Kernow Positive Support

HIV, Housing & Community Care

Section 1 : Allocations

"THE CONNECTION BETWEEN HEALTH AND THE DWELLINGS OF THE POPULATION IS ONE OF THE MOST IMPORTANT THAT EXISTS" FLORENCE NIGHTINGALE.

- GOOD QUALITY HOUSING AND ACCOMMODATION IS AN ESSENTIAL PART OF ANY SUCCESSFUL COMMUNITY CARE IMPLEMENTATION STRATEGY.

- WHILST INFORMATION ABOUT THE NATURE OF HIV AND ITS TREATMENT IS CHANGING THE HOUSING NEEDS OF PEOPLE WITH HIV RELATED ILLNESS HAVE REMAINED CONSISTENT.

- THE PROVISION OF GOOD QUALITY HOUSING AND ACCOMMODATION WILL IMPROVE SOMEONE'S ABILITY TO LIVE INDEPENDENTLY AND MAY REDUCE THEIR DEPENDENCY ON PRIMARY HEALTH CARE SERVICES.

- IF BASIC ACCESSIBILITY STANDARDS ARE OBSERVED PEOPLE WITH HIV CAN LIVE SUCCESSFULLY IN MAINSTREAM HOUSING PROVISION.

- IN SURVEYS OF CONSUMER SATISFACTION THE MOST IMPORTANT FACTORS AFFECTING HOUSING CHOICES WERE HEALTH; SAFETY FROM HARASSMENT; LOCATION; LACK OF STAIRS; HEATING AND NOISE INSULATION; SECURITY; ACCESS TO PRIVATE OUTSIDE SPACE.

- LIVING ALONE OR CHOOSING A PERSON TO SHARE WITH WAS SEEN AS POSITIVE OPTIONS. MOVING TO INSTITUTIONAL SHARED ACCOMMODATION WAS SEEN AS A LAST RESORT.

- PEOPLE WITH HIV MAY EXPERIENCE RAPID CHANGES IN THEIR PHYSICAL WELL-BEING AND THEIR HOUSING NEEDS CAN CHANGE JUST AS RAPIDLY AS A CONSEQUENCE.

- OFFICERS UNDERTAKING NEEDS ASSESSMENT FOR COMMUNITY CARE NEED TO BE TRAINED TO RECOGNISE A NEED FOR EQUIPMENT, ADAPTATIONS, TRANSFER OR REHOUSING.

Housing 'the foundation of care'

There is a long tradition in Britain of using housing to promote public health. From the Public Health Acts of the 1850's to the Housing Acts of the 1980s authorities have routinely intervened to house those whose ability to operate in the housing market is undermined by poor health. However, within the tradition of meeting the housing needs of sick people there are contrasting approaches of on the one hand 'disease prevention and health promotion' and on the other 'containment and control'. The declining significance of public sector housing in recent years has had implications for the effectiveness of mainstream housing provision to meet medical needs. One consequence of this is increasing levels of people who are ill among the homeless population; another is the development of 'special needs housing'.

Special schemes

Many people with HIV have seen special schemes as segregating or stigmatizing and have been suspicious of the thinking behind them:

"I feel strongly that isolation from the general community would be a dangerous precedent although I recognise the need for group support. "

However, four surveys into the housing experience of people with HIV in Lambeth and Southwark and Kensington and Chelsea in 1990. London, Portsmouth and Manchester (1991) and Newham (1994) showed a high level of demand *(82%, 54% 80% and 99%)* for self-contained accommodation but with supportive or HIV-educated housing management. By April 1993 there were 371 units of specialist accommodation mostly provided through the Housing Corporation Approved Development Programme. However, this represents a significant shortfall against real need.

Mainstream provision

Many people with HIV are already housed by a local authority or housing associations. Many will have been housed without knowing or without reference to their HIV status. In the above surveys a high proportion were already tenants *(48%, 40%, nla, and 19%).* For some housing organisations it came as a shock that they might be housing 'these people' already. For this reason organisations like the Local Authority Associations and the National Federation of Housing Associations produced guidance 'Housing and HIV Infection - the Challenge to Local Authorities' and 'Housing and HIV Disease - Guidelines for Housing Association Action'. These were designed to encourage not only good access and good management but also to promote health by encouraging housing organisations to take on a wider role in creating environments in which healthy living could take place.

Adaptations

However, of those surveyed 54%, 53%, *nla* and 60% wanted to move and 17%, 26%, *nla* and 11 % wanted to stay but with adaptations. The list of adaptations is long but not prohibitive. The ten most popular were:

- Central heating. 2 - Showers
- Entry phone
- Central alarm
- Double glazing
- Laundry facilities
- Window locks
- Stair lift
- Separate WC
- Noise insulation

Discrimination and harassment

The surveys although based on relatively small samples provide a consistent picture of the housing needs expressed by people with HIV. Some of these are not dissimilar to those expressed by other chronically sick people or frail older people. However, the fear of discrimination or harassment can add to the list of demands in a way that may need explaining - for example in the Rowntree survey many respondents said they wanted a garden:

"I can face the world without really having to face it. "

In all the surveys there was a high level of harassment experienced by the respondents:

"I had a letter through the door saying you're gay, twice the door was burnt in the shape of a cross upside down"

Harassment and discrimination are important additional factors in allocating scarce commodities.

HIV related health conditions and their implications for housing

HIV disease is characterized by a wide range of symptoms often occurring concurrently. It is possible to group them under a number of general headings and identify the impact they have on the design and management of housing stock.

Breathing difficulties

There are a number of common illnesses, including Pneumocystis Carinii Pneumonia, which result in shortness of breath and associated difficulties with mobility. Properties with internal stairs will present mobility difficulties. It may be possible to improve access by ramping stairs, providing stair lifts and grab rails. If a flat is above the ground floor in a block with a lift, lift maintenance and the speed of repairs is important. Damp housing conditions will also aggravate these symptoms.

Persistent diarrhoea and night sweats

These may be experienced by those who have not had a diagnosis of an AIDS defining illness as well as some of those who have. Easy access to a toilet is essential and when designing new provision, locating a toilet next to the bedroom could be considered. Shower facilities have proved to be the most commonly requested adaptation, and again could be considered when designing new stock. Persistent diarrhoea will leave someone feeling extremely weak and there are consequently mobility considerations too. People with nightsweats often have to make regular changes of bedding and so laundry and drying facilities are important.

