TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

Report: Updated July 2009

Housing and HIV

Contents

Executive Summary 3

Introduction 4

1. Housing and the law 5

1.1 Entitlement to social housing 5

1.2 Asylum seekers and housing entitlement 6

1.3 Homelessness 8

2. HIV and housing 10

2.1 HIV and housing entitlement – the current situation 10

2.2. Health implications 11

2.3. HIV and discrimination 13

2.4. Mental health, well-being, HIV and housing 13

2.5. The implications of living in shared accommodation 14

2.6. The impact of ageing on housing need 14

2.7. Provision and upkeep of housing 14

3. Supporting People programme 15

3.1 Needs for Supporting People to address 16

3.2 The future of Supporting People in England 18

4. Conclusion and Recommendations 20

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Executive Summary

Housing and HIV

An overview by NAT of the impact housing has on the health and well-being of people living with HIV

Executive Summary

Effective treatment in the UK has transformed HIV from being a terminal illness to, for most people infected, a long-term manageable condition. HIV does, however, remain a complex condition which has an impact on many areas of life and which can be challenging to manage. Good quality and stable housing is particularly important in maintaining the health and well-being of an HIV positive person. By contrast, poor quality, inappropriate or unstable housing can seriously undermine an individual's health, for example by:

- Making adherence to treatment difficult – which causes treatment to stop working thus endangering future health
- Making people more vulnerable to certain illnesses, such as tuberculosis
- Accelerating ill-health and a decline in the immune system, meaning treatment has to be begun earlier than would otherwise be the case
- Causing stress and/or depression which reduce the effectiveness of treatment
- Undermining privacy, making individuals vulnerable to discrimination and harassment
- Causing real difficulty in managing or mitigating side-effects and health impacts resulting from HIV infection.

Too often decisions on the priority to be given to individuals with HIV for social housing are based on out-of-date criteria such as whether or not someone has an AIDS diagnosis, or the presence of certain 'symptoms' or a particular CD4 count. This approach fails to address HIV as a long-term condition and a disability, which involves continuing vulnerability and very often fluctuating health. Poor housing can mean that the health of someone with HIV who had previously been doing well on treatment declines dangerously.

This report explores the relationship between housing and HIV and, at the end, identifies recommendations for action.

Key recommendations include:

- Local authorities should always consider awarding people living with HIV priority for social housing on medical grounds, on the basis of a comprehensive needs assessment, bearing in mind the importance of treatment adherence and the fluctuating nature of the condition
- People living with HIV who are homeless, or at risk of homelessness, should always be considered 'vulnerable' and should qualify for emergency support and be awarded the appropriate priority on the housing register, regardless of their current health
- Both local authorities and the UK Border Agency should ensure that the accommodation they provide, whether directly or through private landlords, is of a standard that meets the needs of people living with HIV
- People living with HIV should only be housed in shared accommodation as an emergency and not for longer than six weeks
- The benefits of the Supporting People programme must be maintained – in particular through effective needs assessments for people living with HIV and properly funded and targeted support.

Introduction

Housing conditions for people living with HIV

There is increasing evidence both from the UK and internationally of the harm poor housing can do to the health and well-being of people living with HIV. The NAT/Crusaid 2006 report *Poverty and HIV* highlighted housing as a key concern for people living with HIV who are experiencing poverty;[1] a finding which was later echoed in the Waverley Care and Crusaid report focusing on Scotland.[2]

A study of people living with HIV in London carried out in 2004 and 2005 showed that 49 per cent of people living with HIV were renting from a local authority or housing association, and up to 11 per cent were within the statutory definition of homelessness.[3]

A survey of people living with HIV conducted by Sigma Research in 2008 found that:

- 22 per cent felt unhappy about their housing and living conditions
- 24 per cent had experienced housing problems in the past year
- 20 per cent had ongoing housing problems and felt that further help or support would be useful, or did not rule this out.[4]

NAT (National AIDS Trust) decided to explore further the relationship between HIV and housing. With 1.6 million households on the social housing waiting list and this figure likely to rise, it is an important time to consider the housing needs of people living with HIV and whether these are being met.[5]

Structure of the report

This report looks at the current structures for housing provision and whether these meet the particular needs of people living with HIV. The paper begins by setting out the legal landscape of housing, focusing on the duties of local authorities to provide housing. Readers already familiar with housing law may wish to move straight to Section 2 - 'HIV and housing'.

Section 2 looks specifically at housing in relation to HIV, surveying existing literature and drawing on the experiences of a range of organisations providing housing support to people with HIV. The impact of poor housing on health is assessed, as well as additional housing needs related to HIV. Telephone and face-to-face interviews were conducted with organisations from April to July 2008. The interviews were semi-structured to allow the interviewee to lead the conversation and identify for themselves their key concerns.

Section 3 looks at the Supporting People programme and identifies areas of need that could be addressed under this programme, and potential barriers to doing so.

Finally, this report makes a series of recommendations for actions needed to address the issues raised.

The focus of this paper is primarily on access to social housing and the support available for homeless people. However, it is also important to remember that many people will be in private accommodation paid for out of their own funds. Many of the issues around HIV and housing raised here will also apply to individuals in private accommodation.

1: The National AIDS Trust and Crusaid (2006) *Poverty and HIV: Findings from the Crusaid Hardship Fund* www.nat.org.uk

2: Waverley Care and Crusaid (2007) *Poverty and HIV: Findings from the Crusaid Hardship Fund in Scotland* www.waverleycare.org.uk

3: Ibrahim F, Anderson J, Bukutu C, Elford J (2008) *Social and economic hardship among people living with HIV in London* HIV Medicine 2008; 9:616-624

4: Local Government Association (2008) *Councils and the housing crisis* www.lga.gov.uk

5: Sigma Research (2008) *What do you need? Findings from a national survey of people living with HIV* www.sigmaresearch.org.uk

1. Housing and the law

1. Housing and the law

This section provides an overview of housing law for those not familiar with the relevant legislation and duties on local authorities. It looks at entitlement to social housing, the housing of asylum seekers, and provision of support for homeless people.

The most significant legislation for housing in England and Wales is the Housing Act 1996 as amended by the Homelessness Act 2002, Housing Act 2004 and the Housing and Regeneration Act 2008. The Scottish equivalent is the Housing Act Scotland 1988 as amended by the 2001 and 2006 Acts. These Acts set out the way private and social housing must be provided in the UK.

1.1 Entitlement to social housing

Social housing is theoretically available to most UK citizens, as well as refugees and those with unconditional leave to remain or with exceptional or discretionary leave to remain. In addition non-UK citizens who are members of the European Economic Area and are working in the UK can apply. Housing provided by local authorities and homelessness assistance are both considered 'public funds'. Individuals whose entitlement to stay in the UK has a 'no recourse to public funds' condition attached cannot access it.[6]

Asylum seekers are not eligible for council housing and it is the responsibility of the UK Border Agency (UKBA) to arrange their housing. The UKBA only has to provide housing for those who applied for asylum at the first opportunity, and meet further criteria. Those who have been ruled not to have applied for asylum early enough do not have to be housed, but may be able to claim assistance from local authorities. More information on this is contained in Section 1.2.

Local authorities are required under Section 167 [1] of the Housing Act 1996 to have a scheme setting out how housing priority is allocated. Requests for housing are placed on a waiting list and are prioritised according to how an individual's circumstances meet the criteria of the local authority's scheme. This is usually done via a points system; the more points you accrue the higher up on the waiting list you are. Local authorities set the exact criteria for their schemes. However, section 167 of the Housing Act 1996, as modified by the Homelessness Act 2002 and the Housing Act 2004[7], requires specific attention to be paid to the following:

- The homeless or those about to lose their home
- People living in insanitary or unsuitable conditions
- People living in overcrowded conditions[8]
- People who need to move on medical or welfare grounds, or on grounds relating to a disability[9]
- People who need to move to a particular area to avoid hardship (e.g. for studies, access to support or carers).

