billed for hospital treatment, as her status could not be proved. In this case the error was with the Home Office, but *A* had to deal with the stress and worry of being invoiced for her treatment. *A* has since died with invoices of approximately £4,000 issued to her.

28. **Case study 2**
A client was receiving HIV treatment in London and was then was relocated to Bristol; however, he was told that he would be refused treatment unless he paid. He was on antiretroviral therapy and needed to continue treatment if he was to remain in good health. He was distressed and afraid he would die without treatment. The client disappeared – outcome not known.

[6] A PDF of additional case studies can be accessed by visiting www.nat.org.uk/document/368.

29. **Case study 3**
Client collapsed with a fit and was taken in via Accident & Emergency. He was subsequently diagnosed with HIV and treated for a number of conditions including tuberculosis. He was billed for approximately £5,000. He was discharged and vanished without ongoing treatment. The outcome of his tuberculosis treatment is not known.

30. **Case study 4**
Angela arrived in the UK in 2003 and applied for leave to remain later that year on the grounds of ill health while living with a friend. As a result, Angela has never been entitled to NASS support. Diagnosed with HIV in 1998, Angela accessed treatment in the UK to combat HIV, allowing her to maintain reasonable health. However in 2004, Angela was issued with a bill for £21,000 for her treatment. Angela cannot afford to pay the bill, and was referred to a voluntary sector organisation that can provide free legal advice and support challenging the debt. While Angela is still able to receive treatment for her condition, she has constantly been sent court letters asking for payment which has amounted to £30,000.

31. As these case studies illustrate, it is often the most vulnerable who suffer from delayed, denied, interrupted or withdrawn care because they are unable to pay such HIV-related bills for treatment. Many have been pursued aggressively by debt collectors. The consequences for the health and well-being of those affected are grave, and could well result in serious illness and sometimes death.

32. A Government review board is looking at the NHS charges applied to refused asylum seekers and other undocumented migrants, and is expected to report in December 2007. It is hoped that the review board will respond positively to the many submissions made over time by the voluntary sector on this issue, and to the report from the Joint Committee on Human Rights on the Treatment of Asylum Seekers, which recommended the restoration of free secondary care to refused asylum seekers.

33. The National AIDS Trust believes these charging regulations are not only inhumane, a danger to public health and a breach of human rights, but increase avoidable and unnecessary costs to the NHS.

34. Department of Health and Home Office Border and Immigration Agency guidance state that debt for NHS treatment can be written off if a PCT has taken reasonable steps to secure payment but there is no realistic prospect of success. Those refused asylum seekers previously in receipt of Home Office Border and Immigration Agency benefits and/or initial accommodation have already been assessed as destitute and thus are wholly unable to pay such NHS bills. Yet in the case of HIV, public funds are wasted pursuing an unpayable debt for life-saving treatment with the real possibility that the process will deter the patient from continuing to access care.

35. Currently GPs have discretion on whether or not to charge these individuals for primary care. The National AIDS Trust understands, however, that compulsory charging in primary care is being actively considered by the review board.

36. **<u>Recommendations</u>: In accordance with the recent recommendations of the Joint Committee on Human Rights, the National AIDS Trust urges the Independent Asylum Commission to recommend free secondary care to**

all those who have claimed asylum or leave to remain in the UK under the ECHR for as long as they remain in the country, and resist any extension of mandatory charging to primary care.[7]

37. **Whilst charges remain in place, the Independent Asylum Commission should require a charging system which supports rather than undermines the right to life-saving treatment. Current bills terrorise many into withdrawal from essential healthcare. As a matter of urgency, a streamlined system of debt write-off must be established across all PCTs which writes off promptly and efficiently the debt of those who are destitute and without income.**

Care and support

38. Living well with HIV is not simply a matter of accessing HIV medication and treatment. Stable and supportive circumstances are necessary if people are going to be able to adhere to ARV therapy. Such adherence is essential so it is important asylum seekers can access appropriate care and support. People will need some privacy in their asylum accommodation to take their pills, and some drugs may require refrigeration. There are also dietary requirements for some medications. Healthcare staff working with asylum seekers are well placed to support these needs confidentially.

