HIGHLAND USERS GROUP

HOUSING

A Report on the views of Highland Users Group about Housing and it`s connection with people with mental health problems.

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HIGHLAND USERS GROUP

The Highland Users Group (HUG) was established on 11 June 1996.

Its aims are to:

1. Represent the interests of users of mental health services living in the Highlands.
2. To identify gaps in services and to find ways of improving services for mental health service users.
3. To provide information about mental health issues to users living in the Highlands.
4. To participate in the planning and management of services for mental health service users.
5. To pass on information and news amongst mental health user groups in the Highlands and to interested parties.
6. To increase knowledge about resources, alternative treatments and rights for users of mental health services.
7. To promote co-operation between agencies concerned with mental health.
8. To promote equality of opportunity and to break down discrimination against mental health.

At present (March 99) HUG has 174 members and 12 branches in:

- Caithness
- Sutherland
- Easter Ross
- Wester Ross
- Nairn
- Inverness
- Craig Dunain
- Lochaber
- Skye and Lochalsh

Between them, members of HUG have experience of nearly all the mental health services in the Highlands.

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"Your home is the place where you want to be even if it sometimes drives you round the bend" – Member of HUG.

WHY LOOK AT HOUSING AND MENTAL HEALTH?

Over the last couple of years members of the Highland Users Group have discussed a diverse range of subjects and in many ways that is one of the reasons we ended up talking about housing – it was a natural point that we had reached in our conversations. There were however a number of other reasons that prompted these talks:

Ann Evans of Highland Council`s Housing Department has over the last year been researching the housing needs of people receiving community care services. Highland Users Group offer this report as a reflection of the user's perspective for people with mental health problems.

During the production of our last report (Our contribution to a mental health strategy for the Highlands) housing issues were frequently raised by members and made it important that we looked at the subject in more detail.

The main reason though, for looking at housing came from the Caithness Branch of HUG. In the Thurso section members have been talking for a long time about the difficulty of maintaining accommodation whilst living on tight budgets and having to endure mental health problems. In the Wick section members have become increasingly concerned about the lack of support for people with severe mental health problems who have problems maintaining their housing. This has led to a feeling that people are being admitted to hospital more frequently than would be necessary if they had support. People, some of whom are members of HUG, have had to move to Inverness in order to access services, especially supported accommodation. In addition it was known that some very vulnerable people were housed in very poor accommodation. This has led to calls for supported accommodation to be introduced in Caithness and a series of meetings about accommodation.

The meetings that informed this report were held in June 98. Inadvertently the number of people involved was not recorded but would have been between 50 and 70.

THE SORT OF ACCOMMODATION THAT PEOPLE NEED WHEN THEY HAVE A MENTAL HEALTH PROBLEM

People with mental health problems generally need the same sort of accommodation as anyone else when thinking of the buildings themselves – the buildings do not need adaptations, other than those that would be provided for anyone else – however there are a number of aspects that do apply:

Support In order to remain in the accommodation, people need varying levels of support ranging from the continual 24 hour support that might be found in a nursing home to the infrequent but intensive support that someone might need if they were in a crisis. Support can be of an emotional variety or more practical and focused on helping a user to carry out everyday activities that their mental health problems prevent them from doing.

Company Many users find the worst times are those when they are on their own staring at the walls of their room and unable to avoid the distressing thoughts that occur to them. In these situations some users find company (especially that of fellow users) to be a life saver and may spend more time in other people`s houses and sleeping on other people`s couches than in their own houses.

Privacy In contrast some users, especially when they are getting ill, may find that their home acts as a refuge from the pain of being in other people`s company when the strain of maintaining a public face can prove too much. It may be a place that has to be kept as a sanctuary away from other people.

Safety This issue was raised time and time again. The feeling of being insecure and vulnerable only served to increase people`s mental health problems.

It is very important to know that you will be safe, that you will not be 'chucked out' and that you will blend in and not be harassed. You can settle down really well if you think that where you live is secure and is a base – you know it is `your place`.

INFORMATION, RIGHTS AND ALLOCATIONS POLICY

There was general agreement amongst members of HUG that there was a lack of information available to people looking for accommodation – people didn`t know where to go to or who to turn to for the various types of accommodation that is available.

There was a call for there to be an integrated approach to housing options so that people could go to one place to apply for the various types of accommodation.