As the interpretation and weight given to each of these conditions is decided by the local authority, there is often inconsistent practice in who is prioritised for housing. In the case of HIV, in some areas having a diagnosis may be enough to make an individual a priority for housing. However, in other areas it may not make any difference to an application unless they were very unwell.

Individuals apply to go on to the housing list by completing an application form available from their local authority. The application forms vary but all ask questions to establish eligibility and priority for housing, including a question about any relevant health conditions. Individuals are encouraged to include as much relevant information in support of their application as possible, to ensure they receive all the support they are entitled too.

In the event of an individual disagreeing with the local authority's decision, either the banding/points they receive or a decision that they are not entitled to housing, the individual can then ask the local authority to review the decision and submit additional information in support of their claim. If the local authority still decides an individual is not entitled to housing a judicial review can be sought.

6: This could include individuals with a work permit, student visa, or marriage visa, or someone who has had one of these and are applying for further or indefinite leave to remain.

7: The legislation in Scotland outlines similar criteria and is found in the Housing (Scotland) Act 1987, Part 1.20.

8: Overcrowding is legally defined as a household where two individuals of the opposite sex have to share a bedroom when they are not a married/cohabiting couple and are both over 10 years old. Overcrowding can also be defined by size, regardless of sex of the occupants. This can either be based on the square footage of rooms or the number of people living in a room. Rooms are not restricted to bedrooms; living rooms and large kitchens may also be included, providing the room is over 50 square feet.

9: People living with HIV could be covered on all grounds in this, but the accommodation they are currently residing in must be having a negative impact on their health.

1.2 Asylum seekers and housing entitlement

The majority of asylum seekers are not entitled to housing support from local authorities; those who need accommodation have it provided by the UKBA. In order to be eligible for UKBA housing asylum seekers must have:

- Claimed asylum 'as soon as reasonably practicable' after arrival in the UK[10]
- Have no access to alternative support
- And/or be able to show that refusing them support would breach their human rights.[11]

Asylum seekers can claim for accommodation support, or subsistence support, or both of these. In 2007 around 70 per cent of support applications were for accommodation and subsistence support. In the first quarter of 2008, 175 principal asylum applicants, out of 4,770 total applications, were ruled ineligible for support.[12]

Accommodation is paid for by the UKBA and may be provided by local authority housing, a registered social landlord or a private landlord. Asylum seekers cannot choose where they will live and will be dispersed to identified areas across the country, staying in self-contained accommodation or hostels.[13] They cannot move from their assigned accommodation without permission from the UKBA.

Housing for asylum seekers is often of a particularly poor standard, shared and overcrowded, causing significant vulnerability and harm. A 2001 Shelter study into quality of private rented housing provided by agencies to asylum seekers, found that 86 per cent of houses of multiple occupancy were unfit for the number of occupants and 17 per cent of dwellings were unfit for human habitation.[14] A 2005 study in Leeds uncovered further evidence of poor quality housing, including a woman with two young children living in accommodation with a leaking toilet and collapsing ceilings.[15] An asylum seeker quoted in a 2006 study of housing needs in Nottingham described accommodation for asylum seekers as "places where no one else wants to live."[16] In 2007 the Joint Committee on Human Rights concluded that in some cases the quality of the accommodation provided contravened the human rights of asylum seekers.[17]

Once a decision is made on their asylum claim, asylum seekers may lose the right to their existing housing support, whether their claim is accepted or not. If their claim is accepted they have 28 days to find alternative accommodation and can apply to their local authority for housing assistance. The Home Office also offers an interest-free loan of between £100 and £1,000 depending on need to help with a deposit for accommodation, training for a job or buying essential items for their home. However, problems can arise here where applications for housing benefit take longer to come through and there is a gap between UKBA support being withdrawn and new support becoming available.

If an asylum seeker's claim is refused and they opt to return home voluntarily they can continue to receive their accommodation support under Section 4 of the Immigration and Asylum Act 1999, commonly known as 'hard case' support.

Case Study

Ruth is an HIV-positive asylum seeker waiting for a decision on her claim.

She was given private accommodation by the UKBA which was dirty, damp and in poor repair. She requested alternative accommodation as she has two young children who could not live in those conditions.

With just 24 hours notice she was told she would be moved to new accommodation, giving her very little time to pack and let friends know she was moving.

She had no opportunity to check if the new flat was suitable. When she arrived she discovered it was so dirty that her children could not stay there the first night.

When she asked for improvements to be made the private landlord said she would have to pay half the costs for repair work.

10: On 17 December 2003, the Home Secretary announced that asylum seekers would be considered to have made their claim 'as soon as reasonably practicable' if they could give a 'credible explanation' of how they arrived in the UK within three days of applying for asylum.

11: NAT (2008) *HIV and the UK asylum pathway* www.nat.org.uk

12: Home Office (March 2008) *Asylum Statistics: 1st Quarter 2008 United Kingdom* www.homeoffice.gov.uk

13: Information on the dispersal process for asylum seekers living with HIV and the asylum process is available from NAT at: www.nat.org.uk/Poverty-and-Social-Disadvantage/Migration-policy

14: Deborah Garvie (2001) *Far from home: the housing of asylum seekers in private rented accommodation* www.shelter.org.uk

15: Peter Dwyer (2005) *Meeting basic needs? Exploring the survival strategies of displaced migrants'* www.esrcsocietytoday.ac.uk

16: Sigma Research (2006) *Supporting People with HIV: Research into the housing and related support needs of people with HIV in Nottingham City* www.sigmaresearch.org.uk

17: Joint Committee on Human Rights (2007) *The Treatment of Asylum Seekers Tenth Report of Session 2006–07* www.publications.parliament.uk

This support is for those who are assessed as destitute, are taking reasonable steps to return home, but are unable to do so immediately.[18]

Although the majority of asylum seekers are not entitled to support from the local authority, there are exceptions. Some destitute asylum seekers who are deemed to be particularly vulnerable may be entitled to help from local authorities under Section 21 of the National Assistance Act 1948. This support may also be available to refused asylum seekers who are co-operating with the removal process or are currently unable to return to their home country, again where particularly vulnerable.

Section 21 outlines the responsibilities of local authorities to provide accommodation to those:
"who by reason of age, illness, disability or any other circumstances are in need of care and attention which is otherwise not available to them."[19]

For Section 21 to apply it must be only possible to meet the need for 'care and attention' through providing accommodation. If there is any other way of meeting the need the rules do not apply.

Section 21 support is not a specific support for asylum seekers. Asylum seekers (including refused asylum seekers and those applying for leave to remain under the European Convention on Human Rights) have additional criteria to fulfil, that British citizens do not need to meet, in order to be considered under this rule. That is that the need for care and attention cannot have arisen solely because of destitution or the anticipated physical effects of destitution.[20] This means there must be something beyond the lack of accommodation that makes them eligible for support, commonly referred to as 'destitution-plus'.

The entitlement of HIV-positive asylum seekers to Section 21 support has been examined by the courts. A Court of Appeal ruling in R[M] v Slough Borough Council had found that Slough Borough Council was responsible for housing a HIV-positive asylum seeker who had no need for care and attention beyond the need to take medication and visit his HIV clinic. In July 2008 the House of Lords overturned this judgment, ruling that M did not have a need for care and attention that required the local authority to support him.

The Lords decided that a need for care and attention had to mean that an individual needed some help looking after themselves. This could be help with domestic chores or psychological support, and did not have to be personal physical care. As M did not need any such support he did not qualify. As Lady Justice Hale said "Looking after means doing something for the person being cared for which he cannot or should not be expected to do for himself."

The Lords also defined what they meant by 'need' in this situation. Lord Neuberger said: "'in need of' plainly means more than merely 'want' but it falls far short of 'cannot survive without'". So a 'need for care and attention' does not have to mean the person will die or suffer severe harm if that need is unmet, but there must be some basis for the need. The person therefore will have to be able to show that there is something they cannot do or have trouble doing for themselves which it is reasonable for someone else to help them with.

