

**HIGHLAND USERS GROUP**

**A MENTAL HEALTH STRATEGY FOR THE HIGHLANDS**

**The view of Highland Users Group on the main problems people with a mental illness face in the Highlands.**

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**Highland Users Group can be contacted through Graham Morgan,  
Highland Community Care Forum, 1 Ardross Street, Inverness IV3 5NN  
(Telephone 01463 718817)**

## 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 users.

At present (20 September 1998) HUG has 162 members and 10 branches in:

- ◆ Caithness
- ◆ Sutherland
- ◆ Easter 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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## **WHY PARTICIPATE IN A STRATEGY FOR MENTAL HEALTH?**

In 1998 The Scottish Office produced 'A Framework for Mental Health' which required Health Boards in Scotland to co-ordinate the production of a Strategy for Mental Health Services in each Health Board area.

A key element of the Strategy is to concentrate on the needs of users and carers in order that any Strategy produced identifies services that genuinely respond to those areas of peoples' lives in which they may need help.

Late in 1997 Highland Health Board set up two multi-agency groups to produce a Mental Health Strategy for the Highlands. These groups were a Steering Group whose function was to drive the creation of a Strategy, and a Reference Group to whom the Steering Group was accountable.

Highland Users Group is represented on both these groups by the Advocacy Development Officer for Highland Community Care Forum who facilitates HUG.

HUG recognised the importance of being able to contribute directly to the Mental Health Strategy and set aside its meetings in March 1998 to discuss life whilst having a mental health problem.

The discussions were based around a few basic questions:

- What problems people still faced whilst living with a mental health problem.
- What the possible solutions to these problems could be.
- Whether present services responded to the needs of people with mental health problems.
- Priorities for developments.

In total, discussions took place in all areas of the Highlands, except North West Sutherland. A total of 99 people participated. In areas where no HUG branch existed users were kind enough to meet to discuss these issues.

This document represents a distillation of the common themes emerging from the discussions arising in HUG in different areas of the Highlands.

## **PRIORITY SETTING**

In April 1998 the HUG Round Table (which is the elected committee that represents the interests of HUG) met to discuss certain aspects of the Strategy for Mental Health.

### **Priority Setting**

HUG has noted that, despite there being a requirement to produce a Strategy for Mental Health, no new resources are allocated to this and also that existing services should not regard their funding as sacrosanct.

The HUG Round Table believes that, in order for new services to be developed, money will have to be found by either cutting existing mental health services funding or by obtaining resources that would previously have gone to other client groups.

The Round Table committee has decided that it would not participate in identifying services that should be cut, or argue that people with mental health problems have a greater right to resources than another client group.

### **Present Services**

In almost every area users felt that present services were vital to help people with mental health problems in the community.

Where they did not personally like all services, they were aware of other people who regularly used them and valued them.

Accordingly, the priorities that have been set represent future work that could be carried out as resources become available.

# **THE MAIN DIFFICULTIES PEOPLE WITH MENTAL HEALTH PROBLEMS EXPERIENCE WHILST TRYING TO MAINTAIN A GOOD QUALITY LIFE.**

The areas that are described on the following pages are reported according to the frequency with which they were mentioned in different areas. This does not necessarily reflect on how important they are to people. In order to find out what the most important themes are to HUG it is necessary to look at the priorities for action that they have set. These are contained in the Appendix.

## **1. STIGMA**

One of the definitions of stigma is 'disgrace'. In the eyes of the majority of members of HUG this unjustifiable description is routinely applied to people with a mental illness and is the biggest problem (apart from the illness itself) people face while trying to live in the community.

People with a mental illness, the professionals that help them, and even the buildings in which users receive services are all marked out for suspicion by certain members of the community. The media and British society routinely portray people with a mental illness as potentially violent, or in other ways, which all give a negative impression about people with a mental illness.

This leads to hostility about services by some users, and reluctance from many other people to seek help when they need it. It can also lead to abuse and discrimination from the public towards people who have a mental illness.

Within the Highlands (and especially in smaller communities) mental health services, professionals and users are readily identified. This can lead to acts by the community against people with mental illness, which lead to a loss of confidence and often a reluctance to go out or mix with other people. It can also cause people to feel great anger and resentment towards those responsible for this situation.