The variety of conflicting ideas about people`s rights when concerned with housing provided ample proof that people didn`t know what they were entitled to and also graphic descriptions of the anxiety people felt as a result of not knowing this or only having a partial grasp of the issues.

There was a belief that people with mental health problems were less entitled to housing than people with other disabilities. There was also the belief held by some people that if it was thought that people had a mental health problem then they would be likely to be offered a house in the most undesirable areas and not treated kindly if they did not take up the offer.

Through contact with HUG members and knowledge of people with a mental illness who had experienced homelessness, it was thought that the number of people recorded as being homeless and having a mental health problem was a very low and possibly inaccurate figure.

'INCOMERS'

There seem to be variable reactions to people moving into the Highlands from other areas.

Some people have said that the move to the Highlands may represent a final grasp at solutions to their distress. The Highlands can represent the `end of the road`, a last resort for help and hope. (With the underlying feeling that if that is not found then suicide is the other solution). Other people see the Highlands as a sanctuary from the problems of urban life or an escape from mental health services that have been perceived as unhelpful.

Reactions to people moving into the Highlands who are on benefits and have a mental illness vary. Seemingly with different responses in different areas, in some places the most common response is to provide the person looking for accommodation with an overnight stay and a bus ticket back to where they have come from. In other areas the most likely response is to be housed in caravan type accommodation or given a list of private landlords and in rare instances people have found themselves housed in supported accommodation (admittedly after having slept rough for a long time).

It can be easier to get accommodation if people have a connection to the area, for instance, if they have relatives in the area but otherwise people may have to wait a long time to obtain a house even though they are put on the council housing list. This can result in people having to manage in inadequate accommodation whilst trying to cope with a mental illness.

Some people thought that there should be a quota of housing available to people with a mental illness and thought that some people could avoid repeated hospital admissions if they are provided with adequate housing and support. At the same time though, it was acknowledged that there was a general housing shortage for everyone in the Highlands.

"INTENTIONAL HOMELESSNESS"

Sometimes people with a mental illness can also be regarded as becoming intentionally homeless. For instance, because of illness people may find it impossible to be in the company of other people and may leave their accommodation. Or, someone's room, that has been a sanctuary, may turn into the place where all the horrors of mental illness are experienced and therefore may become somewhere that that person can no longer stay.

Many people talked of how it became impossible when ill to fill in or face benefits forms and of the consequences this may bring. Other people talked of the need to escape, sometimes people have so much difficulty in facing their situation or illness that the only option seems to be to leave home in the hope of something better.

Many people, in these circumstances, may be regarded as `intentionally homeless` when, in the opinion of many HUG members, there is no intention to be homeless or to abuse the benefits system. In fact, there is a great need for help and the homelessness that has occurred is a result of an illness.

It was requested that each person who may be refused accommodation because of an assumption that they are intentionally homeless be looked at as an individual, possibly with unavoidable reasons for being homeless, each case should be looked at on it`s own merits as the code of guidance states.

FINDING A HOME

Many people with mental health problems find themselves looking for accommodation at points where there are other crises going on in their life. They may be looking for accommodation while being prepared for discharge from hospital. They may be moving from an intolerable situation in one area to another area or they may be homeless. They may also be on benefits and therefore not in a position where they have a great deal of choice. All this can conspire to make people take hasty decisions. In the word of one user.....

"People often just jump at the chance of getting a house and don't think of the consequences of where they are living because they are desperate."

VULNERABILITY

There was a feeling, when looking for accommodation, that in some circumstances it is the most vulnerable people who ended up homeless or in sub standard accommodation or continually moving because they cannot maintain their tenancy.

People who have personality disorders, alcohol and drug problems, mental illness and behavioural problems or mild learning disabilities or combinations of all of these were thought to be the most likely to be homeless or in poor accommodation. To be exploited or unable to keep their accommodation but also unlikely to qualify for, or ask for, the help of any particular service.

It was thought that the areas in which housing was easily available were often those areas where the housing and environment was of the worst quality and that there was a temptation, when desperate, to accept this housing.

SAFETY AND SECURITY

Safety can be a reflection on the area that people live in, for instance, people mentioned living in an area where young people gathered and drank alcohol and talked of the feelings of insecurity this gave.