While the House of Lords ruling removes the right to Section 21 support from many whose HIV is well managed, where people need some help, such as nursing care in their own home, or a counsellor, or help with domestic chores, there may be a case for receiving Section 21 support. If someone needs personal care in their own home then they will certainly still be eligible for Section 21 support. If they have other care needs they may well be able to make a case for receiving Section 21 support.
For these particularly vulnerable asylum seekers, local authority housing will be preferable to UKBA housing as it does not require them to be dispersed.

18: NAT (2008)

19: National Assistance Act 1948, section 21(1)

20: According to the Nationality, Immigration and Asylum Act 2002, destitution means that the asylum seeker does not have adequate, or cannot obtain adequate, accommodation, food and essential items for themselves and their dependents.

1.3 Homelessness

Entitlement to support when an individual is homeless or at risk of homelessness is based on separate legislation from other housing support. Local authorities have specific duties to house individuals in these situations. The Housing Act 1996 provides a legal definition of homelessness in England and Wales.

A person is considered homeless if:

- They have no accommodation they are entitled to occupy
- They have accommodation but they cannot secure entry to it
- They have accommodation but it is of a moveable nature (e.g. caravan) and there is no place to legally park and live in it
- They have accommodation but it is not reasonable for them to continue to occupy it. This can be due to risk of domestic violence or because the accommodation is in very bad repair compared to other available accommodation and is harming health.[21]

The Housing Act Scotland 1987 includes all these definitions and the following additional definition:

- It is overcrowded (within the legal definition of overcrowding) and may endanger the health of the occupants.[22]

These definitions are intentionally broad to avoid being overly prescriptive and allow for interpretation in individual cases. The definitions recognise that people can be homeless without having to be sleeping on the streets; they may be staying with friends and family, squatting, or be in accommodation that they are being forced to leave. Individuals that are threatened with homelessness within the next 28 days in England and Wales, and two months in Scotland, can also make an application under the homelessness provision. In these cases the local authority should either assist the individual to stay in their existing home if this is possible, or alternative accommodation should be found.

If a person thinks they are homeless or threatened with homelessness they can apply to the local authority for accommodation. A homeless application is different to a request to be put on the housing register and requires specific actions from the local authority. The applicant does not need to ask explicitly to make a homeless application: the authority should recognise from their circumstances that they may be homeless and in priority need, and it must then consider whether it owes a duty to accommodate them. The applicant will complete a form, including all information relevant to their situation, and will then be interviewed by a Homelessness Officer. If the individual has nowhere to stay this interview should generally happen on the same day an application is made. Emergency accommodation may be provided while the local authority reaches its decision.

The local authority does not only consider whether an individual is legally homeless when reaching a decision on whether they have a duty to provide assistance. The Homelessness Officer must also consider whether the individual is entitled to assistance and whether they are in priority need.

To be eligible for assistance an individual must be:

- A British citizen or been granted asylum, or indefinite or exceptional leave to remain;[23] or
- A European national with a right of residence; and
- Habitually resident in the UK.

If an applicant is both considered homeless under the legal definition and is eligible for assistance, the next test is whether they, or one of the people included in their application, are in priority need of emergency accommodation. If the Homelessness Officer considers an individual not to be in priority need they do not have to provide emergency accommodation, although they may choose to do so.

The categories for priority need are:

- Pregnant women and those who live with them
- People responsible for dependent children who normally live with them. Dependent children are classified as either under 16, or under 19 and in full-time education
- People made homeless due to flood, fire or other disaster
- Young people aged 16-17 (except if they have been in care for at least 13 weeks since the age of 14, or are classed as a child in need, or are not eligible for assistance. In these cases the duty of care normally resides with social services)[24]
- Care leavers aged 18-21, who have spent at least one night in care since their 16th birthday
- Other people who are particularly vulnerable.

21: Housing Act 1996, section 175

22: Housing Act Scotland 1987, Part II, section 24

23: The draft (partial) Citizenship and Immigration Bill proposes changes to the immigration system which, if passed, will impact on this entitlement. It introduces longer time lines for citizenship and permanent residency and during these times there will not be full access to benefits. Indefinite and exceptional leave to remain will be replaced by temporary or permanent permission.

24: For a full explanation of the duties around young people who have been in care see Shelter's guide to Priority Need categories at www.shelter.org.uk

25: Department for Communities and Local Government (2006) *Homelessness Code of Guidance for Local authorities,* paragraph 10.13 www.communities.gov.uk

26: All information from Shelter England and Shelter Scotland, www.shelter.org.uk

The vulnerable category is where HIV-positive people would make a claim and is the most open to interpretation. The definition of vulnerability is: "When homeless the person is less able to fend for himself than the ordinary homeless person so that injury or detriment to him will result when a less vulnerable man would be able to cope without harmful effects."[25]

This can be taken to include having a physical or mental illness, having a disability, or being an older person. However, as the examples below show, depending on how the local authority applies the definition, an HIV diagnosis alone may not be enough to be considered in priority need. This is illustrated in the case study opposite. If a claim for assistance meets both the definition of homelessness, eligibility for assistance, and priority need tests, the final step is for the applicant to show that he or she did not become homeless intentionally.

A person becomes homeless intentionally if s/he deliberately does or fails to do anything in consequence of which s/he ceases to occupy accommodation which is available for his/her occupation and which it would have been reasonable for him/her to continue to occupy. An act or omission in good faith on the part of a person who was unaware of any relevant fact is not to be treated as deliberate (s.191, Housing Act 1996). Examples of situations where a person may be treated as intentionally homeless or otherwise are given in paras 11.9-11.28 of the Homelessness Code of Guidance, and they include cases where that person has failed to pay the rent on their previous accommodation when they could have afforded to do so, and they have been evicted as a result.

Where a local authority has accepted that the applicant fulfils the four criteria and that it owes them a housing duty (but not before), the authority may consider whether the applicant has a local connection with its district. This could be having lived in the area for six months out of the last 12 months, or three years out of the last five years. It could also be having family or work connections in the area. If there is no local connection the application can be referred to another local authority where there is a connection. If there is no connection with any area, or there is a risk of violence from returning to the area where there is a connection, the case cannot be referred and the original local authority must consider the application.

If an application is accepted then temporary accommodation is provided by the local authority until they can provide permanent housing. The temporary accommodation may be a house or flat, or it may be a place in a hostel or bed and breakfast. Families with dependent children or pregnant women should only be placed in bed and breakfast accommodation in an emergency and for a maximum of six weeks.

If a claim is rejected the applicant has 21 days to launch a request for review of that decision. In the first instance the local authority will review the decision again and the applicant can submit more supporting information. If the review is unsuccessful a further appeal can be made to the County Court, on the basis that the decision is legally incorrect. The local authority does not have a legal duty to provide accommodation while the review takes place. If the authority refuses to provide temporary accommodation, it may be possible to bring proceedings for Judicial Review to challenge the way in which the authority exercised its discretion.[26]

Housing in Northern Ireland

The Housing Executive Act (Northern Ireland) 1971 created the Northern Ireland Housing Executive (NIHE) which is Northern Ireland's strategic housing authority.

The NIHE has 35 district offices which oversee all housing issues for their local communities. District offices provide a range of services including maintenance, repairs, housing benefit, rent collection, allocations, transfers, housing management, and work with community groups.

Housing allocation and transfers, as well as homelessness support are provided by these district offices. These services are carried out in a similar way (for example using a points system) as they are in local authorities in the rest of the UK.

2. HIV and housing

2. HIV and housing

This section looks specifically at HIV.[27] It examines how the housing needs of people living with HIV are addressed currently, drawing on interviews with HIV and housing support organisations, existing literature, and case studies. It looks at when a HIV diagnosis should be considered grounds for being given greater priority in housing allocation, examining the medical evidence and the effects of poor housing on health.