Impaired Eyesight

HIV infection in the brain and nervous system can affect eyesight. CMV Retinitis can cause severely impaired vision and bilateral blindness. Straightforward controls on heating systems, cookers, etc, will make life easier. For someone with failing eyesight the familiarity of the home and the locality is important - moving to a new home will involve new difficulties. There will be instances where the current home is so unsuitable that a move is unavoidable but there is an argument for early assessment of other future needs *(particularly mobility)* when allocating housing.

Memory loss, confusion and dementia

There is a considerable range of neurological manifestations of AIDS. The HIV virus is thought to attack certain cells in the brain and nervous system and as many as 75 per cent of those dying from AIDS-related illnesses have symptoms associated with disease in the central nervous system. HIV infection in the brain can cause meningitis with severe headaches and fevers. It can also cause impairment of thinking and memory.

When severe it is often referred to as AIDS Dementia and is likely to be more common in the later stages of illness and in people who have had AIDS for a long time. A person may become bedridden and incontinent. Homes need to be made as safe as possible with safety catches on kettles, gas that cannot be left on etc. In some cases continuing may not be possible and a move into supported accommodation may be needed.

General frailty, weakness and fatigue

Many of the HIV-related illnesses including Pneumocystis Carinii Pneumonia *(PCP)* and Kaposi's Sarcoma *(KS),* will lead to general symptoms of weakness and exhaustion. They are also general symptoms of anyone in the later stages of a terminal illness. Difficulties with mobility are inevitable and can be reduced by appropriate allocation of accommodation at earlier stages and by the kind of adaptations mentioned above. In addition, a person will need to be warm, implying the need for central heating they can control. Good sound insulation becomes even more important when you are very ill, bed or housebound, partly because of noise from neighbours but people were also concerned that they could not use toilets or laundry facilities during the night.

Anti-retroviral drugs for treating the disease also play a part here. Progress in drug research to date has not been around immunisation and a 'cure' but in the development of drugs that slow down the debilitating and fatal consequences of getting infected by the disease. The implication is that those undergoing treatment may live longer but may be in a weakened state.

They are, therefore, likely to have long term, high care needs. Wherever possible they will still wish for their needs to be catered for at home. In order for medical care to be able to function in a person's home, the home must meet certain basic requirements. It must be warm, have hot and cold running water, a proper kitchen and bathroom or shower, and have enough space to allow professional and other carers to move around the home and to store equipment.

Design requirements

The medical consequences of HIV lead therefore to the following design checklist:

Security and Privacy

- well-lit approach; entry-phone; spy-hole; adequate safeguards against break-in ego window-locks, laminated glass, self-extinguishing letter boxes; private, safe, secure outside space; link to central alarm.

Accessibility

- located near shops, transport and support networks; level access or well lifted; car park nearby; no internal steps; stairs suitable for chair-lift.

Internal features

- bedroom large enough for equipment storage; kitchen large enough for food preparation and cooking whilst seated; shower; handles and ironmongery should facilitate easy use; bathroom large enough for chair, walking frame and assistance; second bedroom for carer or partner *(during disturbed nights);* layout should facilitate easy movement from one room to another; dry central heating; good sound and heat insulation; double glazing.

Elements of a sensitive allocations policy

A confidential interview could be offered to any applicant. Private interviews in enclosed offices could be offered by prior arrangement.

Recognising that housing organisations are often working within considerable resource constraints when trying to meet the needs of people with HIV. In these circumstances they can be of help by making a timely response to a referral.

When defining the physical needs of people with HIV it is easy to think of them as a homogeneous group. People living with HIV have different physical needs and will need encouragement to express them.

It is important to remember with anyone who has a chronic condition that they will often attempt to sort out their housing at a time of relative good health. One of the challenges of HIV is the way in which someone's condition can change so markedly over short periods.

Wherever possible, the use of bed and breakfast accommodation should be avoided because of the vulnerability of people living with HIV to infection and harassment.

Wherever possible, all accommodation should be a minimum of one bedroom *(for a childless couple)* and serious consideration should be given to an extra bedroom so that a carer can stay over or a partner sleep separately during periods of illness.

Conclusion

There is no simple definition of what it means to have AIDS. However, for those seeking to assess what services people with HIV might need these notes will provide a good guide. Of course they are no substitute for the information people with HIV will bring themselves. One thing that continues to shock people is the rapid changes that people with HIV experience in their physical well-being. There will be a tendency for people to come and sort out their problems when they are relatively well and it will be difficult to assess their real level of need.

Section 2 : Assessment

ASSESSING LOCAL HOUSING NEED FOR PEOPLE WITH HIV.

- IDENTIFY A MEMBER OF STAFF IN THE HOUSING AUTHORITY WHO IS RESPONSIBLE FOR INCLUDING HIV-RELATED HOUSING NEED IN THE HOUSING STRATEGY STATEMENT. ENCOURAGE THE HOUSING AUTHORITY TO KEEP STATISTICS OF PEOPLE WITH HIV WHO APPROACH THEM WITH HOUSING PROBLEMS.

- AGREE COMMON APPROACHES TO THE COLLECTION OF STATISTICS: COMPARABLE FORMATS, COMMON DEFINITIONS OF THE ITEMS RECORDED, EG OF TYPES OF HOUSING PROBLEMS, AGE RANGES, DEGREES OF ILLNESS ETC.

- DISCUSS METHODS OF SHARING STATISTICAL INFORMATION ABOUT INDIVIDUALS WITHOUT COMPROMISING CONFIDENTIALITY AND DISCUSS THE POSSIBILITY OF COMMON MONITORING ARRANGEMENTS, EG USING SOUNDEX OR OTHER WAYS OF AVOIDING COUNTING PEOPLE TWICE.

- ENSURE THAT FRONT LINE STAFF, IN THE STATUTORY, INDEPENDENT AND VOLUNTARY SECTORS WHO COME INTO CONTACT WITH PEOPLE WITH HIV WHO HAVE HOUSING NEEDS CAN CONTRIBUTE TO THE THINKING OF SENIOR STAFF AND PLANNERS.

- CONSULT SERVICE USERS AND HIV SUPPORT SERVICES.

- MAKE USE OF SURVEYS FROM OTHER AREAS OR CONSIDER UNDERTAKING A SURVEY.