It can also be a reflection of the security of the building, for instance, the existence of an intercom increases feelings of safety while the presence of a common stair can decrease them.

Knowing the future is another feature of safety. People who do not have security of tenure or who have little idea of how long they will stay in their present home can feel extremely insecure and unsettled.

The standard of the accommodation and the other people who live in it also impact on people`s feelings of safety.

Other factors that can make people feel unsafe and therefore impact on their mental health include

- Noise especially at night
- Accessibility to the outside
- Presence of an `escape route`
- The comfort of the accommodation, for instance, homely well heated accommodation feels very secure.

Bad lighting, noisy argumentative neighbours, people drinking or using drugs in the street, people who harassed people because they were vulnerable or had mental health problems, houses that were in poor condition were all things that people repeated that they didn`t want.

In some areas it is possible to end up in accommodation in what is thought to be a `bad area` - living in that area can be stressful but equally being known as someone who comes from that area can be hard to cope with.

This list is probably similar to most people`s requirements but some members of HUG pointed out that people with a mental health problem could be quite likely to end up in this situation. Also, people in this situation are more likely to become mentally ill or have a relapse.

TYPES OF ACCOMMODATION

TENTS AND BENDERS

A very small number of members of HUG have lived rough through choice although that choice has sometimes been influenced by illness. These members have lived in tents or makeshift shelters on the outskirts of towns or have travelled around the Highlands. For some people this decision was a way of avoiding other people, of avoiding services, especially mental health services and escaping from a way of life that they didn`t agree with.

However the majority of people who had experienced homelessness found that it was frightening and traumatic.

HOSTELS

Hostel accommodation was acknowledged to be the preferred home for some people but again the majority of HUG members would not choose this form of accommodation (some would even rather live rough than live in hostels). The main reasons for this were the rules and regulations which were seen as harsh and controlling and the occasional violence and frightening behaviour of other residents.

BED AND BREAKFAST ACCOMMODATION

In some areas this form of accommodation is not available as it is purely used for the tourism industry.

In general people did not like this form of accommodation because of the uncertainty of how long it would last and because of the rules and regulations concerning it.

People feeling unhappy and distressed talked about how hard it is to cope when they have to be out of the house in the daytime and unable to have visitors or to choose when to eat.

An additional problem was that although this accommodation was available in the winter it often became unavailable in the summer. Some people also said that the charges for such accommodation can be very high and that even if this form of accommodation is useful the money may be better spent on other forms of accommodation.

Some people placed in this form of accommodation may be there due to some form of crisis. Some people told of the distress they felt at not having access to their children (or pets) for any length of time while in this accommodation.

Some people said, in contrast, that with the right family, this accommodation can be very good. When people are feeling very vulnerable and lonely the feeling of being included by a family, and helped both emotionally and practically, can be a great relief.

PRIVATE ACCOMMODATION

Again the quality of this accommodation varies from superb to awful – there are a number of issues relating to it though.

It may be very hard to get the accommodation. Landlords will often state that they don't want D.S.S. Tenants, therefore excluding many people with mental health problems. In contrast, other landlords may specialise in people on benefits but in an exploitative way.

People have described some of the bad forms of private accommodation. One support worker described the rooms provided by one landlord as unfit for a dog to live in. Other people have described having to live in a room with no furniture or heating and peeling wallpaper or with other people in the house of whom they were frightened.

Other people have described landlords seizing their possessions while the tenant is in residence (which is illegal) to get bills paid and of people who live in this accommodation, who are clearly ill and vulnerable, being exploited both by the landlord and other tenants. At it`s very extreme people have said that they have heard of people being housed in huts or caravans at the back of the house.

The use of caravans as a form of semi-permanent (or sometimes permanent) accommodation was described in various places such as Caithness, Inverness and Lochalsh. Whilst the descriptions of these forms of accommodation were not acceptable to many members of HUG, many people who had actually stayed in them were very positive about the experience. Like the description of the nursing home accommodation later on, the possibility of caravan accommodation was felt by some to be a good experience because the alternative was homelessness.

Some of the houses described by members of HUG in this way appear on lists of accommodation handed to people looking for somewhere to stay. There was a temptation by some members of HUG to name these landlords but, being unsure of the consequences, this was decided against.

There was a request that accommodation provided by private landlords be inspected regularly.