2.1 HIV and housing entitlement – the current situation

As outlined above, when making applications for social housing individuals are banded according to need, and local authorities will assess who is most in need of housing and is placed at the top of the list. As a serious medical condition, one might assume that an HIV diagnosis would accord people additional priority in housing. However, in practice HIV is not always considered sufficient medical or disability grounds to guarantee people a higher place on the list, even when accompanied by other needs. People have had requests for housing turned down or placed in a low priority band despite their HIV status being known.

In some cases even people with HIV who are homeless have been refused emergency housing. In many cases, for local authorities to consider someone in need they will have to have a CD4 count under 200 or have other symptoms of infection, and even this may not be enough to be considered a priority.

Local authorities should always consider awarding people living with HIV priority for social housing on medical grounds, on the basis of a comprehensive needs assessment, bearing in mind the importance of treatment adherence and the fluctuating nature of the condition. People living with HIV who are homeless should always be considered 'vulnerable' and should qualify for emergency support and be awarded the appropriate priority on the housing register, regardless of their current health.

The case studies throughout this document highlight circumstances where a local authority has paid very little attention to an individual's HIV status and they have been left in unsuitable accommodation that had a negative impact on their health. Individuals with a high CD4 count and suppressed viral load are likely to be considered to have a managed condition that does not put them at increased need. However, this does not account for those who may see fluctuations in their health, being well at times and at other times suffering from treatment side-effects or ill health caused by HIV.

It also does not recognise the other effects HIV can have on an individual, even where their condition is well managed. Simply being able to adhere to treatment regimes requires a stable environment that can only exist if adequate, secure housing is available.

The HIV Capital Grant scheme

This scheme is funded by the Department of Health and is targeted at supporting local authority HIV-related capital schemes in England, with priority given to the purchasing and refurbishing of properties, as well as support services, to allow people living with HIV to live independently in the community.

The scheme has also been used to support the refurbishment of voluntary sector and local authority premises, as well as funding IT equipment to help deliver social care initiatives in the community.

The continuation of the scheme following the 2007 Comprehensive Spending Review was welcomed by both the voluntary sector and local authorities. The funding continues to be ring fenced, ensuring that the money only goes directly to those projects providing housing and support for people living with HIV.

27: See Appendix I for a basic overview of HIV.

28: The Scottish Office (1999) *Poor Housing and Ill Health – a summary of research evidence* www.scotland.gov.uk

29: The Scottish Office (1999)

30: Joseph Rowntree Foundation (2001) *The impact of housing conditions on excess winter deaths* www.jrf.org.

31:Scottish Office (1999)

32: Health Protection Agency (2007a) *Testing Times - HIV and other Sexually Transmitted Infections in the UK* www.hpa.org.uk

33: Tuberculosis *AIDSmap* www.aidsmap.org.uk/cms1032644.asp

34: Health Protection Agency (2007b) *Tuberculosis in the UK - Annual report on tuberculosis surveillance and control in the UK 2007* www.hpa.org.uk

35: The no-blame game *The Guardian* Jan 28 2008 www.guardian.co.uk/society/2008/jan/28/tb.london

Fluctuating conditions associated with HIV, such as peripheral neuropathy can mean that whilst an individual may have a stable CD4 count and appear well most of the time, at other times they may be very ill.

The following sections look in more detail at how housing can impact on the health of people living with HIV. As well as focusing on specific needs around HIV, such as disease progression, it looks at wider problems around physical, social, emotional and mental health needs. These are areas that may not currently be considered when assessing need for housing. However, they all impact on the health and well-being of people living with HIV and can create additional housing needs.

2.2. Health implications

Poor quality housing can harm the health of an HIV-negative person with no pre-existing health conditions; for an HIV-positive person the consequences are likely to be far more severe and this should impact on the local authority's assessment of their need.

Poor housing can aggravate health complaints. A 1995 study into health risks in buildings highlighted heating and ventilation issues (primarily damp and cold), radon, dust mites, carbon monoxide, and security as amongst the most significant risks.[28] For HIV-positive people, heating and ventilation and security issues are of particular concern.

Damp conditions can cause funguses to grow which can be toxic in themselves or exacerbate existing conditions such as asthma. A study of the general population in 1988 showed that adults and children in damp or mouldy housing were more likely to have experienced respiratory symptoms, nausea, and fainting.[29]

The link between cold housing and ill-health is well established, particularly amongst older people.[30] The number of deaths amongst older people increases in cold weather. Most deaths are attributed to cardiovascular and respiratory conditions exacerbated by the cold, rather than hypothermia.[31]

For people with HIV who are not on treatment the risks could be amplified as their immune system will be less able to respond. With a suppressed immune system the ability to fight off infections is reduced and the potential impact of conditions that can cause illness, such as damp or cold, are increased. The two most common AIDS-defining illnesses in 2006 were both conditions affecting the lungs, pneumocystis pneumonia (PCP) and Tuberculosis (TB), illustrating the risk of respiratory infections in HIV-positive people.[32] For those who are on treatment poor conditions can impact on their ability to adhere to treatment, as a result of stress or because of the health problems caused by their housing.

In the case of TB, overcrowding in housing is a known risk for transmission. Placing HIV-positive people in overcrowded, shared housing can result in serious ill health. People living with HIV are over seven times more likely to develop TB after exposure than HIV-negative people. They are also far more likely to develop active TB if they have a latent infection. Being on treatment does not completely alleviate this risk; they are still more likely to develop TB than those who are HIV-negative.[33] There were 8,497 reported cases of TB in 2007, similar to figures reported for 2006 and 2005, with most cases occurring in London.[34] The TB epidemic in the UK is primarily the result of latent infection reactivating amongst migrant populations. TB Alert state that the reason for this is poverty, with poor housing and poor diet being key factors.[35]

Case Study

Angela is HIV-positive and living in a one bedroom flat with two pre-school children. Angela has a low CD4 count and suffers from chronic fatigue and back pain.

Due to overcrowding she has to keep her orthopaedic bed in the small sitting room, meaning she has no privacy when she is ill.

An appeal was made to the local authority to rehouse the family, with supporting evidence from social workers and her hospital consultant. The local authority has refused and ruled that she is not a high enough priority for rehousing.

As her children are both under 10 years of age she does not meet the legal definition of overcrowding.

Homelessness also makes people particularly susceptible to developing infections and illnesses. In a 2002 Sigma Research survey of the needs of people living with HIV, 3.5 per cent of respondents had experienced homelessness in the past 12 months. The reasons for homelessness included relationship break up, eviction, and refusal of refugee status.[36] Stonewall Housing reports that 16.5 per cent of HIV-positive people requesting help in one 16-month period cited homelessness as a problem.[37]

Case Study

John was HIV-positive and suffered constant abuse from a group of local youths. Police intervention failed to resolve the issue and he became scared to leave his home. The abuse escalated to the point where his home was broken into, ransacked, and homophobic graffiti scrawled over his walls. The level of abuse meant he was forced to leave his home and move to a new area.

Injecting drug users are particularly vulnerable both to homelessness and to HIV. Research conducted by the Health Protection Agency revealed that three-quarters of injecting drug users surveyed had been homeless at some point, and half of those had been homeless in the past 12 months. Homelessness is known to be a risk both for the spread of TB and for the emergence of illness in those with latent TB. In recognition of this the Health Protection Agency are to begin collecting information on homelessness for their surveillance data in order to monitor the risk.[38]

Homelessness also increases the risk of injecting drug users acquiring HIV, as there is an increased level of sharing needles. They are also vulnerable to hepatitis C and infections caused by poor injecting practice. With nowhere to stay it becomes more difficult to store clean needles or find somewhere private to inject, which may increase needle sharing as it is quicker to share or reuse rather than start again.[39] Drug free hostels can exacerbate this problem if individuals cannot keep their own private injecting equipment with them. Support services for homeless injecting drug users are needed to ensure that they can access accommodation, and also to help them learn to inject more safely, access treatment for their addiction if desired, and be tested and treated for HIV and hepatitis C.