39. It is equally important to consider the mental health and psychosocial needs of asylum seekers living with HIV. The asylum process in itself can be both frightening and stressful, particularly for a person unfamiliar with the UK and its regulations. Thus, it is extremely important that those working with asylum seekers establish strong links with local HIV organisations and support services so that asylum seekers living with HIV can access these while in initial accommodation, upon dispersal and during removal or integration.

40. In addition, asylum seekers are denied the right to work. Having no regular income leads to not only financial difficulties, but poverty and the inability to sustain a decent standard of living and accommodation, which in turn may result in poorer healthcare and inadequate adherence to ARV therapy. The current subsistence provided for asylum seekers is minimal and significantly below income support.

41. **<u>Recommendations</u>: To respond effectively to the needs of asylum seekers living with HIV, healthcare staff working at each point along the asylum pathway should have a basic level of knowledge about HIV and AIDS. It is vital that they have easy access to key resources on HIV. Specific training on HIV should be provided to case owners and those working with asylum seekers in initial accommodation, at dispersal locations and during removal or integration.**

42. **The Independent Asylum Commission should encourage the Home Office Border and Immigration Agency and Department of Health to work in partnership with organisations from the non-profit sector to provide mental health and psychosocial support to HIV positive people during the asylum process.**

---

[7] Joint Committee on Human Rights (2007) *Treatment of Asylum Seekers*, http://www.publications.parliament.uk/pa/jt200607/jtselect/jtrights/81/81i.pdf.

43. **The Independent Asylum Commission should encourage Government to restore an asylum seekers right to work and increase the subsistence provided to the same level as income support, thus addressing the poverty which so undermines the health of those living with HIV.**

44. HIV related stigma and discrimination are persistent problems for those who have been diagnosed with HIV and contribute to reduced health and well-being.[8] [9] Stigma and discrimination also threaten the effectiveness of prevention and care programmes by discouraging individuals from coming forward for testing and from seeking information on how to protect themselves and others. This in turn may increase late diagnosis which lessens the effectiveness of treatment. Developing a stigma and discrimination-free environment in initial accommodation centres, upon dispersal and in immigration removal centres is vital. It is also important that staff reassure asylum seekers about the accessibility and confidentiality of NHS services for HIV and sexual health.

45. **Recommendation: The National AIDS Trust recommends the Independent Asylum Commission encourage the Home Office Border and Immigration Agency and Department of Health to support an HIV stigma and discrimination-free environment at all points along the asylum pathway which can provide reassurance on the accessibility and confidentiality of NHS services for HIV and sexual health. The Home Office could do this by:**

    - **integrating an anti-stigma perspective into all its asylum work; and**
    - **including training on HIV-related stigma and discrimination as a critical element in the 55-day Foundation Training Programme for case owners.**

Conclusion

46. Healthcare clinicians working with asylum seekers are ideally placed to consider HIV risk in their assessment of a patient's health needs and should be supported in this role. With growing numbers of non-UK born individuals diagnosed with HIV in England, Wales and Northern Ireland, many of whom are diagnosed late, and the increase in the number of deaths related to HIV of non-UK born people, there is a demonstrated need for people to consider the HIV needs of asylum seekers early on in the asylum process.

47. Although there are inherent challenges related to HIV prevention, testing, treatment and care during the asylum pathway, it is worth highlighting what might be gained by joining up policy and taking advantage of the many opportunities that exist. In the end, there is not only a need to comply with the duty of care and human rights obligations owed to asylum seekers, but healthcare staff working with asylum seekers can also play their part in protecting public health in the UK.

National AIDS Trust
November 2007

---

[8] UNAIDS, *HIV-related Stigma, Discrimination and Human Rights Violations Case studies of successful programmes*, April 2005.
[9] Sigma Research, *Outsider Status: Stigma and Discrimination Experienced by Gay Men and African People with HIV*, December 2004.