A problem people face in trying to get accommodation is that they will often be asked to pay both a deposit and rent in advance but then find that they will not get benefits to cover the full cost.

Additionally housing benefit is paid in arrears whilst most landlords require rent to be paid in advance. Some private landlords were thought to charge excessive rents, which were unfair and also rebounded unpleasantly on the resident's income. There was a thought that it should be made impossible for landlords to charge these rents. This, in the short term, may cause difficulties for residents but in the long term may create a more just housing situation

For some people there was a feeling that this wasn't home, that they couldn't rely on staying there, that it wasn't theirs and therefore why bother to decorate it and turn it from a place they stayed in to something that felt like their home.

COUNCIL AND HOUSING ASSOCIATION ACCOMMODATION

This form of accommodation received the most praise. People felt that it was usually of good quality, that it would be well maintained, that they had a lot of rights when they got it and if they got into difficulties while tenants, that they would receive a lot of help compared to some other forms of accommodation. However it was also felt to be the hardest form of accommodation to get into.

Again it was felt that in some cases, people might experience discrimination when trying to get it or that people would get the least desirable properties.

Practice varied in this area. There was an account given of a housing officer going out of their way to get accommodation for someone and obtaining them the accommodation that they needed. But in the opposite extreme a member recounted revealing that they had a mental health problem and being told ...

"Why should we house you – you could be from Carstairs for all we know."

SUPPORTED ACCOMMODATION

This form of accommodation came in for a lot of praise with the support and buildings being said to be of a good standard. The fact that in some accommodation, help could be accessed 24 hours a day was greatly welcomed and it was said that even if it wasn't used it gave a great feeling of security.

Unfortunately, this form of accommodation is not available Highland wide. In Caithness the user group is lending it`s support to secure this form of provision there, after witnessing people having to leave the area and their friends and family in order to access this form of support in Inverness.

Some people living in this sort of accommodation have expressed the wish that there be available some sort of `move on` accommodation with reduced levels of support for when they become well and no longer need such high levels of support.

There was also the perception that people in the Highlands had available to them accommodation with a lot of support which may be more than people need and may be intrusive or else mainstream accommodation which is perhaps not supported enough. Another problem is that some supported accommodation schemes have become the targets for some of the worst sorts of harassment from members of the local community and to a lesser extent, the media. There was a call that the police adopt a zero tolerance approach to this sort of problem.

There was a belief that if people were in supported accommodation then the possibilities of getting a job were remote because of the consequences this would have on benefits that pay for people`s support and rent. People thought that they would need to get a very well paid job for work to be feasible. (It was also said that support needs could go up if people got work, instead of down – working does not necessarily mean people are well).

The same beliefs were applied to people who wanted to go back into full time education.

NURSING ACCOMMODATION

This form of accommodation was seen less as a home and more of an alternative to hospital (albeit a very good alternative).

People tended to see nursing home accommodation as somewhere that they had to stay in, either through the circumstances in which they lived, or because of the instructions of professionals. Many people had the wish that they could live more independently whilst at the same time acknowledging that such a prospect was a distant one for them unless considerable support could be provided.

As with supported accommodation there was a resentment that people had very little money whilst the organisation providing the accommodation received a lot of money to provide support. There was further concern that some of this money went to make a profit for some organisations.

OWNER OCCUPIED ACCOMMODATION

This was not talked about much except with the obvious point that if a person owned their house outright they would have a lot of security and be unlikely to lose their accommodation.

The opposite point was also made where a person is paying a mortgage. A story was given about the trauma and anxiety that can be felt when people become seriously ill whilst in employment. In this case, not only did the person become ill, they also lost their job and their income and because of this their home was repossessed when they could no longer make their mortgage payments.

It has been reported that discrimination can occur when people with a mental illness try to take out a mortgage in that they can be subjected to higher charges than people without an illness.

MAINTAINING A TENANCY

For some people there are difficulties in staying in a house:

ISOLATION

Another way of looking at isolation is to call it privacy. For many people, privacy is a large part of their lives and something they would not want removed. However, for a large number of people, isolation is one of the factors that contribute to mental illness – it comes in various ways:

Illness A characteristic of some people`s illness is that they withdraw from society, friends and family. Simple everyday tasks become impossible such as

- Talking to other people
- Getting up in the morning
- Cleaning or cooking
- Finding the motivation to do anything

In this situation the house they live in can become like a prison to them and at the same time the only place that they can cope with being in. A range of support measures are needed varying from support with everyday tasks, to emotional support and psychiatric help.