A review of the literature on the relationship between homelessness and HIV conducted by Dr Jane Anderson outlines the potentials for harm. Evidence of harm identified include:

- The high level of death amongst rough sleepers in general in the UK, with death rates being 25 times greater than those of the housed population
- Research from the USA showing people with asymptomatic HIV who are homeless have a risk of death four times greater than the HIV-positive population average
- Studies from the USA and France showing homeless people with HIV were more likely to miss appointments and be lost to follow up.[40]

While HIV is now, for many people in the UK, a long-term manageable condition, in order to achieve and maintain this state, a certain amount of stability is needed. Treatment must be strictly adhered to; this stops the virus becoming resistant to the drugs being used. Drugs must be stored properly, taken at specific times and with or without certain foods. This adherence would be very difficult to maintain in a situation where an individual is homeless and either living on the streets or staying with friends or relatives who may not be aware of their status.

Regular monitoring by health professionals is required both to establish when to start treatment and to ensure that treatment continues to be effective. Where people have no permanent accommodation and are required to move around, ensuring they can attend clinic appointments and receive proper care is very problematic, as backed up by the evidence from the USA and France.

All these factors demonstrate the link between homelessness, poor quality housing and ill-health, and the increased risks faced when HIV is also an issue. High quality housing is essential if people are to maintain their health and treatment regimes. However, physical reasons are not the only factor to be considered here. The next section looks at the social needs of people living with HIV as well as other barriers to accessing good housing.

36: Sigma Research (2002) *What do you need? Findings from a national survey of people living with HIV* www.sigmaresearch.org.uk

37: Data from Stonewall Housing covering the period April 2007-August 2008

38: Health Protection Agency (2007a)

39: Health Protection Agency (2007c) *Shooting Up – infections among injecting drug users in the UK, 2006* www.hpa.org.uk

40: Dr Jane Anderson (2008) unpublished paper

2.3 HIV and discrimination

Sadly HIV remains a stigmatised condition.[41] Some individuals will fear disclosing their status to family members in case they are thrown out of their home or are subject to violence. Parents may also wish to withhold information about their status from young children in case it causes them unnecessary worry or they inadvertently disclose to others. Here, attitudes of housing staff are crucial as careless disclosure can result in real harm. Local support organisations reported incidents of housing staff discussing clients' HIV diagnosis with family members who were previously unaware of their relative's status.[42] In the worst-case scenario this can result in people being evicted from their homes and being left destitute.

Discrimination from housing staff has also been identified as an issue in some cases. The 2005 amendment to the Disability Discrimination Act 1995 makes it illegal to discriminate against HIV-positive people in the provision of accommodation. Despite this protection, cases of discrimination do happen, both in the private and social sector.

In the private sector discrimination is a significant concern. In one case, uncovered by the Crusaid Hardship Fund, an African woman was denied accommodation by a private landlord as "she was bound to have AIDS."[43]

As a result of the stigma associated with HIV, support networks are important for ensuring people have a safe environment to be. Ensuring accommodation is situated in places where people can access their support groups, or are close to friends or family, can make a big difference to their well-being. In rural or smaller urban areas this can be particularly important as transport may not be readily available, but even in large cities, isolation can be a real problem.

2.4 Mental health, well-being, HIV and housing

Housing problems can also be harmful to the mental health and well-being of HIV-positive people. HIV is not simply a physical condition; the stigma that still surrounds the virus and the difficulty of living with a long-term illness mean it impacts greatly on people's social needs and mental health.

Research on mental health issues for people living with HIV has uncovered a significant level of need. In a recent study conducted in London clinics, a third of HIV-positive patients reported having suicidal thoughts in the previous week.[44] Rates of depression more generally have also been shown to be high, with research conducted by the International Association of Physicians in AIDS Care showing that 70 per cent of people living with HIV experience depression.[45] Other US based studies have estimated prevalence of depression at between 22-45 per cent, compared to 15 per cent for the general population.[46]

Both stress and depression can compromise the effectiveness of treatment. Links have been found between depression in HIV-positive women and disease progression,[47] and between depression and immune responses in HIV-positive men.[48] Depression and other mental health problems have also been shown to make adherence to treatment more difficult. This, in turn, will impact on the health of an individual as they run the risk of developing resistance to their drugs and having to switch to another drug.

Treatment Guide

HIV treatment suppresses the levels of HIV in the body, boosting the immune system and allowing most people to live long, healthy lives.

A CD4 count is a measurement of the health of the immune system. The lower the count, the more damaged the immune system and the more vulnerable an individual is to opportunistic infections. The aim of treatment is to raise the CD4 count and reduce the viral load (the amount of HIV found in the body). In the UK, it is recommended that people begin treatment when their CD4 count falls below 350.

While treatment is very effective, the regime can be complicated and demanding. For example, drugs must be taken in the correct sequence and at the right time according to specific instructions. Some HIV treatment must be taken with food, some two hours after food, and others must be refrigerated.

At least 95 per cent adherence to treatment is required, as even one or two missed doses can be seriously problematic both for efficacy of therapy and in preventing drug resistance. If an individual develops drug resistance those drugs will stop working and they will need to switch to other therapies. The more drugs an individual becomes resistant to, the fewer options they have for successfully treating their HIV.

In a mortality audit conducted by the British HIV Association (BHIVA) for 2004/2005, 27 deaths out of a total of 387 were directly attributable to poor adherence to treatment.[49]

41: For further examples of how stigma impacts on housing need see Sigma Research (2006) *Supporting People with HIV: Research into the housing and related support needs of people with HIV in Nottingham City* www.sigmaresearch.org.uk

42: Interviews conducted by NAT, 2008

43: Crusaid/Waverley Care (2007) op.cit

44: Sherr L et al (2008) Suicidal ideation in UK HIV clinic attenders. *AIDS* 22(13):1651-1658.

45: Mental health problems 'experienced by 70per cent of people with HIV' (2002) *AIDSmap* www.aidsmap.com/en/news/47C679DE-A275-48FD-B525-3B24C3A0B8B0.asp

46: Adherence in depressed HIV-positive patients improved by antidepressant treatment (2005) *Aidsmap* www.aidsmap.com/en/news/CD72A08D-5033-425C-9BDD-EFAFDB23F0EC.asp

47: Dr Jane Anderson, (2008)

48: Dr Jane Anderson, (2008)

49: BHIVA (2006) *Mortality Audit September 2004 – October 2005* www.bhiva.org

Studies on the general population have found that the more housing problems people experience the worse their reported mental health is.[50] This adds to the array of reasons why the mental health needs of people living with HIV should be considered when making decisions on housing need. The issue is not simply one of having access to accommodation, the quality of accommodation is important, as is access to existing support networks.

By providing individuals with stable, quality housing we can help to avoid additional stress, create a situation where other mental health needs can be addressed, and better support individuals with adhering to treatment.

2.5 The implications of living in shared accommodation

Shared accommodation is highlighted as an issue in existing literature on housing.[51] It was also repeatedly cited as a problem by local support services during interviews conducted by NAT.

Shared accommodation can make it difficult for individuals to manage their condition properly because of the lack of privacy and the stigma and discrimination issues explored above. Some drugs for treating HIV can require refrigeration; where kitchens are shared people may not wish to put their medication where others can see it. In research conducted by Sigma Research for Nottingham Council, people in shared accommodation highlighted the difficulties of storing their medication. One person, worried about their housemates discovering their diagnosis, hid their medication under food in a box in the shared fridge. Another was so concerned that they did not keep the medication in the fridge, risking it becoming less effective.[52]

Case Study

Sara was about to be placed into shared accommodation by a housing association. When they found out she was HIV-positive they informed her that the people she was sharing with would need to be told her status.