At its extreme, stigma is found in its overt form of abuse. Members of HUG have experienced rejection from their families and the loss of their friends once they have developed mental health problems. Members have had people deliberately avoid them in the street, some have been spat at and verbally abused and some have had bricks thrown through their windows. Others have found their rooms ransacked, their bins urinated in and more vulnerable people have found themselves exploited, especially financially.

These are the extremes of the consequences of stigma and are rare. They seem to particularly apply to people known to have been in Craig Dunain or living in supported accommodation.

It is hard to know that people have a mental health problem, but those people who remain anonymous are well aware of the suspicions that the public have of them and while not being discriminated against directly many people will go to great lengths to hide the fact that they have experienced mental health problems.

Stigma can manifest itself in otherwise very well meaning people - people can be asked why they attend drop-in centres when 'they're not really like those people'. People can feel smothered with care from their friends, or can just find their friends hesitant about how to talk to them.

The end result of this is a constant process of alienation.

## **Solutions**

Members of HUG are very keen that a major education campaign occurs on a similar scale to those of the HIV or anti-smoking campaigns, and believes that if it were successful the way in which mental health services are delivered and the people that use them would be transformed - as would the quality of life of those with mental health problems.

Members of HUG are already engaged in mental health awareness raising exercises that have been conducted with a range of agencies. Many members are willing to stand up and speak out and some are willing to talk with the media about their experiences.

HUG is involved with the Highland Health Board 'Mind Matters' campaign, and is concentrating on a video and postcard campaign to challenge stigma.

Towards the end of this year we should be releasing a report on Stigma which will summarise discussions held by HUG on the subject.

Highland Community Care Forum has received funding from Highland Communities NHS Trust and the Networks Project to employ a Communications Worker who will challenge popular perceptions of people with a mental health problem amongst employers and health and social care workers. This worker will also build up an information resource to help people participate and come to informed decisions about their treatment.

## **2. CRISIS SERVICES**

When people are becoming unwell they often need help quickly to prevent the situation developing to the point where they may need hospital admission.

The forms of help people need can be very simple:

- Having someone that they know and trust that they can talk to in order to get rid of the 'night terrors' that so many people with a mental illness experience.
- Having access to someone who can calm them down and provide medical assistance (especially for those people who have, or are at risk of, self harm).
- Having someone who can intervene to prevent hospital admission, or alternatively provide hospital admission if the situation merits it.
- Having a sufficiently comprehensive network so that the many people who withdraw from services when they are getting unwell can have help provided early, and in an appropriate manner.

It is extremely difficult to gain access to specialist mental health services in the evening, at night-time and on weekends. There are, however, emergency services that people can access:

- The General Practitioner
- The Emergency Duty Social Work Team
- The Police
- National Telephone Helplines

These services are not always satisfactory, and it is for this reason that crisis services are being called for. Some of the reasons the services don't work are as follows:

### **General Practitioners -**

Many GPs have little knowledge of mental illness and the needs of people with mental illness. It is often reported that some GPs will refuse to come out to see people with a mental illness who are in crisis and that, if they do, they will try to persuade the person concerned to take medication and to go to sleep - despite the fact that this is not always what the person requires.

This could be especially so for people who often go into crisis and for those people who have less 'serious' mental health problems. Recent discussions have highlighted this for people who repeatedly self-harm and also for people with personality disorders.

### **Emergency Duty Social Work Team -**

Members of HUG have been told that this might be an appropriate service. However, the majority of people with mental health problems are not aware of this service and there is some suspicion about contacting a service that has not traditionally been connected with mental health, especially from people who also have children.

### **Police -**

On the whole, members of HUG who have come into contact with the Police have very favourable comments to make about them.

However, this is not a service of first choice and would only be used in extreme emergencies. Many members have also said that, such is the stigma of being involved with the police, that their mental distress would only increase on contact with them.

Many police officers would also admit that they are not qualified to react to a mental health crisis, and that they themselves have difficulties in getting appropriate help for people that they encounter in crisis.

### **Telephone Helplines -**

These are often based in London and are not always appropriate for people phoning from the Highlands.