- IF A SURVEY IS TO BE UNDERTAKEN, SET TARGETS OF DIFFERENT CATEGORIES TO ENSURE THAT ALL SECTIONS OF THE POPULATION HAVE BEEN REACHED. THOSE WHO MAY BE OVERLOOKED INCLUDE FAMILIES WITH CHILDREN. EXAMINE THE HOUSING NEEDS OF ALL PEOPLE WITH HIV BUT BE CLEAR WHETHER PEOPLE ARE SYMPTOMATIC OR ASYMPTOMATIC. THEY MAY HAVE HOUSING NEEDS UNRELATED TO HIV.

- ENSURE THAT AMONG THOSE HOUSING NEEDS THAT ARE IDENTIFIED THERE IS CLEAR IDENTIFICATION OF THOSE THAT ARE RELEVANT TO THE AUTHORITY'S NEEDS ASSESSMENT PRIORITIES.

- USE EVIDENCE COMING THROUGH EXISTING COMPLAINTS PROCEDURES.

- ENSURE THAT HOUSING NEEDS RELATED TO HIV ARE DESCRIBED IN THE HOUSING STRATEGY STATEMENT

- DISSEMINATE THE RESULTS OF YOUR ASSESSMENT OF HOUSING NEED INTO JOINT PLANNING MECHANISMS FOR COMMUNITY CARE.

- MONITOR THE IMPLEMENTATION OF HOUSING DEVELOPMENTS FOR PEOPLE WITH HIV PROPOSED IN THE HIP AND IN HOUSING ASSOCIATION BIDS TO THE HOUSING CORPORATION.

Introduction

Housing is crucial to community care. Yet there can be problems in integrating housing into community care arrangements. This briefing paper suggests ways of approaching the assessment of local housing need for people with HIV. The housing authority has a duty to identify local housing needs and to develop a strategy to meet them. The local population is very likely to include people with HIV or those affected by HIV. This paper suggests ways of approaching a proper assessment of the impact on local housing services.

The context

Housing authorities

Housing authorities have the duty to identify housing needs in their area and to develop a strategy for meeting those needs. The annual housing strategy statement covers all housing in the area, not just the authorities own housing. Indeed, although housing authorities must develop a strategy to meet housing needs they do not have a duty to provide housing themselves.

Each year when the housing authority submits its housing strategy to the Department of the Environment it also submits its bid for permission to spend capital on housing. This bid is called the Housing Investment Programme or HIP.

Very few new council homes are now being built. Housing associations now provide the main increase in housing outside the private sector. Associations get the capital finance for new housing partly from public sources, usually through the Housing Corporation but sometimes through local government, and partly from borrowing in the private sector. Each year, associations have to bid for money from the Corporation. The Housing Corporation will not fund new housing association developments unless they fit in with the housing strategy of the housing authority in that area.

Social services authorities
Under the NHS and Community Care Act 1990, social services authorities have the duty to identify social care needs in their area and to develop a strategy for meeting those needs to be published in their annual community care plan. The law requires to consult with a range of other agencies in the field of housing and health as well as social care in developing their community care strategy. In addition, the housing authority should reflect the community care strategy in its housing strategy.

Guidance

There is relevant guidance describing the importance of housing being included in community care:

- *Housing and Community Care, a circular published jointly by the Department of the Environment (ref 10192) and Department of Health (ref LAC* (92)12) *on 2419192.*

- *Implementing Community Care* - A *Framework for Integrating the Housing Agenda, published by the Community Care Support Force, March 1993.*

- *Implementing Caring For People: The Foster-Laming letters issued from the DoH EL(92) 13ICI(92) 10 and EL(92)65 1 Cl (92)30 concerning practical liaison arrangements between social and health care.*

The implications

If these different requirements are added together, we see that:

- if new public housing is needed to meet the needs of people with HIV, this must be included in the annual housing strategy or it is very unlikely to get funded.

- definitions of the housing needs of people with HIV need to be linked to definitions of their social and health care (i.e. community care) needs.

- if different social or health care provision is needed as a result of the impact of their housing situation on people with HIV, those needs should be included in the community care plan.

- the Community Care Plan and the Housing Investment Programme need to complement each other, with a consistent approach to the community care needs and the housing needs of people with HIV.

Assessing need

Assessing need is the first stage of developing a strategy. In addition to assessing need, the housing authority needs to review existing provision, identify gaps, overlaps and priorities, and set objectives for action.

There are two elements to assessing housing need:

- quantification: attempting to discover how many people in the area are HIV-positive and have housing problems.

- qualitative description of need: finding out what sorts of housing problems are faced by people in the area, and what they feel they need.

Quantification

There are existing national sources of data about HIV incidence, which can be used. Because HIV is classified as a "communicable" disease, statistical information about it is routinely gathered by the Communicable Diseases Surveillance Centre and the Communicable Disease *(Scotland)* Unit, and is regularly reported by the Public Health Laboratory Service.

The problems with using these official statistics to quantity need in an area are:

- statistics record only those people who are known to be HIV positive, and therefore they tend to underestimate levels of future need.

- national health statistics are based on the health authority where the person was diagnosed or is receiving treatment. This is not necessarily the same as the area in which the person now lives, or the area in which they would prefer to live.

- there is a difference between knowing how many people in the area are HIV positive, and knowing how many are HIV positive and in housing need.

It is therefore important to look at local sources of quantitative information as well. The following are likely to have statistics on the numbers of people with HIV who use their services. They may also keep information about the proportion who ask for help with housing and the sort of housing problems they face:

- the social services authority - social workers, meals-on-wheels, home helps and home care workers.

- independent advice agencies and Citizens Advice Bureau.

- primary health care teams - e.g. district nursing, community psychiatric nurses

- out-patient health clinics for people with HIV *(often the Genito-urinary Medicine, "GU" or "GUM" clinics)* - especially their health advisors.

- in-patient health services - especially nurses, discharge and community liaison staff.

- voluntary agencies and self-help groups for people with HIV.

- environmental health departments *(in relation to disabled facilities grants and harassment by landlords).*

In addition to local statistics, it can be helpful to look at information from other areas and make comparisons. Where HIV is more common, agencies have had some time to relate the frequency of housing problems to HIV incidence. This can form a basis for extrapolation to areas where HIV is, as yet, comparatively rare. For example, in a survey carried out by the Royal Borough of Kensington and Chelsea in 1989 of 106 people with HIV in Greater London, 38% of respondents felt their present housing conditions adversely affected their health.