Her social worker questioned the decision, citing discrimination law, and the housing association backed down.

2.6 The impact of ageing on housing need

Consideration of the needs of older people with HIV is also needed. As people on treatment live longer their housing needs may become more critical. In the United Kingdom one in 13 adults who are HIV-positive are 55 years or over.[53] Little research has been done into the likely effects of an ageing HIV-positive population and what their needs might be. Concerns raised to date have focused on the ability of sheltered housing to cope with HIV-positive clients. Knowledge amongst staff and fears over confidentiality were highlighted. In addition, as many of the older age group are gay men, concerns over homophobia and the ability to house gay couples were also raised.[54] A survey conducted by Polari of sheltered accommodation wardens highlighted a lack of interest in the needs of homosexual older people and very negative attitudes.[55]

2.7 Provision and upkeep of housing

When people living with HIV do make claims for accommodation support they can face significant delays in having their case heard. The interviews conducted by NAT, and the earlier survey by Sigma Research, also revealed criticism of local authorities for delays in providing accommodation, providing unsuitable accommodation, and failures of administration.

Failure to resolve problems was also an issue, with 22 per cent of those who had experienced housing problems in the Sigma Research survey stating their health had deteriorated.[56] Many of these problems are due to the lack of decent, affordable housing and not because of the individual's HIV status. However, as discussed above, delays in resolving problems can cause significant stress which can impact on health. Organisations have also reported cases where clinicians are reluctant to start HIV treatment until the person is in stable accommodation and can cope with the treatment regime.[57] If there is little in the way of social housing and private rentals are in bad repair, local authorities have little choice over where they house people. A general improvement in housing stock is desperately needed to ensure all people are housed appropriately.

This section has laid out the case for people living with HIV to be given higher priority for housing or homelessness assistance. While this does not always happen at the moment, the Government has included HIV-positive people as a distinct group requiring assistance under the Supporting People programme. The following section looks at the programme, its aims, and how it can help people stay in housing.

50: See The Scottish Office (1999)

51: Sigma Research (2006)

52: Sigma Research (2006)

53: Ageing with HIV - are cancer, heart disease, dementia the new challenges? *AIDSmap* July 30 2007, www.aidsmap.com/en/news/F67120B0-1FAB-4C7C-A1AE-630C6D6DD65C.asp

54: Interviews conducted by NAT 2008

55: Polari Housing Association (1995) *As We Grow Older. A Study of the Housing and Support Needs of Older Lesbians and Gay Men* www.polari.org.uk

56: Sigma Research (2002)

57: Interviews conducted by NAT 2008

3. Supporting People programme

3. Supporting People programme

The aim of Supporting People, a funding regime which has been operating across the UK, is to allow vulnerable people to live as independently as possible in the local community. It can provide support with:

- Access to benefits and housing
- Filling in forms
- Maintaining a property
- Budgeting.

In addition it can offer assistance with wider issues that might impact on housing needs such as:

- Confidence and self-esteem
- Mental health problems
- Relationship difficulties
- Accessing a GP
- Alcohol use.

It can also provide assistance via a visiting support worker who can help with the transition to independent living and provide support for a maximum of two years. For those requiring further assistance long-term services can continue under different funding streams. If an individual becomes ill and requires support the funding will come from social care budgets and not Supporting People. The programme has been managed and commissioned by local authorities with support from the Department of Communities and Local Government (DCLG).

Supporting People was designed to respond to individual needs. However, a briefing by the then Office of the Deputy Prime Minister (ODPM)[58] on HIV and Supporting People noted that Supporting People authorities were finding assessing the level of need around HIV difficult. Individuals were not coming forward when conventional assessment methods were used and therefore their needs were not being identified. As a result authorities were assuming that there was no need for HIV-specific service provision in their area, when in reality it was that they were not reaching these people.[59] Similar concerns have been raised by local organisations, who identify a failure to conduct proper needs assessments as a key concern.

The ODPM briefing note makes clear the importance of providing services, highlighting the problems stigma and discrimination could pose in accessing them. It is meant to provide some guidance for local authorities on what sort of services people living with HIV may need. However, the information is not very detailed and many of the issues identified in this paper and other literature are neglected. The examples of support that could be provided are help with cooking and budgeting, a floating support worker to build confidence, community alarms to call for help and funding for home adaptations. Up-to-date and more accurate guidance for Supporting People projects is needed to ensure they can assess and meet need properly. With the removal of the ring fencing from Supporting People going ahead in England, discussed in more detail in Section 3.2, guidance is especially needed. When the ring fencing is removed there is potential for housing support services to offer more kinds of support, such as help with training and employment or immigration problems. But for this to happen good needs assessments and co-ordinated thinking are required.

Supporting People in Scotland

Ring fenced funding for Supporting People in Scotland was removed in April 2008. Funding has now been bundled into the local government settlement.

Local authorities in Scotland set priorities for local spending through the Single Outcome Agreements. These are based on the 45 national indicators identified by the Scottish Government. In addition the Improvement Service has drawn up a list of local indicators to help local authorities identify ways to achieve the national indicator.

Local authorities draw up plans on what services they will deliver to meet these indicators based on local need. With no specific national or local indicator covering housing support, although there is a local indicator looking more generally at care and support services, there is real concern that services will suffer. The concerns and recommendations in this section therefore apply equally, if not more so, to Scotland.

In recognition of the concerns raised by the removal of ring fencing, the Housing Support Enabling Unit (previously the Supporting People Unit) conducted a survey of current provision in Scotland. The evidence collected will form a baseline to measure future services in order to determine if the removal of ring fencing does have a negative impact.[60]

58: Now the Department for Communities and Local Government

59: ODPM (undated), *Supporting People Briefing Note: housing related support for people with HIV/AIDS* www.communities.gov.uk

60: For more information on Supporting People in Scotland see www.ccpscotland.org

3.1. Needs for Supporting People to address

In interviews carried out by NAT with organisations providing housing support to people living with HIV, whether funded by Supporting People or otherwise, a range of concerns were raised that ought to be considered in needs assessments. These issues were apparent across the organisations surveyed, in rural areas, small towns and inner-London. They have also been highlighted in existing needs assessments and surveys.[61] While they are not a substitute for a local authority conducting its own needs assessments, they may help to focus thought on what areas to look at in a Supporting People needs assessment.

Key groups to address

The two groups most affected by HIV in the UK are gay men and Black Africans and Supporting People projects will need to ensure they are meeting their needs. The needs of Black Africans living with HIV are particularly acute here. Almost half of HIV diagnoses in 2006 were amongst Black Africans.[62] Black Africans living with HIV are more likely to experience housing problems than White British people living with HIV. Sigma Research calculates that Black Africans are ten times more likely to report financial difficulties and seven times more likely to report housing difficulties.[63] In a recent London study around 40 per cent of Black African respondents living with HIV reported they did not have enough money to meet their basic needs, compared to less than 10 per cent of white gay men.[64] Black Africans living with HIV are also less likely to own their own home, more likely to be staying with friends and family, and more likely to have moved more than three times in the previous three years than white gay men living with HIV.[65] This demonstrates that Supporting People projects ought to pay particular attention to the needs of Black Africans living with HIV in their area.

Case Study

Tess is 18 years old, living with HIV, and being cared for by social services. She attends a support group for young people with HIV and had hoped to share a flat with a friend she made at the group. Because her friend lived in a different London borough to her, they were told they could not be housed together. Tess explains how this makes her feel:

"The chance of living with another young person who you have built up a friendship with would change my life on a day to day basis. It would make going home at night that much easier. It feels hard to understand that just because we live in different parts of London, we are unable to live together."

