REVIEW OF BORDER AND IMMIGRATION AGENCY POLICY BULLETIN ON DISPERSING ASYLUM SEEKERS WITH HEALTHCARE NEEDS INCLUDING PREGNANCY

A response from the National AIDS Trust

Introduction

The National AIDS Trust is the UK's leading independent policy and campaigning voice 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.

The National AIDS Trust welcomes the opportunity to provide input into the updated Policy Bulletin on dispersing asylum seekers with healthcare needs including pregnancy. The National AIDS Trust believes the policy guidelines could significantly and positively affect the lives of those being dispersed if implemented effectively.

Background

In July 2005 the National Asylum Support Service (NASS, which no longer exists but its functions are carried out by the Home Office Border and Immigration Agency) produced a draft policy bulletin on *Dispersing Asylum Seekers With Health Care Needs*. Whilst NASS consulted upon and revised this document, the National AIDS Trust sought to investigate further some of the issues related to dispersal of asylum seekers living with HIV, and produced a report outlining areas of concern and recommendations for improvement.[1] The National AIDS Trust made a submission to the consultation on the NASS draft policy bulletin[2], and was pleased that many of our recommendations were taken up in the final version (Policy Bulletin 85) that was published in December 2005. NASS included a commitment in that bulletin to review it in 12 months' time.

During 2006 the National AIDS Trust, with support from NASS, produced a guide for healthcare and voluntary sector professionals outlining the HIV-related aspects of NASS policy changes on dispersal. The booklet[3], developed in collaboration with the British HIV Association, was distributed to clinicians, relevant sector organisations and other key stakeholders working with asylum seekers during the dispersal process. In 2007 the National AIDS Trust undertook an evaluation of their experience with both the dispersal booklet and dispersal process.

This paper briefly outlines the survey results and key concerns the National AIDS Trust has about implementation of the policy guidelines on dispersing asylum seekers with healthcare needs and pregnancy. In addition, this paper makes recommendations we hope the Border and Immigration Agency will consider as the updated bulletin undergoes review.

[1] National AIDS Trust, *Dispersal of Asylum Seekers Living with HIV*, www.nat.org.uk/document/113, January 2006.
[2] National AIDS Trust, *Response to NASS Consultation on Policy Bulletin Dispersing Asylum Seekers with Healthcare Needs*, www.nat.org.uk/document/97, August 2005.
[3] National AIDS Trust, *The Dispersal Process for Asylum Seekers Living with HIV: Advice for healthcare and voluntary sector professionals*, www.nat.org.uk/document/208, December 2006.

Dispersal evaluation findings

In June and July 2007 the National AIDS Trust undertook an evaluation of the new dispersal process and the booklet entitled: "The Dispersal Process for Asylum Seekers Living with HIV – Advice for healthcare and voluntary sector professionals" (available from the National AIDS Trust).

Questionnaires were distributed widely and completed by relevant healthcare professionals, voluntary sector staff and other key stakeholders with dispersed asylum seekers. Findings from the study showed the booklet was seen as a valuable tool for those working with asylum seekers but also that the Home Office was sometimes breaching its own guidance on dispersal of HIV-positive asylum seekers.

Stakeholders were asked whether their actual experience of the dispersal process matched the policy outlined in the booklet. In relation to actions of Home Office officials, only 23 per cent found that actions had 'always' or 'in most cases' matched the policy. More than half (54 per cent) of respondents found that 'sometimes', 'rarely' or 'never' were actions in line with the policy. In contrast, nearly half of respondents (47 per cent) found actions of healthcare professionals matched the policy 'in most cases'.

Similarly stakeholders were asked if their advice provided on dispersal had been taken into account by Home Office officials. Nearly 40 per cent found that their advice had 'rarely' been taken into account, as opposed to 23 per cent who found their advice was taken 'sometimes' or 'in most cases'.

Evidence gathered prior to the survey as well as cases provided as a result of the evaluation substantiates these findings. They show there is confusion over Home Office policy guidance on the dispersal process and this is having negative effects on both individual and public health.