Qualitative evidence of need
The people and organisations that might have statistics about HIV and housing can also provide anecdotal evidence of the type of housing problems faced by people with HIV. Even those who keep no statistics are likely to be able to quote examples of cases.

Surveys of people with HIV provide evidence of need; but they are time-consuming and may raise issues of confidentiality. They may be open to challenge because of possible sampling biases.

However, although each anecdote about a case and each small user survey can be challenged, the cumulative impact is remarkably consistent. Studies across the country identify similar types of problems and housing needs. On the one hand, this may mean that you do not feel it is useful to do a 19cal study; on the other, a local study may provide information to compare with national patterns, demonstrating how far they are reflected locally.

Problems in assessing need

The impact of timescales and uncertainty on planning for the future
Some housing needs can be met by changes in policies or procedures - for example, in relation to privacy in interviewing or prioritization of repairs. These changes can be effected quickly. But others require investment in housing, whether new stock or the adaptation of existing stock. It takes years to get from the planning stage to the first letting of a new housing scheme. This has two implications for assessment of local housing needs.

First, housing authorities need to predict the housing needs of people with HIV in their area several years in advance. Second, it is important to keep abreast of medical knowledge and resultant needs, to prevent planned housing developments becoming out of date before they are ready.

Housing authorities may not see assessment of local HIV-related housing need as a priority when they are facing major challenges such as stock transfer and CCT. It will be less of a priority where HIV incidence is low, or appears to be low, because it has never been counted.

It can be difficult to get people, from whatever service, to collect information if work with HIV service users is not central to their job. Also there can be a fear that service users will resent such questioning.

Confidentiality

Confidentiality is so important that workers may not want to risk breaching it by exchanging information. This is a particular problem where numbers are so small that the identity of anonymous cases can be easily guessed. However, confidentiality is not secrecy and a proper system of informed consent need not contradict accurate monitoring of services.

Fear of harassment or discrimination means that people with HIV do not always disclose their status to professionals such as housing providers. This means that their needs are not recorded.

Section 3 : Confidentiality

GENERAL PRINCIPLES WHEN REVIEWING OR DRAFTING A POLICY ON CONFIDENTIALITY.

- INFORMATION SHOULD ALWAYS BE USED IN A WAY WHICH PROTECTS AND PROMOTES THE BEST INTERESTS OF THE INDIVIDUAL.

- THE INFORMED CONSENT OF THE INDIVIDUAL SHOULD ALWAYS BE OBTAINED BEFORE DISCLOSING INFORMATION TO A COLLEAGUE OR THIRD PARTY. I.E; THE INDIVIDUAL SHOULD BE MADE AWARE OF WHO MIGHT POTENTIALLY HAVE ACCESS TO THE INFORMATION ONCE IT HAS BEEN DISCLOSED AND ALSO THE EFFECT OF NOT DISCLOSING THE INFORMATION.

- CONFIDENTIALITY POLICIES SHOULD BE PRACTICAL AND WORKABLE. BOUNDARIES TO CONFIDENTIALITY SHOULD BE CLEARLY IDENTIFIED AND THE POLICY AND ITS BOUNDARIES PUBLICISED EXTERNALLY. E.G. EXCEPTIONS TO CONFIDENTIALITY MIGHT BE VIOLENCE, FORCE OF LAW, OR FRAUD.

- INTERNAL PROCEDURES FOR PROCESSING INFORMATION ABOUT TENANTS OR FUTURE. TENANTS SHOULD BE REVIEWED WITH THE PRINCIPLE OF *'WHO NEEDS TO KNOW'* IN MIND. THE *'NEED TO KNOW'* SHOULD BE RESTRICTED TO SITUATIONS WHERE THE INFORMATION IS CRUCIAL, EITHER FOR MAKING A DECISION OR FOR PROVIDING A SERVICE.

- THE NEED TO RETAIN WRITTEN INFORMATION AND MEDICAL REPORTS SHOULD BE EXAMINED. HIV IS NOT A HIGHLY INFECTIOUS DISEASE AND THE FILE OF A TENANT WHO IS HIV POSITIVE SHOULD BE NO DIFFERENT FROM ANY OTHER TENANTS FILE.

- ESSENTIAL CONFIDENTIAL INFORMATION *(E.G. MEDICAL DETAILS), WHICH IS RETAINED,* SHOULD BE SECURE, WITH ACCESS TO IT LIMITED. LOCKABLE FILING SYSTEMS SHOULD BE USED FOR STORING NON-COMPUTERISED INFORMATION.

- WHERE ORGANISATIONS WORK WITH PARTNER AGENCIES BOTH PARTIES SHOULD ENSURE THAT POLICIES ON CONFIDENTIALITY EXIST AND THAT RESIDENTS AND TENANTS ARE AWARE OF THEM. MANAGEMENT AGREEMENTS COULD HAVE A CLAUSE, WHICH STATES THAT A BREACH OF CONFIDENTIALITY ON EITHER SIDE WILL BE TREATED AS A BREACH OF THE AGREEMENT.

- THE REASONS FOR A CONFIDENTIALITY POLICY SHOULD BE CLEARLY UNDERSTOOD BY ALL STAFF. ORGANISATIONS MAY WISH TO PROVIDE TRAINING ON THE PRINCIPLES AND PRACTICE OF CONFIDENTIALITY. THE POLICY SHOULD BE A GENERAL ORGANISATIONAL POLICY AND NOT JUST USED WHEN DEALING WITH A PERSON WHO HAS DISCLOSED INFORMATION ABOUT HIV.

Why confidentiality?

Confidentiality is a good example of how the issues raised by housing people with HIV infection highlight the inadequacy of current procedures and present an opportunity for reviewing or formulating policy for the benefit of all tenants.

Few organisations have had formal policies on confidentiality, yet it is inconceivable that any would question a tenant's, employee's or applicant's right to have all personal information *(for example on marital difficulties or the state of their rent account)* kept entirely confidential to the organisation.