## **Solutions**

HUG has produced a report on Crisis Services that goes into this theme in more detail and can be obtained from the Highland Community Care Forum.

The Inverness and Culloden Health Care Co-operative has submitted a successful bid for the provision of crisis services in their area.

Hug has developed a model for the initial establishment of a Highland-wide crisis service.

### ***Telephone Access -***

There should be a central resource (staffed by professionals capable of assessing people with a mental illness) for people with mental health problems to access by phone at any time of the day.

If the situation merited it, the service would call out the appropriate professional to deal with the crisis. If, however, the user concerned was in need of someone to talk to for a time then this would be done - perhaps by transferring the request to a pool of volunteers trained in telephone counselling.

### ***Training -***

Part of the problem is that professionals based locally will not always respond positively to a mental health crisis. It would be advantageous if mental health awareness training could be provided for such people.

### ***Extending the opening hours of mental health services -***

Whilst not wishing anyone to work excessive hours, services would become closer to users wishes if they were accessible in some way in the evenings or the weekends. Perhaps by making the contracts of new workers more flexible in terms of when their hours are worked - services would become more responsive.

Debate with users in the areas covered by local mental health teams could inform the services at what time people would most like to have access to the mental health team. It may turn out that having someone on call would provide benefits in security for users that outweighed the lost service in the week.

### ***Advanced Directives -***

It would be useful if people in contact with services were given the opportunity to help decide what they would like to happen (in a written form negotiated with a worker) if they were to become ill again.

This would be especially important for people who do not have much insight when ill, or for people who withdraw from services when they get ill.

## **3. POVERTY, MONEY AND BENEFITS**

There is a well-established link between poverty and ill health. HUG believes that this especially reflects on peoples' mental health.

Out of the 162 members of HUG, perhaps three people are in employment with the rest being mainly in receipt of benefits and others in receipt of pensions.

It is clear that, when people have received a comprehensive range of benefits (including Disabled Living Allowance) they can sustain a life in the community. However, members were clear that this allows them to live but does not give them hope and enthusiasm for their situation in the future. A lack of hope and enthusiasm does not contribute to a good mental health.

For people in receipt of benefits, or on a low income, it can be almost impossible to have a social life; to eat well; to buy clothes; to engage in recreation and leisure activities; to travel; to buy presents for children; or to keep accommodation in a reasonable state. A large number of people with mental illness will be in this situation.

It should take little effort to see that this situation can cause a deterioration in mental health rather than an improvement.

A range of departments and agencies may be dealing with people in receipt of benefits. There is a perception that these agencies are not user friendly, and that the forms are so hard to fill in that people often have to get professional help to fill them in. People may be passed from person to person and department to department (not necessarily in the same building). Those mistakes have to be sorted out by the user and the consequences of mistakes affect the user, not the department.

There is a feeling that the various agencies providing benefits aren't in tune with the needs of people with mental health problems. This is especially so with Disability Living Allowance - there is a perception that the form for this is not appropriate for people with mental health problems. People are suspicious of the department dealing with DLA because it is so common to be rejected on the first application.

People do not have enough information about the range of benefits that they are entitled to. They often need the skills of a professional to negotiate the benefits system and do not feel that they receive enough money in any case.

There is also a growing fear that benefits for people with mental health problems are becoming increasingly harder to get and easier to lose.

There is a belief that it is relatively easy to get disability benefits for a 'severe' diagnosis of mental health problems, but that for other people it can be much harder even though they are equally disabled when looking at the consequences of the distress they experience.

HUG will be discussing the subject of poverty and mental health in 1999.

#### **4. THE ATTITUDES OF PROFESSIONALS**

If someone is to talk to another person about highly personal, perhaps embarrassing, shameful or distressing feelings, then they need to feel that they trust that person - perhaps that they like them, that they won't be laughed at, judged or dismissed.

An ordinary person would spend a long time selecting whom they were prepared to confide their innermost feelings to. People with mental health problems are routinely expected to confide these feelings to relative strangers. It is therefore unsurprising that the subject of professional attitudes is so high on the agenda of HUG.

HUG does not claim that the majority of professionals have negative attitudes towards them, but would claim that therapeutic sessions and relationships (and therefore their chances of recovery) can be ruined by inappropriate professional responses.