Effective implementation of existing policy

The updated Policy Bulletin, if implemented effectively, could make a significant and positive impact on the life of an asylum seeker living with HIV. For example, a commitment to dispersing HIV positive asylum seekers only when his or her treating clinician is satisfied that arrangements are in place to ensure continuity of care is welcomed by the National AIDS Trust. **However the bulletin is only helpful if the guidelines are being implemented effectively.**

Case studies

The National AIDS Trust has been alerted by clinicians and support service organisations to several instances over the past 12 months where Border and Immigration Agency dispersal policy does not seem to have been implemented in line with guidance outlined in Policy Bulletin 85 or Policy Bulletin 61. Examples which have been brought to our attention include the following:

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. As the Border & Immigration Agency acknowledged in Annex D of the previous Policy Bulletin 85 and updated Policy Bulletin (Paragraph 2):

"Interruption of antiretroviral drugs is a key determinant in both treatment failure and the development of long term drug resistant HIV. If doses are missed or supplies of medication run out, not only are the beneficial effects lost but there is a real threat that future treatment options will be jeopardised by the development of drug resistance. For some of the drugs used in HIV, missing as few as one or two doses can be a significant risk..."

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

> **Recommendations: The National AIDS Trust believes that the Home Office Border and Immigration Agency should do more to ensure its staff implement and abide by procedures set out in the Policy Bulletin.**
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> **The National AIDS Trust recommends the Home Office Border and Immigration Agency ensure all case owners understand fully the requirements of this Policy Bulletin in relation to dispersal of asylum seekers living with HIV and that it monitors regularly to make sure its own procedures are being followed. This will ensure the guidance is consistently and effectively implemented.**
>
> **In addition, the National AIDS Trust recommends that case owners be trained in the HIV- and sexual-health related needs of asylum seekers as a critical element of the 55-day Foundation Training Programme.**

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. To ensure individuals with complex health needs receive appropriate care, the Border and Immigration Agency stated in the previous Policy Bulletin 85 (Paragraph 9.4):

"When the asylum seeker is pregnant and HIV positive, additional care is required and the case must by transferred to the Complex Casework Team (CCT)."

In the updated Policy Bulletin the same issue is phrased (Paragraph 12.8):

“Pregnant women with HIV infection should be subject to very careful consideration, so that the risk of transmission before, during and after delivery can be kept to the absolute minimum. Such cases should be referred to CCT.”

The National AIDS Trust contacted the Border and Immigration Agency to query the case as to why this happened but no response was received.

> **<u>Recommendations</u>: The Border and Immigration Agency should transfer complex cases where additional care is required, such as those involving pregnant asylum seekers living with HIV, to the Complex Casework Team as a requirement. However, the new language (e.g., “Such cases should be referred to CCT”) is confusing and will lead to inconsistent practice. Language could be changed to read “Such cases must be referred to CCT”. This will ensure clarity and consistency during the dispersal process.**
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> **The National AIDS Trust also recommends that letters from clinicians, whether sent directly or through an asylum seeker’s representative, must be acknowledged 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.**

Case study 3

A third case study is a woman living with HIV who had given birth by caesarean section six weeks previously and 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 <u>begin</u> the dispersal process.

> **<u>Recommendation</u>: The National AIDS Trust recommends that Home Office Border and Immigration Agency officials 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 to Dover initial accommodation centre to begin accessing support given the clinical advice that any move should be delayed.**

<u>HIV testing and HIV-prevention and sexual health promotion</u>

The updated Policy Bulletin states that HIV testing is offered where there is “reason for concern” (Paragraph 5.1). The National AIDS Trust would go further. Discussions with clinicians and support organisations have indicated that information on availability of an HIV test may encourage people to be tested, either at that time or in the future. To support this, the National AIDS Trust is currently mapping the asylum pathway from arrival to removal or integration. Our aims are to better understand the opportunities and challenges that exist for promoting voluntary HIV testing in pre- and post-dispersal areas, including initial accommodation and removal centres, as well as identify and support communications on HIV-prevention and sexual health promotion messages.

Recommendations: The National AIDS Trust recommends that information about the opportunity to have an HIV test, circumstances in which a test is advisable, implications of being HIV positive in the UK compared with other countries (such as access to treatment), and HIV-prevention and sexual health promotion messages in initial accommodation, immigration removal centres and all points along the asylum pathway should be made readily, appropriately and confidentially available.

The Home Office Border and Immigration Agency should also continue to gather examples of best practice and facilitate more detailed discussions with key stakeholders including clinicians on measures undertaken in both pre- and post-dispersal areas to prevent and treat HIV.