In terms of housing people with HIV infection there are two reasons for addressing the issue as a matter of urgency. Firstly, the fear, ignorance and prejudice that have surrounded the illness mean that breaches of confidence can have disastrous effects for the individual concerned. There is significant evidence to show that, where breaches have occurred, victimisation and harassment have followed.

"You wondered about confidentiality - being interviewed in a large room with chairs where you waited. When it was your turn you were just interviewed in plywood cubicles which was a concern as one could possibly be overheard".

Secondly, as a result of the fear or experience of discrimination and/or harassment, people are unwilling to use a service unless they feel sure that any information disclosed will only be used professionally and in confidence. Someone who may have a severely reduced life expectancy should not be denied access to existing services because of a fear that this disclosure might further exacerbate their situation.

Developing a policy

A policy on confidentiality must go further than stating that information is not disclosed to other people/organisations. It must also ensure that, within the organisation, the only people who have access to confidential information are those who require it in order to make a decision or provide a service. The more people who know something, the more likely there are to be accidental breaches of confidence.

HIV

There is never a need for staff to know a tenant's HIV status so that they can adopt health and safety procedures. HIV is not a highly infectious disease. Also any such procedures should be adopted regardless of information about or perceptions of the tenants or colleague concerned.

Information about tenants or applicants with HIV should not be dealt with in a significantly different way from others. This is partly because everyone has the same right to confidentiality, and partly because the use of any special procedure *(for example a "confidential" flag on a file)* could signify that the person concerned has HIV.

Organisations might wish to consider including in every tenant's file an area of restricted access, which would contain any sensitive information. *(In the case of some tenants there would be nothing in this part of the file, but its existence would mean that no tenants were singled out as "different").* This type of system already operates successfully in many social work departments under 'open access' legislation.

Committee Members and staff of all organisations must understand the importance of maintaining confidentiality even within the organisation. However, this responsibility is even more pronounced in the case of community-based associations and housing coops, where committee members and even staff are also tenants and neighbours.

Another consideration must be that annual changes to committees, to encourage the widest possible participation from members, may soon give large numbers of people access to all files and information.

For those organisations the development of a confidentiality policy may require a degree of delegation to staff, or a named committee member, which was not previously thought appropriate. Some organisations have a tradition of involving several committee members in certain procedures, such as prioritising applications for housing. Effective confidentiality procedures may prevent this.

However, the key aspects of the democratic principles will not be at all compromised. Good confidentiality procedures will not prevent committees from continuing to decide *(in considerable detail)* the basis on which decisions will be made by the staff or named committee member.

Elements of good policy and practice

- **Policy works best when it is a general organisation policy and not only used when dealing with a person who has disclosed they have HIV.**

- **Organisations should never per se demand that individuals reveal their HIV status.** Any information, which is received, should always be used in a way, which protects and promotes the best interests of the individual.

- **Internal procedures for processing information about tenants or applicants should be reviewed with the principle of "who needs to know" in mind.** The need to know should be restricted to situations where the information is crucial for making a decision or for providing a service. This review should examine procedures like:

    - who opens the mail?
    - how many people are involved in making rehousing decisions.
    - how cases of harassment are processed.
    - what information is passed to external agencies

- **Caretakers, maintenance staff and outside contractors do not need to know an individual's HIV status to carry out their duties.** However, they may find out or the tenant may tell them. Organisations might therefore consider including a clause in all contracts prohibiting the disclosure of any information and providing procedural guidance applicable to staff whom deal with files.

- **Informed consent should always be obtained.** That is, before any information about someone's HIV status is disclosed (or recorded by the person to whom it is first disclosed) the individual should be made aware of who else might potentially have access to the information, any consequences this might have and also the effect of nondisclosure *(e.g. a longer wait for housing).*

- **Confidentiality policies need to be practical and workable.** Boundaries to confidentiality should be clearly identified and the policy and its boundaries publicised externally. This will give tenants and applicants the confidence to approach the association.

- **The file of a tenant who has HIV should not look different, nor be treated differently, to any other tenant's file.**

- **The automatic retention of written information and medical reports should be examined.** Essential confidential information *(e.g. medical details), which is retained,* should be secure, with access to it limited. Computerised information is protected by the Data Protection Act. Lockable filing systems should be used for storing non-computerised information with access only by authorised staff. The Freedom of Information Act grants tenants the right of access to their own files. Care should be taken that information is not retained on matters, or in a manner, which would cause unnecessary upset, stress or worry to tenants seeing it.

- **Files should be regularly reviewed, and outdated or unnecessary information disposed of.** Organisations should consider. How much medical information it is actually necessary to retain after it has been acted on.

- **Where organisations work with other agencies *(including other housing organisations or the Police)* both parties should ensure that policies on confidentiality exist and that residents and tenants are aware of them.** Each party should provide the other with a copy of their policy. Management agreements should have a clause, which states that a breach of confidentiality on either side will be treated as a breach of the agreement.

- **Residents of shared housing schemes and housing co-ops have as much right to confidentiality as tenants of self-contained housing.**

- **The reasons for a confidentiality policy should be clearly understood by all staff.** It would be beneficial to include a clause on confidentiality in the contract of employment and breaches of confidentiality should be acted upon. Any deliberate breach of confidentiality should be grounds for serious disciplinary action.

- **As employers, organisations should consider having a contact person for their own employees to talk to in confidence if they have HIV,** or if they wish to discuss issues regarding a tenant or applicant who is infected. The contact person should be a member of staff, committee member, or someone outside the organisation.

- **All staff should receive training on the confidentiality policy and the procedures for implementing it, and such training should form part of any induction for new staff.** Tenants and committee members should also be offered training on confidentiality, but this is particularly urgent in those organisations *(such as community based associations or co-ops)* where tenants or committee members may have access to the files.

Section 4 : What is HIV?

TERMINOLOGY AND TRANSMISSION: IMPLICATIONS FOR HOUSING AND COMMUNITY CARE PROVIDERS

- IT IS IMPORTANT TO HAVE AN UNDERSTANDING OF THE TERMINOLOGY, WHICH DESCRIBES HIV AS IT IS OFTEN USED AS THE BASIS OF DECISIONS ABOUT ENTITLEMENT TO CERTAIN SERVICES.

- THE TERMS ASYMPTOMATIC INFECTION, SYMPTOMATIC INFECTION AND AIDS HAVE SPECIFIC MEDICAL MEANING BUT CAN GIVE THE IMPRESSION THAT THEY ARE ENTIRELY DISTINCT PHASES IN THE PROGRESSION OF ILLNESS.

