



HIGHLAND USERS GROUP

Current Issues in Mental Health in the Highlands

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Current Issues in Mental Health in the Highlands – May 2000

REASONS FOR PRODUCING THIS REPORT

Earlier this year we heard that the Scottish Health Advisory Service (SHAS) would be visiting the Highlands to look at the mental health services that people receive.

We felt that it would be very important that we gave as full a picture of services and life in the Highlands as possible. Therefore, we spent a part of each meeting of the Highland Users' Group looking at the services people receive and the sort of messages that people would like to pass on to the Scottish Health Advisory Service.

We spent the March meetings of 2000 in these discussions and involved 79 users of services from most areas of the Highlands.

The following represents the main points raised in these meetings which have been passed onto the Scottish Health Advisory Service team. In addition, SHAS asked us to discuss the issue of confidentiality of patients' case notes and to what extent this information should be shared amongst professionals, and this is also included in this report.

These views can also be used to represent an update on the response that HUG made to the Framework for Mental Health in 1998 and will be part of our working documents that we use to help represent the views of users of services in service planning and development.

WHAT IS HUG?

HUG is the Highland Users Group, a network of users of mental health services in the Highlands. Currently (May 2000), HUG has 13 branches across the Highlands with approximately 200 members.

At present (May 2000) HUG has 13 branches in:

- Caithness
- Sutherland
- Easter Ross
- Wester Ross
- Nairn
- Inverness
- Craig Dunain
- Lochaber

- Skye and Lochalsh

Our main aim is to improve the way in which we, as users of mental health services, are treated. HUG campaigns to improve the rights, services and treatments of people with mental health problems and strives to increase the communication between service users in the Highlands.

HUG works on a local, Highland and national level to influence policy and planning, and to encourage improvements in the management and delivery of mental health services.

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

HUG AIMS:

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

The Main Issues Affecting Users And Mental Health Services By Area

WESTER ROSS

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

- An information system based in GP's surgeries
- Increased hours for the drop-in/outreach service
- Combined relevant local services on one site
- Improve the transport situation

CURRENT ISSUES

- We need a base-line level of services to start with before we can even discuss the lack of facilities.
- There is no easy access to psychology services or Ross House. People have to travel to Inverness and this can be very traumatic if people are unwell and feeling vulnerable.
- We need effective use of modern Information Technology to link up to services in Inverness e.g. via video conferencing. This would also help us in self-help and in managing our illness and accessing information e.g. by utilising the Internet.
- There is little access to services locally.
- Transport is a persistent problem in rural areas.
- There is only one Community Psychiatric Nurse based in Wester Ross.
- The waiting time to see a psychiatrist is too long – one member was prescribed tranquillisers for three weeks whilst waiting for an appointment. We are forced to use our own resources to survive what, in our view, is an impending crisis.
- Doctors should acknowledge the limits of their expertise and know when to refer on.
- It feels like you have to have an absolute crisis before you can get help from services.
- It is very difficult to get help when you are ill and isolated. Often asking for help is very difficult due to your illness. It may be useful for some people to have someone who will keep an eye on you and check you are OK, in an unintrusive way.

CONFIDENTIALITY

Confidentiality – it can be very difficult to keep things hidden in small rural communities. The stress of trying to stop people from finding out can be very great.

The group felt that professionals should have access to information about you. However, concern was raised over who is actually part of the Community Mental Health Team. How far can the team be extended? Where do you put a limit on the team? **The most important thing is that your permission is asked first.**

Medical and health professionals often refuse to give information to carers as they say this is a breach of confidentiality. How do you decide what information should be passed on to carers? Probably only information that it would be essential for them to know.

This leads us on to the support for advanced directives (see the HUG report on the Mental Health Act – November 1999).

The Main Issues Affecting Users And Mental Health Services By Area

SKYE AND LOCHALSH

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

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

CURRENT ISSUES

- There is no place of safety or respite on Skye. Sometimes people have to go to the police station in crisis, as this can be the only safe option due to the state they have got into.
- A temporary place of safety, supported accommodation and local acute beds would be very valuable. The trip to Craig Dunain can be extremely traumatic.
- Some people need to get away from their community when they are ill and would prefer to go to Inverness. Others, however, prefer to stay in their local areas. It is vital that people have both options.
- Crisis services are vital to people with mental illnesses. (See Crisis Services Report – August 1997)
- People are often very isolated, both geographically and within the community, due to stigma and/or discrimination.
- The local hospitals and GP's are becoming more responsive to the needs of people with mental health problems, but there is still room for improvement.
- Intervention and support are needed before we reach a crisis situation.
- We need better access to psychology services.
- Video conferencing has been useful for some people in remote areas who have little access to psychology services. This could be expanded upon where appropriate.
- The police can be very good in an emergency and seem to be amongst the most responsive of the professionals.