Access to HIV treatment and care

Charging failed asylum seekers and individuals with uncertain residency status for HIV treatment and care continues to be a critical issue. The National AIDS Trust believes that the *NHS (Charges to Overseas Visitors) Regulations 1989* are a danger to both individual and public health and are preventing vulnerable people living in the UK, including pregnant women, from accessing vital treatment. To charge the destitute for their care is deterring vulnerable people from continuing to access the treatment they need with possibly fatal results and serious consequences for public health.

Recommendation: 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 failed 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. Home Office Border and Immigration Agency officials should be ready to inform PCTs, if approached, not only that an asylum claim has failed but that the individual has been previously assessed as destitute and would therefore be unable to pay bills for NHS treatment and care – such bills should then be automatically written off by the PCT.

Mechanisms for appropriate storage and transfer of patient information between healthcare providers in pre- and post-dispersal areas

The updated Policy Bulletin makes no reference to effective methods for the transfer of patient information between pre- and post-dispersal healthcare providers and does not address the storage of confidential records. Since the very nature of dispersal involves the high mobility of individuals with healthcare needs between areas, confidentiality issues must be integrated into planning for transfer. It is essential that medical information is treated sensitively and confidentially by those processing and storing such information as what may seem as routine administrative issues for some can be regarded by asylum seekers living with HIV as very serious concerns.

Recommendation: The National AIDS Trust recommends that the Policy Bulletin clearly outline protocols for Home Office Border and Immigration officials to facilitate appropriate storing and sharing of asylum seekers healthcare information, including HIV status, in accordance with data protection and confidentiality requirements. This will reassure asylum seekers and may consequently increase the likelihood of vital information being captured at an earlier stage.

Registering for healthcare in post-dispersal areas

The Policy Bulletin states that asylum seekers with existing medical conditions must be registered with a local GP within five working days (Paragraph 14.4) and those with an urgent need of a supply of prescribed medication within one working day (Paragraph 14.5). The National AIDS Trust welcomes this important guidance. However the Policy Bulletin makes no reference to monitoring GP registration which is critical to ensuring continuity of care.

Recommendation: The National AIDS Trust recommends that the Home Office Border and Immigration Agency follow up with accommodation providers to ensure that those asylum seekers with existing medical conditions are registered with a GP within five working days and those asylum seekers in urgent need of prescribed medication within one working day. This tracking will ensure continuity of care and facilitate increased critical communications between the Agency and accommodation providers while supporting best practice related to the HIV-related needs of dispersed asylum seekers.

HIV-related stigma and discrimination

The updated Policy Bulletin makes no reference to HIV-related stigma and discrimination. According to research, stigma and discrimination related to HIV are persistent problems for those who have been diagnosed and contribute to reduced health and well-being particularly for those most vulnerable to infection.[4] [5] In addition HIV-related 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, as well as increasing late diagnosis which lessens the effectiveness of treatment.

Recommendation: The National AIDS Trust recommends the Home Office Border and Immigration Agency support an HIV stigma- and discrimination-free environment at all points along the asylum pathway including dispersal, 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 include training on HIV-related stigma and discrimination as a critical element in the 55-day Foundation Training Programme for case owners.

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

Summary

The updated Policy Bulletin on dispersal of asylum seekers with healthcare needs including pregnancy could make a significant and positive impact on the life of an asylum seeker living with HIV. However the guidelines in the bulletin are only positive if they are being implemented effectively. The National AIDS Trust has been alerted to several instances where dispersal policy does not seem to have been implemented in line with guidance, including:

- **Dispersal at such short notice that HIV treatment was interrupted and health harmed.**
- **Dispersal when asylum seekers with HIV were too ill or vulnerable to travel.**

The National AIDS Trust believes that dispersal of asylum seekers living with HIV should take place only under the below circumstances:

- **Following and in accordance with expert clinical advice.**
- **When dispersal will not cause any harm to the individual and pose no risk to wider public health.**
- **When asylum seekers and clinicians have had time to adequately prepare for dispersal.**

In addition, measures must be in place to fully protect client confidentiality and the transfer of patient information between healthcare providers, support the availability of HIV testing and HIV-prevention and sexual health promotion messages at all points along the asylum pathway, write off charges for HIV treatment and care for failed asylum seekers who have already been assessed as destitute, and avoid occurrences of HIV-related stigma and discrimination.

National AIDS Trust
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