Transport Like everyone else, people with mental illness need access to friends and relatives and facilities such as shops. Without that access people can become very isolated and find it hard to cope. The lack of transport and it`s cost can all create isolation.

Stigma Sometimes, when it is known that people have a mental illness, they can find that other people start to avoid them. This can lead to intense feelings of isolation – at it`s extreme it can cause people to leave their community.

More common is the stigma that people can feel themselves. The feelings of shame, embarrassment or `differentness` that people can feel after a stay in a mental hospital can cause them to find it very hard to mix with other people and therefore also results in isolation.

In contrast, it was said that stigma is usually the result of ignorance and misinformation and that often stigma was at it`s lowest in people`s immediate surroundings. There it is often immediately apparent that there is no reason to be feared or avoided and therefore, unless neighbours are bigoted and malicious, there is very little direct discrimination.

One way of challenging isolation is to have access to a telephone, for many people this can act as a lifeline to the outside world when things are getting bad. Equally some people on benefits find that they cannot afford this.

FINANCE

For many people there can be a delay in getting back onto the right benefits or in getting grants to furnish their rooms. (One person recounting how he had to sleep on the floor of his house in a sleeping bag for three weeks before getting money to furnish it) This sort of situation can cause people to be readmitted to hospital.

INFORMATION

After a first admission or when moving to a new area, members of HUG have repeatedly said that a discharge pack specific to each area of the Highlands should be provided, giving details of rights and services in that area.

SUPPORT

Because this time is so critical it is important that support systems are up and running before a person leaves hospital so that there is as smooth a transition from hospital to community as possible.

Some people leave hospital before such support is in place. It should be realised in this situation that although the person may appear to be rejecting services or advise that they may also be in great need of help.

MOVING BACK TO THE SAME PROBLEMS

Some people are in hospital because of the problems in the environment that they have come from. If it is impossible to change that situation then it is important that people have access to respite care as a way of getting a break which may help them to keep healthy despite having to constantly face the problems of their home situation.

Where it is clear that someone's home situation or environment is the root cause of much of their illness then it should be possible to find ways of changing it or moving away from it, if that is the person's wish.

Some people may have become mentally ill as a result of domestic violence and abuse or be in a situation where this occurs. This situation was not discussed in much detail except to say that people leaving a house in this situation may be at great risk in terms of access to money, housing and emotional support.

HOUSING

Some people cannot leave hospital because there is no appropriate accommodation available. This can create great anxiety for the person concerned , cost more money than it needs to do and in some cases, cause people to leave to inappropriate accommodation.

BENEFITS

For some people, the thought of filling out benefits forms can be almost unbearable – as one person said

"Getting letters from housing – it cuts you in half"

Forms are often felt to be complicated and intrusive. They may also reinforce people`s negative feelings about themselves.

At its' extreme, people will not respond to letters from statutory agencies or, in some cases, claim benefits that they are entitled to or, in other cases, know about benefits that may help them.

In these situations welfare rights advice applied sensitively (or access to advocacy) could help with the strain of maintaining a tenancy on a limited income.

In addition, it was said that benefits advice should be volunteered early on without being asked. Some people have the impression that the only way they can find out about benefits is through their own enquiries or with the help of other users.

Benefits is one of the subjects for discussion in HUG but there was a call for communication between the different people providing benefits. It should not be left for the person concerned to trawl different agencies and workers. Instead the range of benefits a person is entitled to should be dealt with by one person.

When people are in hospital they will find that their benefits are often reduced (on the principal that there are less costs when in hospital). In some ways this is true but it does not acknowledge that many people, when in a psychiatric hospital carry on doing the same things that they did in the community and that this in itself is a therapeutic activity but such things usually cost money. Some people said that because of this they can end up in debt.

An additional factor raised in feeling secure in accommodation was the ability to pay bills and to afford to pay to keep the house warm. This can be very hard on a low income.

SUPPORT, CAN IT TRAVEL?

It was agreed by everyone that the ideal situation is for the support that people receive to be concentrated on the individuals needs and not attached to the house that people live in. People should be able to move around and take on different activities and responsibilities and still have the support that they need.