- Stigma and attitudes to mental health need to be tackled on a national level e.g. a government supported education programme starting at primary school age. In the words of one member this would be '*a dream come true*'.
- People with alcohol and mental health illnesses are often not listened to and need real access to help and advocacy.
- People with alcohol dependency, mental health problems and/or learning disabilities do not seem to fit into any of the services - there is a feeling that you are passed from 'pillar to post' and no one service will take responsibility for you.

CONFIDENTIALITY

One member felt that mental illness is not something you can keep secret. It was felt that if people know about your illness they can help, especially when you know the health and care professionals are working for your benefit. In this situation they should have access to that information.

However, when people feel that this is not the case and/or the user and professional do not have a strong relationship, this can cause difficulties. In addition, conflicts of interests and disagreements *between* professionals in the team can lead to problems.

The Main Issues Affecting Users And Mental Health Services By Area

LOCHABER

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

- 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

CURRENT ISSUES

- There can be specific issues and problems of having a dual diagnosis such as a mental health problem and another disability e.g. learning difficulty and/or physical disability.
- The Mental Illness Specific Grant has been at a standstill budget for the past five years. In real terms this is actually a cut in budget due to inflation.
- Mental health workers in the non-statutory sector are providing a service in increasingly difficult circumstances as a result of funding difficulties.
- If someone is feeling temporarily ill, they should have the opportunity of access to local psychiatric beds. However, if they are very ill they may prefer to go to specialist facilities out of the local community i.e. Craig Dunain.
- It can be very frightening knowing you are getting ill and are not able to get immediate help and support - it is not good having to wait for days or even weeks for professional support.
- People need more access to psychiatric support.
- There is a particular problem in rural areas when the psychiatrist or other professionals are generally confined to a fixed pattern of often widely spaced appointments, which are difficult to change in frequency due to the transport and resource problems.

The Main Issues Affecting Users And Mental Health Services By Area

GARBHEIN HOUSE (SUPPORTED ACCOMMODATION), FORT WILLIAM

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) for the Lochaber area were:

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

CURRENT ISSUES

- There is need for a Community Psychiatric Nurse to be on call out-of-hours and the necessity for resources to be found to support this. At the moment the Community Mental Health Team only works 9am - 5pm. If you are not in Garbhein House you do not even have a support worker out-of-hours.
- Access to beds in the Belford hospital is vital - at the moment it is very difficult to get this access. There seems to be an unwillingness to deal with people with psychiatric illnesses, although this has been improving recently.
- A place of safety - we must have an alternative to the police station, as this is a totally inappropriate place to go if people are ill (which occasionally happens). It is *'very undignified'* in the words of one member.
- Garbhein House is likely to get more tenants - this is a positive development.
- Being on a section whilst in the community is very hard. People are often very unclear about their rights.
- The attitude of the police in the area is generally very good - we feel it is better than in the cities.
- Being in prison can be bad for your mental health - if you are already ill it can be very distressing. Alternately being in prison can lead to a mental health problem.
- In the Care Programme Approach there is a feeling that people do not always have a choice. We understand that it is optional whether to join the Care Programme Approach. If you were on a section would you have this choice?

- Mental illness and the link with criminality are commonly misleading and misrepresented.
- Homelessness is a big problem, especially for young people with mental health problems. There is not enough housing support/provision on discharge from hospital.
- In Craig Dunain appointments with psychiatrists, even when an in-patient, can be very infrequent.
- We need clear explanations and information about rights, treatments and services in an understandable format, in both verbal and written explanations. We may need this information given to us again/later when we are better able to take it in, particularly if we have been ill.
- It is important to find a doctor that suits you i.e. that you trust and feel comfortable with, especially as it can take a long time to be referred to specialist help.
- It is important to challenge stigma and discrimination.
- Sufficient resources are fundamental to effective mental health service provisions.

CONFIDENTIALLY

The group felt that some things should be kept confidential and not passed onto *all* professionals within the Community Mental Health Team.

It is too easy to break confidentiality within a small community. The key thing is that we should always have knowledge of this and that our permission is sought. We should have the right to determine who has access to our information. Are notes from hospital passed on to our GP's, or just reports?