While gay men are less likely to report problems than Black Africans, they still face problems that Supporting People can assist with. Stonewall Housing collects information on the support needs and problems reported by their HIV-positive clients. In the period April 2007 – August 2008, 8 per cent of clients reported family or relationship breakdown as an issue, and 7 per cent reported domestic violence. For gay men domestic violence may be difficult to deal with as the vast majority of domestic violence services are set up to assist women and may exclude men. Domestic violence and family or relationship breakdown will impact on the ability to maintain housing and are therefore areas Supporting People can assist with. The link is highlighted in Stonewall Housing's data, with 6 per cent of those reporting either of these problems also reporting homelessness as an issue.[66]

Another group which requires particular support are young people with HIV. For those leaving care, or leaving the family home due to difficulties at home, setting up their own home can be very daunting. As well as learning to manage their own house, budget, pay bills, and decide on their future they are also learning to manage their HIV by themselves and transitioning from paediatric care to adult care, which can be very stressful. At this time they require additional support and attention to ensure they can negotiate this period and are not left isolated and vulnerable to depression and ill health.

Supporting People programmes can assist by providing support systems to help manage this. As well as having support workers available, local authorities could also consider more innovative approaches to helping young people in this period. For example, in London a frequent complaint is that young people with HIV who would like to share a council or housing association flat are unable to do so because they live in separate boroughs. Entering into pan-London partnerships to provide cross-borough housing for vulnerable young people would provide a solution to this. Similar relocation schemes are in place for ex-gang members who are relocated to new areas so they are not drawn back into the gang, so the concept is not unprecedented.[67]

61: See Sigma Research (2006) and (2002), and Leeds City Council *The housing and support needs of people living with HIV and/or Hepatitis C in Leeds* (2005) www.leeds.gov.uk

62: HPA (2007a)

63: Sigma Research (2006)

64: Ibrahim, Anderson, Bukutu & Elford (2008) Social and economic hardship among people living with HIV in London, HIV Medicine pp1-9

65: Ibrahim et al (2008)

66: Stonewall Housing data April 2007 – August 2008

67: Out of the shadows Inside Housing October 2008 www.insidehousing.co.uk/story.aspx?storycode=6501525

68: Ibrahim et.al (2008)

69: Leeds City Council (2005)

Case Study

Michael was self-employed and a local authority tenant. When he fell ill he did not claim Housing Benefit as he thought, being self-employed, he would not be entitled to it. With no income he quickly fell into rent arrears and the local authority sought to repossess his flat. With assistance from an HIV organisation he was able to make a backdated claim for Housing Benefit. This claim was initially refused but after an appeal his claim was approved.

Access and completing forms

One concern raised in several research interviews conducted by NAT was the use of computer based bidding systems for housing – known as choice based lettings. When people are put on the housing register and accommodation becomes available they can put themselves down to be considered via a website. This causes problems where individuals do not have the language skills, computer knowledge, or computer access to participate in the system. Given that many people with housing problems will be from immigrant communities this is a real barrier to them accessing the best housing available to them. Support in understanding and utilising the bidding system is essential.

Money and benefits

Results from a survey of people living with HIV in London revealed that 41 per cent of Black African heterosexual women, 39 per cent of Black African heterosexual men, and 23 per cent of ethnic minority homosexual men reported not having enough money to cover their basic needs.[68] Debt is an issue both for those on benefits but also those on low incomes in private housing who are just able to cover their rent. Sometimes these individuals may not be aware of extra benefits they may be entitled to. Interventions to ensure they are receiving all their entitled benefits are necessary to ensure they are not putting themselves at unnecessary risk by, for example, choosing to spend money on rent rather than on food or heating. With rising costs in the current economic climate this is even more critical.

Money is also an issue for those who have their asylum claim accepted and find that support that was previously provided to them is withdrawn. The refusal of the right to work and delays in the immigration process means some people will have been out of work for a long period and can face real difficulties finding employment. Delays in receiving housing benefit and/or difficulties of raising a deposit for private accommodation can leave people at risk of homelessness and destitution. Knowing how to apply for new benefits and loans is crucial to ensure individuals do not get lost in the system.

Maintaining a property

Adaptability of homes is an issue for any progressive condition and one that may not be considered for HIV-positive people due to lack of knowledge. If people begin to develop mobility problems or other health concerns due to effects of HIV or its treatment they may find it difficult to stay in their own homes. Creating 'homes for life' which can be adapted as a person's health changes is a long-term process that could ensure people are not abandoned in unsuitable accommodation. As an example, a needs assessment conducted of HIV-positive people in Leeds identified that individuals would prefer two-bedroom properties, so they could accommodate a carer if required in the future.[69]

Assistance with maintaining a property should also include advice on how to report problems so that individuals can ensure repairs are made. Knowledge of their rights as a tenant will help individuals to be more assertive and empower them to take control of their situation. Some groups of people living with HIV may be more wary of complaining. Those with immigration issues may fear that complaining will impact on their claim to stay in the UK. While people who are having health issues may feel unable to pursue a complaint without assistance as their priority is their own health and complaint processes can be difficult to navigate.

Case Study

Graham was living in a sixth floor flat with no lift access. When he first moved in he was in good health, but since then his condition has deteriorated. He acquired an HIV-related infection which resulted in the amputation of two toes on his right foot. He suffers from chronic pain which varies in severity and his condition is likely to deteriorate. He may eventually be reliant on a wheelchair. His sixth floor flat was highly unsuitable and meant he was unable to leave the flat to buy food or attend hospital appointments. His local authority moved him to a ground floor property which could be adapted to meet his needs as they changed.

3.2 The future of Supporting People in England[70]

Another key issue raised in the interviews NAT carried out with HIV housing experts was the future of Supporting People and its funding. Organisations highlighted their concern about cuts in budgets and the move towards providing generic services rather than HIV-specific services. Budget cuts have been a feature of Supporting People since it was first launched. The original funding seriously underestimated the cost of delivering the projects when it launched in 2003. It was originally expected to cost £750m in the first year but ended up costing £1.8 billion.[71] Since then it has faced year-on-year cuts to reverse the original overspend and currently has a budget of just under £1.7 billion per annum. This is due to be cut to £1.63 billion by 2010.

Reduced budgets mean that savings have to be made. Moving to provide more general services and reducing specialised services is a key way of doing this. For people living with HIV this would mean reduced access to specialist HIV workers who have a good understanding of the issues people face. Generic workers may not have the same in-depth knowledge and may not be able to provide the same level of support. In specialist HIV services, other support, such as legal advice, counselling, or peer support are often available and workers can easily refer clients to another part of the organisation for non-housing support needs. If these services are cut this holistic approach may be lost.[72]

The benefit specialist knowledge can bring is illustrated by this example. An HIV-positive client was receiving Supporting People services from a generic organisation. The client was not adhering to treatment and had told the organisation this, but as they believed it was not a housing support need they had not done anything with the information. When the client began to receive housing support from the organisation specialising in HIV they realised the significance of failure to adhere to treatment. As the client was at risk of becoming very ill and would therefore be unable to maintain their housing situation, the organisation intervened and arranged for the adherence problem to be addressed.

This example demonstrates that care needs to be taken to ensure services continue to be able to meet the complex needs of people living with HIV and that staff have a good understanding of this area. One potential benefit of generalised services is that they can help to 'normalise' HIV but to do this specialist skills must be incorporated into the service and not lost in budget cuts.

Budget cuts could also leave small local HIV services, which rely on Supporting People for a significant amount of their budget, under threat. The services are often a lifeline for people living with HIV, providing a safe place to meet, seek support, and meet similar people. To lose these local services would be a disaster, particularly in rural areas and small towns where they may be the only service available.

The removal of the ring fence from Supporting People budgets in 2009 in England, pulling the money into the Area Based Grant (ABG), may also hit services. The plan is to merge Supporting People funds into the ABG by 2009/10. Local authorities will then be able to spend the funding as they see fit in order to meet local need, meaning that not all the money allocated for Supporting People would have to be spent on those projects. Local authorities develop Local Area Agreements to determine priority for spending, identifying from 198 key performance indicators (KPIs) up to 35 which are of greatest importance in their area. Two of these KPIs are linked to Supporting People, but local authorities could choose not to include them in their key targets and therefore they may lose priority.[73]

The concern is that local authorities will focus on high profile indicators to meet the needs of the vocal majority in their area and the needs of marginalised and vulnerable groups could be ignored. In 2007 the Audit Commission's co-ordinator of Supporting People inspections warned that the removal of the ring fence could hit services for unpopular groups such as refugees and offenders.[74] With the stigma that exists both around HIV and the groups most affected by HIV (i.e. gay men and Black Africans) these services could be at risk.