Such responses can be complete mistakes, but they can also be caused by someone being in such a hurry that they only give cursory attention to someone's distress, or so tired that they cannot listen properly or perhaps the relationship can be wrong - neither person likes each other and there is no other person who can provide the service.

A professional can be so convinced of what will help someone that they put a lot of pressure on the user to take a certain course of action that the user completely disagrees with. Without the co-operation and participation of the user it is of very little use to try to force them to do something.

The professional may have a particular role - for instance, they may see their function being principally to prescribe medication, whilst the user may see them in a different light.

Some professionals may have to protect themselves from distress and become distant. Some may be tired of distress - they have heard it many times before and are getting bored.

Users perceive most of these attitudes, however well hidden they are and once noticed they have an effect.

Members of HUG reserve most of their concern for those professionals who only come into contact with people with mental health problems as a peripheral part of their job. The majority of mental health professionals would be as concerned about stigma as HUG, but other people share the prejudices of the rest of the population - they may be scared, ignorant or just disapprove of the actions of people with a mental illness.

## **Solutions**

More information on this subject is contained in the HUG report on Quality.

HUG is engaged in a series of mental health awareness raising exercises with professionals and would wish to continue this.

As far as actual prejudice against people, it would be interesting to see how robust an organisation's complaints system is when dealing with such subtle subjects as the attitude of someone, or putting the word of a person with mental health problems against someone without those problems.

Further action that can be taken is to look at how effective an organisation's equal opportunities procedure is when applied to someone with a mental health problem.

## **5. MOTIVATION AND HAVING SOMETHING TO DO**

This subject has strong links with the sections on employment and on poverty. For anyone who finds themselves with long stretches of time off work boredom and lethargy can quickly set in after the first excitement of not having to get up early in the morning. For many members of HUG all, or substantial portions of their life, will be spent without work and consequently they have to find other things to do. As is popularly known about people who experience long term unemployment, it is not always easy to find things to do that make you feel content, or needed or valued - in fact the television may become the most attractive option.

When people are not only unemployed, but also living close to poverty it can become even harder to find things to do that feel purposeful and meaningful.

For many types of mental illness apathy, listlessness and lack of motivation or desire to see other people can be symptoms of the illness. This makes filling the day even harder.

Despite the widespread existence of drop-in centres and TAG Units in the Highlands, having something to do is a major issue for users.

## **Solutions**

One suggestion made is that, for those people who are leading an isolated existence (and are in agreement with the idea), that people could come to the person's house and take them out to the drop-in centre or off to do something else. This may overcome many of the problems caused by lack of motivation.

## **6. EMPLOYMENT**

The main issues raised were the difficulty of getting into employment - caused by discrimination, the lack of jobs and sometimes by the lack of qualifications obtained by people with mental health problems.

An issue quite frequently raised was the situation of having mental health problems and also being an older person. The two forms of discrimination combined almost made employment an impossibility.

There was a lot of talk about therapeutic earnings. Most groups felt that it was so hard to get onto therapeutic earnings that it was not worth trying. It was also felt that, with so much employment being seasonal in the Highlands, therapeutic earnings were not adaptable enough to use anyway. There was also a fear that being able to work on therapeutic earnings would, in the current climate, act as an indicator that mainstream work could be undertaken and therefore benefits cut.

Equally important to many HUG members is that there should be an acknowledgement that for some people employment would not be an option that they would choose. There are many members of HUG for whom the stress of employment would be the straw that pushed them back into illness. For such people it is essential that individual reactions to long term employment, and the perceived lack of status, are addressed. It should also be possible to have a good quality of life whilst on long term benefits.

## **Solutions**

Please see the HUG report on Employment

## **7. INFORMATION**

Information becomes essential when people find themselves in new situations and surroundings. In the early stages of mental illness the information needed is immense.

\* People need, in the first place, to know that they are ill and need help.

\* People need to know what services are available for them.

\* People need to get used to the terminology used, or have it explained to them.

The words Community Psychiatric Nurse; Social Worker; Psychiatrist and Psychologist are often confusing and alien to most people. A psychiatric hospital, and treatments used, are intimidating and frightening possibilities about which they need reassured.

Medication, with its confusing terminology and strange side effects, is a subject about which people often need information.