The Main Issues Affecting Users And Mental Health Services By Area

INVERNESS

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

- Changing 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-hour services

CURRENT ISSUES

- Crisis services are needed. The out-of-hours CPN service is being re-established in a new form and this is very welcome news, but it needs to be extended to 24-hour coverage.
- The TAG unit is under-funded, yet is an excellent facility and very much valued by users and would benefit greatly from an appropriate level of core funding.
- The new unit looks good, but one member thinks it is very big and 'institutional'.
- People have a choice of mental health services in Inverness, but not in all parts of the Highlands (services are unevenly distributed).
- People very often have to 'qualify' for access to services i.e. there is a 'gate-keeping' system. Members felt that they should be able to access services more easily, prior to reaching a crisis situation.
- There is no 'place of safety' or a refuge and this could be very valuable.
- There is doubt that current services are 'seamless'.
- Information provision needs to be made more appropriate to the individual person.
- Discharge information from Craig Dunain does not include information on drop-in centres.
- Cairdeas Cottage is very well regarded, but far too small.
- It was felt that everyone should have a discharge plan or be offered access to the Care Programme Approach after admission to hospital:
 - People's experiences on discharge were variable depending on staff
 - People need more information on rights e.g. housing

People have to wait a few hours for a prescription following discharge from hospital – this can be very undignified

- GP services are very variable in Inverness.
- Has the voice of HUG been listened to? Yes, however, we need more publicity material to let people know about HUG.
- Is the individual listened to? It depends on how receptive individual health care professionals are.
- Doctors, nurses and psychiatrists should have continuous on-going training to ensure they are up-to-date and responsive to the needs of people with mental health problems. It was felt that they should be accountable in some way to their patients.

CONFIDENTIALITY

Our permission should be asked and only appropriate information should be passed on. In some circumstances this could be over-ruled if we are a danger to others or ourselves.

The Main Issues Affecting Users And Mental Health Services By Area

CRAIG DUNAIN HOSPITAL, INVERNESS

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

- 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 information pack following discharge from hospital
- Awareness raising and education of the general public
- More resources
- Greater employment opportunities

CURRENT ISSUES

- One 'long-term' patient would prefer to be in the community.
- There was a feeling that some of the staff just *'give up on you'* after a while. There is the feeling that prolonged admission equals failure.
- The food at Craig Dunain was felt by some people to be very poor, with small portions and bad quality. Some people, however, think the food is good.
- The attitude of some staff towards the patients is not always very positive and members felt they were often 'fobbed off' with excuses.
- There is a conflict between the threat of being sectioned versus wanting to be kept safe (because people feel suicidal). How do you ensure an acceptable balance?
- Patients would like a 'snoozelum' room to relax, 'chill-out'.
- Although information is being given out about the new unit, some people do not feel this is adequate.
- The Citizens Advice Bureau Advocacy Project is a good service, but can be very hard to access.
- It is felt that people would not conform to the smoking policy in the new unit.

The Main Issues Affecting Users And Mental Health Services By Area

NAIRN

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

- Crisis contact
- Drop-in centre
- Development of TAG Unit
- Public talks and awareness raising

CURRENT ISSUES

- The Nairn Community Mental Health Team is very much appreciated and many people felt that it should stay independent and not be linked to the team in Inverness.
- Interviews for benefits can be very frightening and threatening. The benefits staff has little knowledge of mental health issues. You can actually become worse after an interview with the Benefits Agency.
- It is important that people have access to a drop-in centre like Cairdeas Cottage.
- The Nairn Community Centre (now based in the Nairn Town and County Hospital) is only open a few days per week for mental health support. Members feel they need at least 5 days per week, including evenings.
- Smoking policies - these need to be realistic or people might stop attending the facilities.
- Dieticians are very important as psychiatric drugs can lead to weight gain.
- Equity - will services be equalising up or down? There is a great concern that they will go down and so reduce the frequency and choice of services.
- We need three levels of provision - day hospital, Community Mental Health Team and a drop-in centre, which would be for anyone to access whenever they wish.
- Public transport - some people can't use public transport if they are too ill to face people or can't walk distances to access the transport. One member was paying about £12 per week on taxi fares to get to the community centre.