Given that the Government has previously stated that local authorities are finding it difficult to identify needs, this is potentially an easy area for services to be cut in favour of easier to reach groups. The introduction of Comprehensive Area Assessments (CAA) to assess how well local areas are meeting the needs of their community will allow for some scrutiny of whether the needs of socially disadvantaged groups are being met. The current proposals for the CAA produced by the Audit Commission do stress that they will pay particular attention to these groups during the inspection process.[75]

70: There are currently no plans to remove the ring fence around Support People funding in Wales or Northern Ireland; for details of funding in Scotland please see earlier sidebar

71: Q&A Supporting People *The Guardian* December 3, 2004 www.guardian.co.uk/society/2004/dec/03/housingpolicy

72: Interviews conducted by NAT, 2008

73: The two KPIs are: NI 141 - Service users who have been supported to move on in a planned way from temporary living arrangements and NI 142 - Service users who are supported to establish and maintain independent living

74: Supporting People: projects at risk when ring fence goes *Community Care,* 17 Sept 2007 www.communitycare.co.uk/Articles/2007/09/17/105810/supporting-people-projects-at-risk-when-ring-fence.html

75: For more information see www.auditcommission.gov.uk

The Department for Communities and Local Government recognised these concerns over the changes to Supporting People in England and initiated pilots in 2008 to measure the effects of withdrawing ring fencing. Pilots took place in:

- Barking and Dagenham
- Bath and North East Somerset Council
- Birmingham City Council
- Bournemouth Borough Council
- Dudley Metropolitan Borough Council
- Durham County Council
- Essex County Council
- Gloucestershire County Council
- Hampshire County Council
- Leicestershire County Council
- Liverpool City Council
- Norfolk County Council
- North Yorkshire County Council
- Rutland County Council District Council
- Tameside Metropolitan Borough Council.

As well as information from participating local authorities, current service providers were surveyed to assess their views and highlight concerns. A report on the results of the pilot was produced in 2008. This highlighted the concerns outlined here and also identified potential benefits, which are discussed below.[76]

In order for concerns over removal of ring fenced funding to be addressed certain actions need to take place. Local authorities must ensure systems are put in place to ensure the removal of ring fencing does not result in a reduction or loss of services for people living with HIV. Proper commissioning, involvement of local organisations supporting people living with HIV, and assessing of impact beyond the pilot process are required. Whilst the pilot process was very welcome, the time frame was short. Now the removal of ring fencing is going ahead, the continued assessment of the impact by all local authorities should take place to ensure they are not failing to meet the needs of vulnerable groups.

While there are real concerns over the removal of ring fencing, there are also potentially some benefits to it. Previously services were confined to providing housing support services alone, although clients may have had much wider needs. The end of ring fencing allows for more services to be provided, such as help getting into employment or training. This will benefit clients and also service providers who can expand their work as a result. But for this to happen local authorities must be able to identify the needs and commission services to meet them.

The introduction of Joint Strategic Needs Assessments (JSNA), requiring Primary Care Trusts (PCTs) and local authorities to work together to assess the health and well-being needs of their local population could be a tool to ensure vulnerable groups are not ignored. The JSNA is designed to feed into the Local Area Agreement.

By bringing PCTs and local authorities together it allows for a more integrated approach to planning. For HIV this is an important approach as people will have needs that cross between health, social care and other issues. Many different factors impact on housing needs, as demonstrated above, and the integration of planning around health and more general well-being could help to address many of these issues.

However, in order for this to work, support for commissioners on conducting effective needs assessments, involving hard-to-reach groups, and finding sources of information is vital. Support organisations and people living with HIV will need to be assisted to ensure they can participate in decision-making processes. Without this it will be all too easy for HIV to be ignored, particularly in areas with lower prevalence.

76: Department for Communities and Local Government (2008) *Changing Supporting People funding in England: Results from a pilot exercise - Summary* www.communities.gov.uk

4. Conclusion and Recommendations

4. Conclusion

With a third of people living with HIV having experienced poverty at some point[77], housing is an issue that impacts on the real lives of HIV-positive people. Whether it is access to social housing, tackling homelessness or supporting people to stay in accommodation, HIV is an issue that should be on the housing agenda.

Professionals involved in the housing sector, particularly those responsible for making housing decisions, must understand HIV and the many effects it can have on an individual's life. High quality housing is essential to maintain health and well-being for anyone, but people living with HIV have particular needs that place them at greater risk. Too often these needs are neglected, ignored or misunderstood and people are harmed as a result. The following recommendations outline what is needed to provide people living with HIV with the best standard of care in housing and ensure their needs are met.

5. Recommendations

Information

Information on HIV for local authority employees involved in housing and homelessness should be produced. This should:

- Provide basic information about HIV
- Explain the ways HIV may impact on an individual's need for housing
- Provide guidance on how needs can be met
- Stress the importance of privacy, confidentiality and non-discrimination.

National Government

- The Government should ensure there is sufficient social housing to meet the requirements of those in need
- The Government and local authorities should invest in improving the condition of the general social housing stock to ensure nobody is forced to live in damp, cold, or otherwise poorly maintained homes
- The UK Border Agency should increase the available support to asylum seekers for securing new accommodation after their claim is accepted. The loan that is currently available to successful asylum seekers should be replaced by a grant with no requirement for repayment. UKBA support should not be ended until it is replaced by other benefits as appropriate
- The UK Border Agency should ensure that any private landlords they contract with for housing asylum seekers are providing acceptable accommodation.

Local Authorities

- Local authorities should always consider awarding people living with HIV priority for social housing on medical grounds, on the basis of a comprehensive needs assessment
- In determining the degree of priority an individual should receive, the full implications of an HIV diagnosis should be considered. This includes, but is not limited to, social support, mental health implications, fluctuations in condition, privacy requirements, and ability to adhere to treatment
- People living with HIV who are homeless, or at risk of homelessness, should always be considered 'vulnerable' and should qualify for emergency support and be awarded the appropriate priority on the housing register, regardless of their current health
- People living with HIV should only be housed in shared accommodation as an emergency and not for longer than six weeks
- Local authorities should ensure that any private landlords they contract with are providing accommodation of a standard that supports the health needs of people living with HIV
- Joint strategic needs assessments conducted by local authorities and Primary Care Trusts should ensure the provision of integrated services around health, social care and housing for vulnerable groups such as people living with HIV.

Supporting People

- Local authorities should provide housing support officers with specific training on HIV to ensure that where generic services are supplied they can meet HIV-related needs
- Now the ring fence for Supporting People funding is being removed in England, local authorities should provide services which integrate housing support with other services, such as employment and training support, to best meet the multiple needs of people living with HIV
- The Comprehensive Area Assessment should always scrutinise housing support provision to ensure it meets the needs of those groups identified by the Supporting People Programme, including people living with HIV

77: NAT/Crusaid (2006)

Shelter

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

www.nat.org.uk

About NAT

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change.

SHAPING ATTITUDES.
CHALLENGING INJUSTICE.
CHANGING LIVES.

All NAT's work is focused on achieving four strategic goals:

- Effective HIV prevention in order to halt the spread of HIV
- Early diagnosis of HIV through ethical, accessible and appropriate testing
- Equitable access to treatment, care and support for people living with HIV
- Eradication of HIV-related stigma and discrimination

About Shelter

Shelter believes everyone should have a home. We help people find and keep a home. We campaign for decent housing for all.

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