People also need to know what to expect - much conflict could be avoided if professionals could explain what their job is and what the limits of it are and what they can actually do to help.

In other words, information is especially important when people are first getting ill or new things are happening to them. At these times information is needed on almost every subject with which the users comes into contact, whilst at the same time it may be the hardest time to take in information.

It is also important that information is provided in different formats. For instance, although an admission pack for Craig Dunain would be useful, it is likely that in such a situation the information provided verbally could be the best way of dealing with a person's need for information - whilst the opposite may be the situation on discharge from hospital.

### **Solutions**

Two key areas about which information is required are:

1. On discharge from hospital what help there is available in the community. There are calls to develop a 'discharge from hospital' pack which users could participate in writing.
2. Medication - Craig Dunain Pharmacy now has funding for an Information Service which, if successful, would fulfil the majority of the aims of the HUG Medication report.

## **8. HOUSING**

HUG has just completed a series of discussions on housing and a report will be available in due course. Some of the key issues to come out of these discussions are that very few people had much idea of their

rights to housing and housing benefit, and that many people felt that they would lose their accommodation quickly if they were admitted to hospital.

As with other benefits, people talked about how hard it was to claim housing benefits, or to deal with housing agencies when they were ill.

Some private landlords state on their adverts for accommodation - 'No DSS' - thereby excluding the majority of people with mental health problems. Others, however, specialised in catering for people in receipt of benefit but in return provided accommodation in an extremely poor state of repair, and may go as far as exploiting more vulnerable people.

Whilst people were relatively secure in council accommodation, people in private accommodation felt that they were at a greater risk of losing their homes through illness and hospital admission.

Some people could avoid hospital admission, or maintain their homes, if they had support provided for those times when they were ill but were left alone when they had become better again. Other people have a need for a greater degree of support than this. Supported accommodation of this sort is not available in all parts of the Highlands, and has resulted in people moving areas to places such as Inverness where the support and other services are available. In very rare cases users had been put into inappropriate accommodation, such as that for elderly people, when they were themselves young.

The Highlands was thought to be a destination for people in search of 'sanctuary' and had been used in this way by some members of HUG. For some people this worked very well, whilst for others who have just arrived in the area the response has been to provide a bus ticket back to the area they came from.

A key feature mentioned was for the need to feel safe. This could be provided for some people by always being around people that they know. For others it is provided by being able to seal themselves off in their room, or by not being in an area where they are known to have a mental health problem.

A feature of bed and breakfast accommodation was the lack of security that it provided because people were conscious that they would be moved on at some stage. This would also apply to people living in accommodation that is let seasonally.

## **9. OUT-OF-HOURS SERVICE**

There are many links between crisis services and out-of hours services. There is a feeling that the more that services operate out of hours the less need there would be for a crisis service.

A phrase repeated amongst members of HUG is that 'mental illness doesn't finish at five o'clock', whilst of course community mental health services tend to do so.

More and more of the voluntary sector services are now staying open on the weekends or in the evenings. This is less apparent with the statutory services.

There is also a call for there to be somewhere to go to in Craig Dunain on the weekends and those evenings when the social centre is shut.

## **10. TRANSPORT**

The majority of HUG members do not have private transport and rely on public transport to get them to any sort of service.

There is a feeling that public transport is not up to this task - in some areas being non-existent or so infrequent as to be not worth the effort. Despite concessionary bus passes being in existence, some people were also put off by the cost of public transport.

This problem can lead to isolation of people with a mental illness, which only serves to increase mental health problems. It can also lead to people not accessing services that they otherwise would do.

It has been said that people can often find ways of accessing informal transport services, which is clearly true, but equally people have also spoken of the embarrassment of continually asking for lifts until a point is reached where they stop asking.

### **Solutions**

Solutions to this that have been suggested are:

- to expand community transport schemes
- to have services going to people (which is happening more and more often)
- to pay peoples' fares to access services - whether they be statutory or voluntary services

## **11. ADVOCACY**

Whilst rarely calling it advocacy, people often talked about the need for the support of an advocacy worker. This worker would be someone who could help with forms, benefits and awkward situations. Someone who will stick up for a user's rights and know how to negotiate the various systems a user will inevitably encounter and would ideally come out to where the user was.