The Main Issues Affecting Users And Mental Health Services By Area

EASTER-ROSS

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

- Concentration 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 good 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 users of that service

CURRENT ISSUES

ALNESS

- It was felt that some staff in social work are perceived as not being so good with parents who have mental health problems. It was felt that some social workers tended to discriminate against parents because they have mental health problems and regarded them as a threat to their children.
- The needs of parents with mental health problems needs to be addressed. For instance, some parents feel they cannot access mental health services for fear of the consequences to their children.
- There was great concern over the fact that the Mental Illness Specific Grant is frozen once again.
- The attitude of some professionals who come in contact with us (e.g. police, doctors) raised concerns; they need to know how to respond more appropriately.
- Disabled access to all buildings providing a service is essential and does not exist yet.
- When are we getting a 24-hour crisis line for mental health? This phone-line could then be linked to specialist places such as the Samaritans, hospital or a 'buddy scheme'.
- Drop-in centres are vital places and Campanas is a good place to go to.

- There is not enough or appropriate information available on mental health issues; information needs to be more balanced.
- Upon discharge from hospital, people are not always fully ready or prepared to leave. These concerns need to be listened to and acknowledged by staff.

CONFIDENTIALITY

- It was felt that there is no such thing as confidentiality within a small community as information 'travels'.
- It is vital that team members ask our permission first if they wish to divulge information.
- Confidentiality can work against you in some circumstances e.g. if key people cannot discuss your case with all relevant people you can 'drop through the system'.
- What about the idea of advanced directives?
- Confidentiality could be appropriately broken if you are a danger to yourself or others.

The group acknowledged that different people can have different perceptions of what 'confidentiality' actually is and that it is important to establish boundaries between personal and general information.

The Main Issues Affecting Users And Mental Health Services By Area

EASTER-ROSS

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INVERGORDON

CURRENT ISSUES

- Employment issues were repeatedly raised and were clearly a concern for members:
 - i. People with mental health problems have major barriers to accessing employment – one HUG member said 'I need something real'
 - ii. Employers need to address the issue of mental health in the workplace
 - iii. People with mental health problems often end up in menial jobs
- Training and Guidance Unit (TAG):
 - i. More money for TAG is greatly needed – people find it an excellent service.
 - ii. The TAG unit is more than a training facility – it also helps build up your confidence and ability/chances of social interaction.
 - iii. The therapeutic benefit of TAG needs to be recognised.
 - iv. People find the training at TAG very valuable and find it difficult if have to move on.
 - v. There can be great frustration when TAG helps build up your confidence, which is then knocked back badly when you can't get a job.
- The group would like the chance to visit drop-ins and other services.

- Drop-in centres have a therapeutic value and are very important.
- In rural areas the cost of living is more than in cities e.g. bus fares.
- Subsidised bus fare – the travel pass should be easier to access as public transport is the most frequently used form of transport for HUG members and can give access to therapeutic activities.
- If people are on benefits, it is almost impossible to access 'semi-therapeutic' activities such as the gym and other leisure facilities due to the cost.
- There is often a long-time delay before people are told about services e.g. one member was ill for two years before being told that support was available.
- There is need for more preventative/intermediary support. It seems we only have access to help when have a severe and enduring illness.
- It can feel like 'pot-luck' with doctors; some are very good, others are not interested.
- Discrimination can be on the grounds of ethnic origin, mental health and physical disability. Members have experienced combinations of these.
- Highland Health Board, Highland Council and the NHS Trust should have clear and accessible guidelines on mental health policies and tackling discrimination.
- It can be very stressful if you are a parent with a mental health problem.

CONFIDENTIALITY

The group felt that as long as we know and our permission has been sought information can be shared. However, discretion needs to be used; if agencies are working with your best interests at heart it is OK, but what happens if they are not?

The Main Issues Affecting Users And Mental Health Services By Area

EASTER-ROSS

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

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- 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 good 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 users of that service

CATALINA HOUSE, ALNESS

CURRENT ISSUES

- Accessing employment opportunities and voluntary placements can be difficult.
- The issue of discrimination and employment was raised, for example, when job application forms ask for details of mental health problems but with no opportunity to explain or qualify the answer (as you would usually have for explaining any physical disability).
- Therapeutic earnings are a very valuable idea, but people find it very hard to find out about them and very few people are on them.