Support should be flexible. At some times a person may need a high level of support and at others they may need little. An individuals perception of how much support they need should have a large influence on the amount of support provided.

RESPITE CARE

A mixture of regular support and regular respite care in a pleasant environment may be enough to avoid repeated hospital admission or having to move out of "mainstream" housing into more intensively supported housing.

CRISIS CARE

For some people having access to crisis care or support locally may also avoid hospitalisation or difficulties in maintaining accommodation. This is discussed in previous HUG reports.

KNOWLEDGE AND COMMUNICATION BETWEEN WORKERS.

It was thought that if workers not traditionally connected to housing such as Community Psychiatric Nurses or Social Workers had a good grasp of housing issues and a knowledge of where to go when these issues became too complicated, then it would be easier to maintain tenancies.

HOUSING WORKERS ATTACHED TO MENTAL HEALTH TEAMS

This practice, which has occurred in some parts of the Highlands, has come in for a lot of praise. Although sometimes the difficulties that can occur in creating the best possible package of accommodation and support has caused a mixture of resentment, frustration and sympathy when seeing someone trying extremely hard to help, but because of events outwith their control, not always succeeding.

SINGLE PERSON ACCOMMODATION

There was a call for there to be a variety in the types of housing available to people but there was also an acknowledgement that many people with a mental health problem are single and a feeling that there is a shortage of this type of accommodation.

In contrast, some people talked of the need, when single, to have other rooms in the house for people to stay in. This may be when someone is getting ill and would be helped by someone, perhaps, a friend sleeping over. It may also be needed where a parent with a mental illness, but not custody of their children needs room for their children to sleep in when visiting.

Some people have also called for there to be accommodation of the sort which allows privacy but also access to people as well. For instance, sharing a large house, or having access to a communal area for people who may be lonely or isolated and living on their own.

TOLERANCE AND UNDERSTANDING

Just as some people felt unsafe and vulnerable when faced by noisy or rowdy neighbours, it was also acknowledged that some people with mental health problems could, through their behaviour, appear different or frightening.

There was a call for tolerance, understanding and respect between people. Although how that could be achieved was not addressed.

YOUNG PEOPLE

There was a perception that young people were not entitled to stay in one area when on benefits. This was true some years ago but does not apply now.

MOVING BETWEEN HOUSES

For people who are moving house and also on benefits there was a call for `double` housing benefit to be paid for the period required to move between houses, which may take some time. In some cases this double housing benefit can be paid already.

HOME HELPS

Some people said that having access to a home help could be a great relief in times of difficulty and would be a good way of keeping a house in good condition. In contrast, other people said that if they became ill enough to need help with practical tasks, then they would be so ill that they needed hospitalisation.

There was some worry over the cost of home helps. People saying that if they had to pay for home helps then they would not be able to access them.

It was also said that the use of support workers from the mental health teams who could also help in other ways and had an understanding of mental health could be very useful too.

ACCESS TO A WASHING MACHINE

In some forms of accommodation there is not access to washing facilities for clothes. People were very pleased that some mental health projects provided access to washing machines.

LIVING WITH RELATIVES

This is the situation that a lot of people are in. Some specific problems attached to this are the lack of understanding they sometimes have of what people are going through, and on occasion what is perceived as an overprotective attitude to the person with mental health problems.

On the other hand relatives do provide considerable support and may even move nearer the person to provide that support. It was thought that people moving for this purpose should be given extra housing points to help them move.

GOING BACK HOME OR INTO A NEW HOME AFTER HOSPITAL ADMISSION

There was a widely held belief that, after a few weeks in hospital, people would lose their housing benefit and therefore their homes. This causes considerable anxiety to some people, despite being untrue, (housing benefit will in fact be paid for 52 weeks) and illustrated the need for good information provision. The time after discharge can be critical to people`s chances of recovery and is a time when a number of things are needed.

CONCLUSION

This report concentrates on some of the main issues about housing that people with a mental health problem may face in the Highlands. It does not attempt to describe life for the majority of people with a mental illness for whom housing is perhaps not a major problem but does highlight areas of concern.

One of the main areas of concern is for people with a range of problems including mental illness or drug and alcohol problems, who may be homeless or in sub standard accommodation.