This model (suggested in areas where advocacy doesn't exist as well as areas that it does exist) sounds very similar to the model developed by the Inverness CAB.

For further information please see the Advocacy Strategy developed by Highland Community Care Forum.

## **12. RESPITE CARE**

Long term mental health problems can leave everyone - user, carer, friends and so on - sick of the whole situation. In fact so fed up and bound in by it all that the user may get ill again, or people close to the user become exhausted and depressed.

When HUG talked about respite care some months ago everyone was clear of the benefit of people getting a break from the situation they were in.

Some people can get this break by going on holiday, but this depends on having the money to pay for it and the ability to take a holiday.

Members of HUG are sure that the severity of mental illness could be reduced by providing breaks away from a person's usual environment, in a pleasant homely place where there were things to do, but also staff who know how to help people with a mental health problem.

Whilst willing to pay a contribution to this, HUG members stated that they would not be able to afford to pay for a break whilst also paying for their own accommodation. They said that it could cost them more to have respite care, as part of it is to do with enjoyment - which in some of its forms costs money.

There was some suggestion that a break in a safe, relaxed environment could also be an ideal opportunity for some of the problems at home to be sorted out so that people did not have to return to a situation that would inevitably mean that they would get ill or need respite again.

Allied to that suggestion was the thought that, during the break, work could be done in helping people find ways of coping with what are often intolerable situations. However, the relaxation gained by respite may disappear if people have to look at their home situation whilst receiving it.

Members of HUG were convinced that the respite care that has traditionally been provided in hospital is a negative experience compared to the vision of respite care that they have. Being in hospital carries images of distress and illness which does not compare with the positive message that respite should convey.

### **13. TALKING THERAPIES**

This heading refers to therapies that are often seen as being on the far side of conventional therapies. Therapies such as art therapy, or counselling, or psychotherapies or the various group therapies that are seen by some people as being extremely useful.

Those that are provided on the NHS are often hard to get referred to, or have a long waiting list and those that are not on the NHS are out of the price range of most HUG members.

### **14. STAYING STABLE**

There was a feeling amongst many members of HUG that success in mental health services is seen by the absence of the worst features of illness. That if people are going into hospital less frequently, or get acutely ill less often, then treatment is successful - which in some ways it is.

However, the person who is having less symptoms may still be in the situation where they expect to remain on benefits and go to a drop-in centre month in and month out - or wake up muzzy with medication day after day, or struggle in badly paid employment. This situation can appear to stretch out indefinitely.

For some people this is not acceptable. There seems to be such a lack of hope, and a vision of the future, that is so constrained that it seems to hold little worth within it.

There is a need to believe in the possibility of a fully recovery, or at the very least a fulfilling life that has adjusted to the problems that go along with a mental health disability.

## **15. INDEPENDENCE**

A common statement used by professionals is that someone has become dependant on services and that efforts should be made to wean them away from them.

This judgmental attitude opens up a can of worms about the way that services are run. Members of HUG would agree that ultimately people should become independent, but would also say that there are many stages on the route to independence that should also be respected.

Who determines whether someone is independent is open to debate, and what independence is would be worthy of debate. In 'ordinary' life people are regarded as independent, but at the same time they will depend to some extent on those people that are close to them. If a user's main contacts are fellow users, or services, is it wrong or surprising that they may rely on those people to some extent.

## **16. SANCTUARY**

Although the discussions that we had concentrated on services in the community, the necessity of places like Craig Dunain could not be avoided.

It was stated that a place of sanctuary and safety was needed, and that Craig Dunain fulfilled this to a large extent.

However, it was also said that in a crisis that is likely to last for just a short time then local psychiatric beds in places a long way from Craig Dunain would be very good.

## **17. CHILDREN**

Although there are very few members of HUG who are under 18, members have raised the issue of services for young people. There seem to be few services for children, and access to the services that exist was considered to be off putting to young people.

There was also a feeling that children may miss out on schooling by being signed off sick for long periods if they developed mental health problems.

There did not seem to be appropriate services for children with serious mental health problems. Some members of HUG have recounted being sent away from the Highlands and their homes to other areas because there was no appropriate specialised service in the Highlands.