- THE MAIN WAYS IN WHICH THE VIRUS CAN BE PASSED ON ARE THROUGH PENETRATIVE SEX WITH AN INFECTED PERSON OR THROUGH SHARING INFECTED NEEDLES. GOOD HEALTH AND SAFETY PROCEDURES AND EFFECTIVE INFECTION CONTROL POLICIES WILL PREVENT ANY EMPLOYEE OF A LOCAL AUTHORITY BEING AT RISK.

- 4) HIV IS A HOUSING AND COMMUNITY CARE ISSUE BECAUSE IT AFFECTS PEOPLE WHO RECEIVE SERVICES FROM LOCAL AUTHORITIES. WHILE SOCIAL SERVICES AUTHORITIES HAVE SPECIFIC LEGAL DUTIES TOWARDS PEOPLE WITH HIV, THEY WORK CLOSELY WITH
- HOUSING DEPARTMENTS WHEN MAKING ASSESSMENTS. SO IT IS IMPORTANT THAT HOUSING STAFF ALSO HAVE AN UNDERSTANDING OF HIV.

- HIV DOES NOT FOLLOW PREDICTABLE PATTERNS BUT MANY AUTHORITIES RESTRICT ACCESS TO SERVICES ON THE BASIS OF MISLEADING MEDICAL TERMINOLOGY.

- THE ONSET OF HIV RELATED ILLNESS CAN BE EXTREMELY RAPID. HOUSING CAN QUICKLY BECOME UNSUITABLE AND PEOPLE WITH HIV MAY DIE BEFORE BEING ALLOCATED PERMANENT HOUSING.

- PEOPLE WITH HIV ARE GENERALLY YOUNGER THAN PEOPLE WHO CONTRACT OTHER LIFE THREATENING CONDITIONS. THEY ARE LESS LIKELY TO LIVE IN TRADITIONAL FAMILY SETTINGS.

- UNLIKE MOST PEOPLE WITH OTHER LIFE THREATENING ILLNESSES, PEOPLE WITH HIV FREQUENTLY FACE DISCRIMINATION AND HARASSMENT.

- IT IS IMPORTANT THAT LOCAL AUTHORITY STAFF ARE SENSITIVE TO BOTH THE MEDICAL AND SOCIAL IMPLICATIONS OF HIV.

The Terminology

HIV is a relatively new condition and research is constantly increasing knowledge of it and its effects. It can be confusing for people with no medical training but it is important to have an understanding of the terms used because they sometimes form the basis of decisions about the level of service people with HIV are entitled to.

HIV

HIV stands for Human Immunodeficiency Virus and it is the virus, which leads to AIDS. The virus infects a certain set of blood cells *(the t4 helper cells)*, which are crucial to the effective functioning of the body's immune system. This suppression of the immune system means that people with HIV cannot fight off infection, as they would normally be able to do. There is no cure for HIV though there are drugs, which can treat many of the illnesses associated with HIV infection.

Many people who have HIV do not show any symptoms. They may be unaware that they are infected and may remain well for many years. This is known as asymptomatic HIV infection. Some people with HIV suffer from a range of symptoms including breathlessness and fatigue; severe weight loss; night sweats; persistent diarrhoea, and outbreaks of thrush, herpes and shingles. This is often referred to as symptomatic HIV infection. This terminology can be unhelpful because it suggests that asymptomatic and symptomatic infections are discrete phases in a progression towards AIDS. The course of HIV is not so easy to predict. Indeed many people with an asymptomatic diagnosis may have periods of illness interspersed with periods of asymptomatic infection.

AIDS

AIDS stands for Acquired Immune Deficiency Syndrome. It is the diagnosis usually given to someone with HIV infection who is suffering from one or more of a particular group of disorders or opportunistic infections.

AIDS is a life threatening illness but as new drugs are developed, it is likely that people will live longer with chronic illness and in a weakened state. This has implications for the providers of services to people with HIV.

How is HIV transmitted?

The virus is passed on by semen, vaginal secretions, or blood of an infected person entering the bloodstream of another. There are four main routes of infection:

- Penetrative sex with an infected person *(vaginal or anal).*
- Sharing infected needles.
- Women may pass the virus on to their babies during pregnancy, at birth or through their breast milk.
- Through infected blood products, though routine screening now makes this risk remote.

It is important to recognise that people are not at risk because of who they are, but because of what they do. So, although in Britain most people who currently have the virus are gay men, drug users or refugees from some African countries, this is not the case in other countries and is unlikely to be the case in the future.

The virus is not passed on by shaking hands or through saliva and tears. Cups, cutlery, glasses, food, drink, clothes, towels, toilet seats and doorknobs present no risk. You cannot contract the virus by touching objects used by a person with HIV.

The virus itself is not very strong and dies quickly outside the body so blood stains, for example, present no risk. .

Housing workers and support workers caring for people with HIV do not contract the virus because of their occupation. Good health and safety procedure and effective infection control policies will prevent any employee being at risk.

Why is HIV a housing and community care issue?

Stated simply, HIV is a housing and community care issue because it affects people who are receivers of services from local authority housing and social services departments.

Housing departments have certain legal duties and powers in relation to the housing needs of the people in their areas. This includes people with HIV who may already be their tenants or who may be in housing need.

In the case of social services departments, The National Health Service and Community Care Act 1990 gives them the responsibility for assessing local and individual need among people with HIV for community care services. They also arrange for the provision of such services. It is important that they work closely with Housing Departments while making assessments and many authorities are developing fruitful Community Care partnerships.

For most people with HIV, their first approach to statutory services is to the social services. However, it is very important that staff in housing departments, particularly those who deal with applications, assessment and allocations have an understanding of HIV so that they can offer their clients the best possible service.

Is HIV different?

Housing departments are used to dealing with people who have long-term illness and responding sensitively to their needs in providing housing services. However, HIV is a relatively new condition, which presents new challenges.

Most authorities are already well placed to deal with the physical effects of HIV. However, there are social aspects to HIV infection, which make it different from other illnesses. Some of these issues are considered below.

Social Aspects of HIV

The most important factor, which makes HIV different, is the degree of prejudice and discrimination people face. This is often linked to prejudice based on race, sexuality or drug use. People who have HIV are too often blamed for 'bringing it on themselves' where most people with other life threatening conditions would be treated with sympathy and understanding.