The Main Issues Affecting Users And Mental Health Services By Area

EAST SUTHERLAND

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

- Mental health awareness training 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 exist already
- Support services are needed and it is vital that existing services keep going

CURRENT ISSUES

- Respite facilities vitally important, and planned respite should not be broken.
- The benefits system is unclear and confusing for many people. Changes in a person's circumstances, such as admission to hospital, can result in a disruption to benefits payments. This does not help people with their mental health.
- There appears to be a lack of communication between agencies e.g. benefits and hospital.
- Support is needed to build confidence during recovery. The first steps are the most difficult and people need help to keep going.
- Crisis services and out-of-hour provision are vital.
- Community Psychiatric Nurses have very high workloads and community care resources are very scarce. They often come when we are feeling OK and not when we really need help.
- The vastness of the area means there are only a small number of services available e.g. you cannot always see the Community Psychiatric Nurse as often as you need.
- People with mental health problems can also be carers – it can be very difficult to stay well due to this added burden and pressure.

CONFIDENTIALITY

Confidentiality – in small communities situations can develop in which a professional could be providing support to people from the same family.

The Main Issues Affecting Users And Mental Health Services By Area

WICK

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

- 24-hour crisis service and local hospital beds
- Appropriate accommodation, including supported accommodation
- Changing attitudes and improving understanding so that mental illness becomes acceptable and easy to get help for

CURRENT ISSUES

- There are some good things happening at the moment: The Good Companion Scheme, the Media Group and the 'Talking Groat'.
- The Good Companion Scheme (accompanying people from Craig Dunain back to Caithness) is developing well and has about six volunteers already.
- The Media Group is being led by a HUG member in Caithness and has successfully co-ordinated a radio interview and is working on a feature article in the local paper.
- The 'Talking Groat' is of great benefit to people who have sight impairments and/or difficulty reading due to the effects of their medication.
- There is great concern that funding for the voluntary sector is being reduced.
- Drop-in centres are very important; one HUG member said drop-ins are a '*life saver*'.
- It can be difficult to get complaints acted upon; complaints are listened to but it often feels as though nothing is done.
- Ward 4 can be a terrible place to be in for some people; in the words of one member, '*it was soul destroying*'. However, it has improved greatly in recent months.
- It can be very difficult to re-integrate into the community after being in hospital.
- On the Care Programme Approach (CPA) it can be very intimidating to be in a room with so many professionals discussing your welfare. However, having all professionals together can denote respect for the user.
- In the Care Programme Approach there seems to be a lack of understandable information in a format that is accessible and comprehensible to users.
- There is some concern that on the Care Programme Approach the police may have your name on a database. How can we be assured that this information/knowledge will always be used with our best interests at heart?

The Main Issues Affecting Users And Mental Health Services By Area

THURSO

The priorities identified from the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) were:

- Local psychiatric beds
- Housing (the availability of supported accommodation)
- Crisis and out-of-hour services
- Education and awareness raising about mental health, with information provision reducing fear

CURRENT ISSUES

- **Self-help groups are very important as we can learn from each other by sharing experiences.**
 - **Drop-in centres can act as a place of sanctuary.**
- **Mental health illnesses can draw people together – do people with experiences of mental illness have a distinct culture?**
- The need for local respite is very important.
- After leaving hospital people need more help to assist them in re-integrating into the community.
- Transport problems and the isolation in rural communities can make people ill again.
- There is a need for supported accommodation; people have had to leave Thurso because this does not exist at the moment.

CONFIDENTIALITY

The group agreed with the principle of an integrated information system within the community mental health team, but with some reservations. To break confidentiality can be very traumatic and destroy any trust that is built up, yet sometimes it is necessary if we are in danger of hurting others or ourselves.

FINAL THOUGHTS

The issues presented at the various HUG groups in April 2000 represent a snapshot into the current issues affecting users in those areas.

Snapshots can change over weeks and days and even hours, but are none-the-less important in that they raise areas of concern.

This report is intended to act as a reference document for the current work of HUG in the Highlands. It has already been used to inform the Scottish Health Advisory Service visit in April 2000 and we hope it will be used to inform the Framework for Mental Health, Community Care Plan and other relevant policy documents.

It should be read in conjunction with the HUG report 'A Mental Health Strategy for the Highlands' (September 1998) as well as the other HUG reports, which are:

- ❖ Closure of Craig Dunain
- ❖ Medication
- ❖ Suicide
- ❖ Employment
- ❖ Ward Rounds
- ❖ Crisis Services
- ❖ Quality
- ❖ A Mental Health Strategy for the Highlands
- ❖ Rural Mental Health in the Highlands
- ❖ Housing
- ❖ The Mental Health Act

These are available free for people in the Highlands and at a cost of £2 each for people outside the area.

ACKNOWLEDGEMENTS

With thanks to all the members of HUG
who contributed to this report.

For more information on HUG, or an information pack, please contact:

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