## **18. COMMUNICATION BETWEEN AGENCIES**

There was a feeling that there is a degree of competition between agencies, where personality clashes and differences in the philosophy of how to treat users can lead to a lack of co-operation.

It was thought that this situation caused the greatest harm to users. Some users were aware that some professionals would not tell other users about services that they could use.

## **19. DIAGNOSIS**

Having a diagnosis can be crucial to getting services and has a major influence on how users view themselves and plan for the future.

HUG should soon be producing a report on Labelling which will contain a wide variety of views.

Being given a diagnosis of a mental health problem can lead to stereotyped reactions from the public, professionals and the users themselves and can detract from the 'real' person.

Having a diagnosis can also mean that treatment can start, users can begin to come to terms and try to understand their problem, instead of worrying about this ill defined illness, which although it is serious seems to have no name. It can also lead to getting services and benefits.

At the same time, services that respond mainly to diagnosis may leave users with a high level of need without help because, although they are in huge distress, they are not officially ill.

One of the most common complaints is when people have been given a diagnosis, which is then after a number of years changed. It is quite common to hear of people being diagnosed as having schizophrenia, and then later on as having manic-depression. This leads to different treatments, but also causes users to reassess their vision of themselves. It can lead to a great deal of confusion and mistrust in services.

## **20. PERSONAL KNOWLEDGE**

Having contact with someone that a user knows and trusts can make all the difference when using services, especially when a user is getting into crisis and is debating whether to try and get help.

A point that has been raised is that some users don't see a consultant psychiatrist, but instead see a 'junior' doctor. This can mean that, just as they have built a trusting relationship, that trust is broken because the doctor moves on.

## **21. PREVENTION AND EARLY INTERVENTION**

There is a feeling that a lot of problems could be avoided if treatment was available just as mental health problems began to occur.

How this is done is another matter, but probably ties in with challenging stigma and providing public education.

If people knew more about mental health problems, and felt less shame for them, and if the initial person they contacted (probably their GP) had enough knowledge about mental illness, then perhaps some of the problems could be avoided.

Some HUG members have started talking about the idea of having mental health clinics in GP surgeries.

## **22. UNDERSTANDING EACH OTHER**

Nowadays people talk of a partnership between the professional and the user in solving problems and receiving treatment. HUG would like this to occur.

Before this happens we need to create a situation where users are treated and respected as equals by professionals, and vice-versa.

This shift in attitudes is easy to talk about but harder to create. If users have abiding memories of mistreatment in the past it is hard to forget them, and if a professional has been brought up to believe that their skills are also a sign of superiority then that is equally hard to forget.

One of the first points for this change in attitudes is for everyone to be clear about where they fit into the whole process. Users need to know what they can expect from a professional and what they shouldn't expect - and likewise a professional should know what the user expects of them.

## **23. MODERN TECHNOLOGY**

Advances in modern technology were thought to be very useful events, especially for areas like the Highlands.

Video consultations have been experienced by some members of HUG and, after a few hiccups, have been found to be helpful for some people.

There is some thought that having computers in doctor's surgeries with information, and possibly even therapeutic programmes could be useful.

## **24. SELF HELP**

The idea of self help is attractive. It seems to be a way of gaining motivation and control and of finding ways to participate.

It means that people do not have to rely totally on experts and can start to find solutions for themselves and learn from others.

HUG is due to write a report on this subject.

## **25. ISOLATION**

Mental illness can be very isolating in itself. Stigma can increase this, lack of motivation can further increase it and living in a rural area with poor transport links and distant services can further increase isolation.

This can increase mental health problems and make services hard to deliver.

HUG thinks that a rural weighting should be applied to mental health services in the Highlands when calculating the resources devoted to mental health.

## **26. ENJOYMENT**

It is easy to get bogged down with problems and yet, as the phrase goes, 'laughter is the best cure'. Perhaps it is hard to see where it would fit in with mental illness, but its good when it happens.

## CONCLUSION

The above represents the main themes in mental health in the Highlands in which HUG wants to see developments and will be used by HUG when talking about the ways in which present services could be enhanced.