These prejudices can lead to harassment of people with HIV. The perpetrators could be anyone including landlords, neighbours or local authority staff. People with other life threatening conditions do not have to deal with harassment because of their illness. Similarly, a local authority dealing with a tenant or applicant with, for example, cancer, would not normally have to deal with harassment at the same time.

People with HIV are generally younger than people who contract other life threatening conditions. They are therefore less likely to have secure housing of their own and may be staying with friends or family, living in bed and breakfast or privately rented accommodation or is homeless. Also, they are less likely to be looked after in traditional family settings.

Housing department staff need to be aware of these social factors, which affect people with HIV. They can exacerbate the physical effects and make the housing needs of people with HIV particularly acute.

Medical Considerations

- HIV, unlike, for example, cancer, is a complex condition which can manifest itself in a range of different ways. The onset of illness can be extremely rapid and the progression of illness is unpredictable. This has the following results:

- Not all people with HIV have the same housing needs

- Housing can quickly become unsuitable if, for example, mobility becomes restricted or if the person with HIV needs a carer present on a 24hour basis.

- Someone with HIV who approaches a Housing Department may appear, and may in fact be, perfectly well. Similarly, a person with an asymptomatic diagnosis may have periods when s/he is very ill.

Services to people with HIV, therefore, need to be flexible and client led. It is important to remember that the people who best understand the effects of illness are the client and his or her doctor. Many Housing Departments already use self-assessment backed up by a medical practitioner when deciding on the allocation of houses to people with a variety of illnesses. The same principles apply when dealing with people with HIV. It is important in housing people with HIV to be aware of the rapid changes in health, which people with HIV can experience. Many authorities already deal sensitively with people who have conditions such as multiple sclerosis, where periods of ill health are interspersed with periods of remission. Similar skills and the sensitive application of policy also apply in the case of people with HIV. Rigid policies, which restrict single people to bed-sit or one bedroom accommodation, for example, are not helpful to people with HIV.

Section 5 : Harassment

- HIV RELATED HARASSMENT IS ON THE INCREASE.

- HIV RELATED HARASSMENT IS OFTEN ACCOMPANIED OR TRIGGERED BY HARASSMENT ON THE GROUNDS OF RACE, GENDER OR SEXUALITY. IT IS IMPORTANT THAT THERE ARE SPECIFIC REFERENCES TO THESE AND OTHER TYPES OF HARASSMENT IN POLICIES AND OTHER PUBLICITY MATERIAL.

- THERE IS NO LAW RELATING SPECIFICALLY TO HIV AND HARASSMENT. RACE RELATIONS AND SEX DISCRIMINATION LEGISLATION MAY BE USEFUL IN ADDRESSING SOME C~SES OF
- HARASSMENT.

- PUBLIC SECTOR AND CHARI1"ABLE LANDLORDS MAY WISH TO ENSURE THAT THEY HAVE DEVELOPED POLICIES ON HARASSMENT AND DISCRIMINATION WHICH INCLUDE GUIDANCE ON HOW THEY WILL TACKLE VIOLENCE OR INTIMIDATION TO SOMEONE LIVING WITH HIV.

- MANY PUBLIC SECTOR AND CHARITABLE LANDLORDS HAVE GENERAL ANTIHARASSMENT POLICIES, WHICH, EVEN IF THEY DO NOT SPECIFICALLY MENTION HIV, IT MAY BE POSSIBLE TO USE.

- POLICIES CAN BE A USEFUL WAY FOR AN ORGANISATION TO MAKE A PUBLIC STATEMENT OF THE ETHOS OF THE ORGANISATION AND ITS INTENTION TO DEAL SERIOUSLY WITH INCIDENTS OF HARASSMENT.

- TENANCY OR LICENCE AGREEMENTS CAN BE USED TO DRAW ATTENTION TO AND FOLLOW THROUGH ON AN ANTI-HARASSMENT POLICY BY INSERTION OF A CLAUSE IN THE AGREEMENT.

- POLICIES NEED TO CONSIDER BOTH WHAT ACTIONS MAY BE TAKEN AGAINST PERPETRATORS AND ALSO HOW THE PERSON BEING HARASSED MAY BE ASSISTED, SUPPORTED OR PROTECTED.

- IT IS IMPORTANT, WHATEVER ACTIONS ARE TAKEN, TO TAKE INTO ACCOUNT THE NEEDS AND WISHES OF THE PERSON BEING HARASSED EG FOR CONFIDENTIALITY, FOR BEING KEPT INFORMED OF ANY ACTIONS BEING TAKEN, FOR A MOVE OR TRANSFER IF THIS IS POSSIBLE ETC.

Harassment and HIV

HIV-related harassment can affect i) people living with HIV and ii) people perceived to be living with HIV.

Harassment may also be linked to pre-existing prejudice based on others' reactions to individuals' ethnic origin, gender, sexuality, disability, age, personal history or lifestyle.

Being subject to harassment can have serious implications for an individual's health. Feelings of fear, anger, isolation and lack of control mean high levels of stress, which can make it more difficult to fight off infection and maintain a healthy lifestyle. Even if others are not actively hostile, people living with HIV can experience discrimination in access to basic services.

Evidence of harassment

Four surveys into the housing experiences of people with HIV in Lambeth and Southwark *(1990);* Kensington and Chelsea *(1990);* London, Portsmouth and Manchester *(1991);* and Newham *(1994)* showed alarmingly high levels of harassment, much of it directly HIV related. In Lambeth and Southwark 10% of the sample had experienced harassment:

"I had a letter through the door saying you're gay, twice the door was burnt in the shape of a cross upside down. "

and one woman spoke of difficulties getting action from the landlord:

"I spent a year trying to convince them (the council) I was genuine. "

In Newham 79% of the sample had been forced to move by friend, family or landlords and a third of respondents had faced harassment. Private sector tenants were not only living in worse conditions but also were more likely to experience harassment. Two separate respondents spoke of very similar experiences. A partner of a private sector tenant said:

"The landlord said there were too many nurses and social workers visiting and so our lease would not be renewed."

A couple living in an estate property said:

"The harassment started after the ambulance came one day. Everyone put two and two together and since then it's been hell. Kids shout abuse and put excrement through the letter box, and neighbours told us to move or be killed."