People with a mental illness need a range of different types of accommodation and differing levels of support according to their needs and circumstances at the time.

People with a mental illness can often be isolated and on benefits – circumstances which can exacerbate mental illness and make it harder to maintain a tenancy.

There is a great deal of ignorance about peoples rights to housing and about the housing options available to people.

There is a perception that some people are discriminated against in housing because of mental illness.

In common with most other people, people with a mental illness need accommodation in an area where they have privacy and company when they want it, where they feel safe and secure in both their house and neighbourhood. There is also a feeling that if people don't get this then they can be more prone to relapse.

RECOMMENDATIONS

1. People should have a choice in where they live and in the type of accommodation that they need.

2. People should feel safe and secure in their accommodation.

3. People should have access to support to help them maintain their tenancy – this support should be `attached to them` and should vary according to the users needs and wishes.

4. The support that is needed is variable, some people need practical support others emotional and psychological.

5. Tenancies may be maintained better by offering people a range of respite care, crisis care and flexible support – this may reduce the need for specialised accommodation or hospitalisation.

6. There should be a `one stop shop` for access to housing.

7. There should be improved access to welfare rights and advocacy with regard to housing across the Highlands.

8. There needs to be a discussion about the links between mental illness and perceptions of intentional homelessness.

9. Effort must be made to combat isolation through better transport, the use of support workers, challenging stigma, having access to telephones and having access to places to meet people.

10. When people are discharged from hospital it should be with appropriate information and with a full range of support packages. Where someone discharges themselves before this is in place this should not be taken as meaning they do not want help unless that has been explicitly stated.

11. In reflection of the number of people in HUG who have experienced homelessness the system of recording homelessness applications and mental illness should be revisited for it`s accuracy and accessibility.

12. There should be a way of dealing with landlords who provide costly accommodation in which vulnerable people are open to exploitation – perhaps an inspection body.

13. People should be able to access a range of benefits quickly and by going to one person.

14. There should be housing officers based with the mental health teams.

15. Workers in mental health should have training in housing issues.

16. There is a need for a choice of accommodation – especially single person's accommodation and `shared` accommodation.

17. There is a need for widely available straight forward information, which includes types of housing and tenancies; allocation policies and facts related to Housing Benefit.

APPENDIX 1

The following is a copy of a talk given around the subject of housing at a conference held at the same time as the publication of this report - we hope that it gives a human touch to the subject of housing.

MODERNISING COMMUNITY CARE
SEMINAR - 23 APRIL 1999

HIGHLAND USERS GROUP PRESENTATION

"HOME IS WHERE YOU WANT TO BE, EVEN IF IT SOMETIMES DRIVES YOU ROUND THE BEND"

Hello, my name is Graham Morgan. I facilitate the Highland Users Group, which represents people with mental health problems and am, myself, diagnosed as having Schizophrenia.

HUG has about 170 members and 11 branches across the Highlands.

In this short talk I am going to get emotional about documents like Modernising Community Care. What I want to show is that documents that make overarching statements of principle or need - whether produced by the Scottish Office, the Council, the Health Board or by Groups like HUG - can obscure the very real issues and differences of opinion felt by the multitude of people that will be affected by them.

I would like to show that simple statements, such as the idea that people should live and be treated at home, can give rise to dangerous new orthodoxy's. Because we believe that one way of living is good we can be tempted to think that its opposite is bad - when in fact both can be good and both bad.

I would like to show how, despite there being over 20,000 people with a mental illness in the Highlands and 134 hospital beds, that on many occasions staying at home can be the worst thing that can happen to someone.

I expect all of us know the feeling of when life becomes dark and there is no joy to be found. Sometimes this feeling can deepen and extend - there can be days and weeks when the worries and despair crowd in; when it becomes impossible to face other people; when the privacy and safety of your room becomes a trap; where the idea of moving out of your seat and making a decision about whether to eat or tidy up is impossible; where it is a struggle to think about anything *the phone is ringing and it is a struggle to know what this means)* - life becomes a 'muzzled' blur in some inaccessible place.

For some people, this ends in the trauma and drama of hospital admission following the splintering of their front door by the police - an occasion that represents both relief from the intolerable situation at home and fear of the new circumstances.