For a better picture of how HUG wants to see services develop we would recommend that this report is read in conjunction with the reports that it has produced so far. These are:

1. Closure of Craig Dunain
2. Medication
3. Suicide
4. Employment
5. Ward Rounds
6. Crisis Services
7. Quality

In the areas in which HUG has branches, a list of the priorities for future development has been created. This is included in the Appendix.

For people who want to find out what has been said in particular areas of the Highlands, there are separate smaller reports available for:

- Caithness
- East Sutherland
- East and West Ross
- Inverness
- Skye and Lochalsh
- Nairn
- Badenoch and Strathspey
- Lochaber

Any replies on the content of this document will be gratefully received. Please write to Graham Morgan at the HCCF offices at 1 Ardross Street, Inverness IV3 5NN with any comments you may have.

### PRIORITIES FOR FUTURE DEVELOPMENT

#### Caithness West -

- ◆ Local psychiatric beds.
- ◆ Housing.
- ◆ Crisis and out-of-hours service.
- ◆ Education and awareness raising about mental health, with information provision reducing fear.

#### Caithness East -

- ◆ 24 hour crisis service.
- ◆ Local hospital beds.
- ◆ Appropriate accommodation.
- ◆ Change attitudes and improve understanding so that mental illness becomes acceptable and easy to get help for.

#### East Sutherland -

- ◆ Mental health awareness raising and a reduction of stigma will lead to better services and a changed pattern of demand for services - probably an increased demand. This would lead to a need for more resources than exists already.
- ◆ Support services are needed.
- ◆ It is vital that existing services keep going.

#### Ross-shire -

- ◆ Concentrate on the needs and feelings of carers.
- ◆ Provide continuity of funding and resources to give security to service providers and users alike.
- ◆ Crisis services.
- ◆ No services should be re-allocated or cut unless provision for all users of that service has been made.
- ◆ Any service should ensure that it knows how satisfied users are with it, and no service should ever close without consultation with the users of that service.

#### West Ross -

- ◆ An information system based in GPs surgeries.
- ◆ Increased hours for the drop-in/outreach service.
- ◆ Combine relevant local services on one site.

- ◆ Improve the transport situation.

### **Inverness -**

- ◆ Change the attitude of some professionals.
- ◆ Reduce stigma about people with mental health problems and the services themselves. This should be done both within a mental health service context and also a wider public context.
- ◆ Provide out-of-hours and crisis services.

*(Note: There is further work being carried out on day services in Inverness at present which may result in additional priorities being created.)*

### **Craig Dunain Hospital, Inverness -**

- ◆ Access to services, especially crisis services.
- ◆ Help with understanding and coping with mental health problems to be started off in the first instance with a user friendly discharge from hospital information pack.
- ◆ Awareness raising and education of the public.
- ◆ More resources.
- ◆ Greater employment opportunities.

### **Skye and Lochalsh -**

- ◆ Employment.
- ◆ Crisis intervention.
- ◆ Housing.
- ◆ Changing attitudes to people with mental health problems.
- ◆ Rural weighting to services.
- ◆ Help with money and benefits.

### **Nairn -**

- ◆ Crisis contact.
- ◆ Drop-in Centre.
- ◆ Development of TAG Unit.
- ◆ Public talks and awareness raising.

*(Note: There is a recently established HUG Group in Nairn which could come up with its own priorities that are different to these.)*

### **Badenoch and Strathspey -**

- This group could not decide on priorities and instead settled for two statements:

- ◆ Are we to be viewed as worse than criminals. They seem to receive substantially more in the way of resources for rehabilitation and occupation than do people with mental health problems.
- ◆ We have become the work for highly paid professionals and yet we receive a minimal amount, and are consistently undervalued in the things that we can do as people.

**Lochaber -**

- ◆ Stigma and public awareness - if we can succeed in this then all other services will improve and change.
- ◆ Access to training and education.
- ◆ Transport.
- ◆ 24 hour helpline with access to services.

## **ACKNOWLEDGEMENTS**

**With thanks to all the members of HUG, and other mental health service users, who contributed to this report.**

For more information on HUG, or an information pack, call:

Graham Morgan  
Highland Users Group  
c/o Highland Community Care Forum  
1 Ardross Street  
Inverness  
IV3 5NN

Telephone: (01463) 718817