Many respondents spoke of their determination to resist harassment and intimidation but were terribly aware of the toll this took on their health and the difficulties they faced keeping up their resistance during periods of ill-health.

Considerations for housing organizations when reviewing or drafting a policy on harassment

- A policy statement should cover harassment on the grounds of someone's race, gender, sexuality, health or disability.

- It should provide guidance on i) harassment of a tenant by another tenant, ii) harassment of a tenant by an employee or committee member, iii) harassment of an employee by another employee, iv) harassment of an employee by a tenant.

- A policy should combine maximum support to the subject with strong action against the perpetrators.

- It should not be the responsibility of the complainant to prove that harassment is taking place. The housing provider should instigate an investigation as soon as they receive a complaint and then take the appropriate action, keeping the person who is being harassed informed.

- Action should not depend on the complainant being able to identify the perpetrator.

- Support should include repairing damage as a matter of urgency, removing offensive graffiti within 48hours, improving home security and advising tenants of rehousing options.

- Procedures for rehousing in cases of harassment should be as quick and efficient as possible. Procedures should bear in mind the stress related nature of HIV illnesses and the fact that life expectancy is dramatically reduced with some AIDS related infections.

- A clause in the tenancy agreement can make explicit the organisation's commitment to anti-harassment.

- The policy should be publicised to staff and tenants, for example in its equal opportunity literature.

- The policy will need to be supported by a system of monitoring. Additionally, a record of charges made against individuals and incidents of reports of harassment need to be in place.

Harassment and confidentiality

Some people with HIV infection are unwilling to take action against harassment or discrimination because they do not wish their status to become public knowledge. There is often a conflict between maintaining confidentiality and pursuing a charge. This needs to be recognised at the outset and explained.

People are entitled to the protection of the police and the law without having to discuss why they may be facing violence or threats. However, legal options are likely to involve naming names. It is important to tell the person making the complaint what will happen to information or allegations, to whom it will be passed and the likelihood of the matter becoming public.

Advice for advocates and people experiencing harassment

Dealing with harassment by other residents

- Local authority and most housing associations and charitable landlords have written tenancy or license agreements, which prohibit harassment or threatening behavior or any other kind of nuisance.

- Typical actions that can be taken are, formal investigation of the complaint by staff and meetings with everyone involved to try and come to an agreement. Serious incidents may lead to the perpetrator being given notice to quit and a court case if they do not leave voluntarily. It is important to document the problem thoroughly and witnesses should be prepared to go to court.

- Sharing a house with someone who has been violent and threatening while waiting for a case to go to court can be very stressful especially as this can take several months. The person affected may be able to take out an injunction. Where there has been an assault, serious threat or damage to property, the police can take immediate action if they believe a crime has been committed.

- For someone living with HIV the level of stress in this situation may increase his or her vulnerability to infection. With medical support, it may be possible to argue for more suitable housing from the local authority or a housing association; if this is what the person affected wants.

- Nuisance clauses in most tenancy agreements prohibit nuisance or disturbance by friends and visitors as well as the residents themselves.

Dealing with problems from neighbours

- Taking action against threats and intimidation from neighbours can be very difficult, particularly if it is hard to identify who is responsible. Often the situation has to be extremely serious before any action can be taken. Collecting clear evidence is CRITICAL to tackling the problem.

- It is also likely that the individual's HIV status *(if it is known to neighbours)* will be disclosed by someone to the police or courts whether they wish it to be or not.

- Calling the police - if a criminal offence such as assault or criminal damage has taken place, the police must come, investigate the problem and decide what *(if any)* action to take. A case for possession is strengthened by a conviction or even an arrest and the fact of the police's involvement can add weight to a case. It is important to keep a record of the names and numbers of officers involved so that they can be contacted afterwards. It is worth asking at the time whether the police will be making a report even if no further action is to be taken.

- If the people responsible for harassment rent their home from the same landlord. The landlord may be able to help tackle the problem through the use of systems developed to deal with neighbour disputes. Some landlords may be prepared to take court action to try and evict neighbours who are violent or intimidating; although this is not always successful. It may also be possible to arrange an emergency transfer away from the situation.

- The landlord may be able to pay for improved security measures e.g. peepholes in doors, window locks. Owner-occupiers and people living in private rented accommodation will generally have to pay for these themselves. Tenants may need permission from their landlord if major changes are planned.

- The need for witnesses and clear evidence as to who is responsible for harassment can make the legal system difficult to use successfully. In local authority or housing association properties, the housing officer may be willing to try to negotiate a solution. In some areas there are mediation schemes, which work on neighbour disputes, although they have not been established specifically around HIV and may not be equipped to provide help. Self help groups for people living with HIV may be able to provide advice, support or practical help.

Leaving the accommodation

- If the person being harassed is in fear of their safety and the effect of constant stress on their health, they may want to leave their home and find alternative housing. It may be possible for them to be housed as a homeless person by the local authority. They will need to show either that they are not "intentionally homeless" or that it was "unreasonable for them to remain" in their home. Witness statements, a record of all incidents and other evidence of the seriousness of the situation will be required to support the case. They may need to show that every effort was made to try and retain their home e.g. police involvement, taking out of injunctions.

- Housing association or local authority landlords may be able to arrange a transfer to other property they manage or to another public sector landlord. Allocation of property should preferably allow the individual choice in terms of area, so as to try to avoid a repeat situation.

Gathering evidence

It is very important that staff, the victim, witnesses or those supporting the victim keep full and detailed notes of incidents. Whether to present to a landlord or ultimately in court similar principles apply.

Unfortunately, it is impossible to predict what evidence might eventually be needed in a harassment case. However, certain ground rules for recording information can be made for guidance.

All conversations with possible perpetrators should be recorded in full. Where possible the exact words used should be noted. This should preferably be done while the conversation is in progress, but if this is not possible, it should be recorded immediately afterwards while the events are still fresh in the mind. A note should then be made of how long after the conversation the note was made.

Conclusion

HIV-related harassment does occur and housing providers will want to ensure that they respond appropriately to these experiences. People with HIV or those working on their behalf need to gather as much evidence as possible to enable good landlords to respond. Even then successful outcomes are difficult to achieve. However, greater understanding of each other's situations will go a long way to make the reality of living with HIV more bearable.

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