My psychosis bubbles along quite happily, but there are occasions when it flares up into something else. The last time was five and a half years ago, when for some reason every bright light and every

spark of sunlight became a demon or spirit that could read my thoughts and was after me. To hide from them I chose to go and hide under the 4 foot gap between our floorboards and the rubble of the foundations of our house. It was frightening and cold down there, mould grew on my blankets and above my son *(who was just learning words and sentences)* would come and squat above the loose floorboards and point and say "Daddy".

C is 7 now - he has boundless joy and enthusiasm for life. At the moment, when he grows up one of the things that he wants to do is buy us all a rocket each to explore unknown planets. That will change, I suppose, but let me not be the instrument of a sudden cruel awakening to agony and fear. C sees me as a silly daddy - let him, if at all possible, never have to come downstairs to see his silly daddy staring at the blood coming from his wrist as happened regularly before he was born.

When I came out from under the floorboards I sat dressed in oilskins for day after day, staring into space and into my head came the idea that if I could burn patterns into my hand *(like in the past)* then I, and everyone else, would be safe and my hand holding my cigarette would start waving in circles and my stomach would go hollow and my wife K would shout: ***"STOP",*** and burst into tears and anger.

This carried on for day after day with no break and no help, and in those days a culmination of my past illnesses came to a head and K, who loves me, found that I looked different; moved differently; felt different; believed and smelt different and our vision that we shared as a partnership of joy and hope for life together was betrayed and shattered. Five years later we are still putting the painful pieces back together.

If some new orthodoxy says I should be treated at home, and that intensity of illness returns, then those shards that we are rebuilding may as well be ground to ashes and let free upon the wind.

If the Mentally Incapable Adults Bill, or the Review of the Mental Health Act, makes Living Wills or Advance Directives legally enforceable let me publicly state my own will - if I ever get into that state again, take me away from the house that is my home and from those that I love more than anything; take me away from those tears *(I don't care where)*; lock me up; put me in prison; take me away - and when I am better let me back.

That is what I want. Let us briefly look at the situation for other people. When I read about "home" in the Modernising Community Care document, I thought about my home with its comfort and heating and lack of worry about bills. Yes, in most circumstances, I want to be there, but should people be treated in the following circumstances - as happens to many members of HUG:

- In tents and benders in the woods.
- in damp, cold, untidy caravans whose water supply freezes in winter.
- in private lets where there are only the bare floorboards to sleep on.
- in Bed and Breakfasts which have to be left between 9am and 5pm.

- and should they be treated in places with people:

- who, because of their love and concern, smother and overprotect those they care for.
- where the other tenants also often have problems such as drug and alcohol or social problems.
- where it is common for people to be frightened of each other.
- where security and privacy are alien and abuse and exploitation widespread.

- or:

- live in hostels where the police come out to disturbances with monotonous regularity.
- live in houses where their mental illness is a result of the physical or sexual abuse of their family.
- be in communities where, for some people, care consists of avoidance or verbal abuse or having stones thrown at the windows.

Most members of HUG would say:

"No - those are not situations to be cared for or treated in"

and yet we all know people who, whilst not wanting to live that way, would also say that yes for them during that period of their life they would want to be in that house or place and to be treated with those people - and even that those people who are responsible for their exploitation are people that they care deeply for.

Let me finish on a note of sentimentality:

"HOME IS WHERE THE HEART IS"

When I look at this, I think of a place where I feel secure, safe, accepted and known for who I am - a place where I can grow and where there is a degree of friendship and hope. If we can accept this version of "home" as the place that we should be treated; if it reflects more on <u>where</u> we want to be and <u>how</u> we want to feel, and acknowledges that for some of us this place may be some turbulent for of refuge or even some form of institution - then for some of us "home" can be, by our own choice, a hospital ward. If we can acknowledge that "home" involves a great deal more than a building, then I welcome this as a great step forward in community care.

To conclude, even the most basic of principles can have exceptions and differences. It is tempting to believe that we have the answers to the way forward - that we have the theory or the principle, moral code or set of ethics that will make life better for everyone - and of course we don't. When you look at mental illness at its simplest, it is possible to say that it is misery that has become disabling. We all know and experience misery, we all know that you can't legislate to eradicate it, that all we can do is struggle forward trying to make things better and trying to remove some of the barriers that are so easy for us to erect for our own sense of security.

Thank you.

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