

HIGHLAND USERS GROUP

**THE
MENTAL HEALTH ACT**

**A response by the Highland Users Group to the review of the
1984 Mental Health Act (Scotland)**

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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 (October 99) HUG has 185 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.

CONTENTS

1. WHY LOOK AT THE 1984 MENTAL HEALTH ACT SCOTLAND.....	4
2. THE KEY PRINCIPLES OF A MENTAL HEALTH ACT	5
2.1 WHO IT SHOULD CONCERN.....	5
2.2 EQUALITY.....	5
2.3 RESPONSIBILITY	5
2.4 REGAINING RESPONSIBILITY.....	6
2.5 DIFFERENCE.....	6
3. IS THE DETENTION AND TREATMENT OF SOMEONE WHO IS MENTALLY ILL JUSTIFIED	6
4. BEING SECTIONED – WHAT IS IT LIKE.....	7
4.1 THE GOOD SIDE.....	7
4.2 THE BAD SIDE.....	7
4.3 BEING ABLE TO MAKE INFORMED DECISIONS	8
4.4 WHERE SHOULD SOMEONE BE DETAINED OR TREATED. IS THE COMMUNITY AN OPTION	9
4.5 SHOULD IT BE POSSIBLE TO REFUSE TREATMENT WHEN ON A SECTION	10
4.6 SHOULD IT BE POSSIBLE TO FORCE PEOPLE TO TAKE THEIR MEDICATION WHILE IN THE COMMUNITY.....	10
4.7 SHOULD A PERSON BE TREATABLE IF THEY ARE TO BE DETAINED UNDER THE MENTAL HEALTH ACT	11
4.8 PEOPLE WITH A PERSONALITY DISORDER.....	11
4.9 THE USE OF THE COURTS FOR SECTIONS AND APPEALS	12
4.10 THE TREATMENT OF OFFENDERS	13
4.11 PRISON	13
4.12 THE POLICE.....	14
4.13 HARASSMENT AND DISCRIMINATION	14
4.14 THE MENTAL WELFARE COMMISSION.....	15
4.15 ADVOCACY.....	15
4.16 THE ROLE OF CARERS	15
4.17 CARERS AND CONFIDENTIAL INFORMATION.....	16
4.18 CARERS AND CONSENT TO A SECTION.....	16
4.19 THE MENTAL HEALTH ACT AND VOLUNTARY PATIENTS	16
4.20 RIGHTS TO SERVICES.....	17
4.21 WHO THE MENTAL HEALTH ACT SHOULD APPLY TO.....	17
4.22 SHOULD THERE BE SPECIAL PROVISION FOR PEOPLE FROM ANY ‘MINORITY GROUPS’	18
4.23 IMPROVING THE PROCESS.....	18
4.24 HEALTH PREVENTION AND PROMOTION	19
4.25 SEGREGATION AND INTEGRATION.....	19
4.26 EMPLOYMENT	19
4.27 LISTENING TO USERS.....	19
4.28 BEING TOGETHER.....	20
4.29 MAKING CONTACT.....	20
4.30 MAKING THE SECTIONING PROCESS EASIER.....	20
4.31 ADVANCE DIRECTIVES	21
4.32 RURAL AREAS	22
4.33 ACCOUNTABILITY.....	22
ACKNOWLEDGEMENTS.....	23

1. WHY LOOK AT THE 1984 MENTAL HEALTH ACT SCOTLAND?

Many members of HUG have experienced compulsory detention or the effects of the possibility of being detained. For some members being 'sectioned' is a common experience and a major part of their life, whilst for other people their main experience has been to witness the effect of sectioning on their friends or relatives and of being aware that the Mental Health Act could possibly be used on them.

With this perspective the convening of the Milan Committee in 1999 to review the 1984 act gave us an opportunity to examine our views in more detail.

We held a series of meetings in the 12 HUG branches in May 1999. These meetings were facilitated by the advocacy development worker and a HUG member on work placement with him. A total of 67 people participated in the discussions.

This series of meetings was different to the normal round of discussions that we are used to. They were difficult, taxing, sometimes emotional, certainly confusing and often very long. We looked at our own experiences and practicalities that would improve the sectioning process. For much of the meeting we were looking at core principles which took us into aspects of morality, ethics and philosophy that were sometimes exciting but, on other occasions, were not only bewildering but brought us into areas where we could not always find satisfactory answers to the ideas that we were discussing.

In a round of HUG meetings it is very common for a strand of ideas to begin to emerge. These are elaborated on at each meeting and as the meetings develop for a great deal of agreement to emerge amongst members. This did happen but equally there were differences that we had to accept as irreconcilable even when politely expressed. For some people the very idea of being sectioned is abhorrent whilst other people have found being sectioned to be literally life saving.

In this report we will try to express views that contradict each other as a way of giving voice to the range of views of HUG members. We also recognise that with issues as complex as these that our ideas may change over time and with further discussion.

In our discussions we inevitably covered areas which may be covered by other pieces of legislation, for instance, ideas of people's capacity to make decisions or the ways in which people with personality disorders should be treated and in addition areas where we think there should be legislation which at present doesn't exist. These are all included in this report.

2. THE KEY PRINCIPLES OF A MENTAL HEALTH ACT

2.1. WHOM IT SHOULD CONCERN

People directly affected by mental illness, especially users, should be at the centre of any new legislation and this legislation should be designed to help them and to improve the quality of their lives.

As far as possible any changes to the act whilst acknowledging that here are some key principles that apply to everyone, should be flexible enough to be appropriate for a wide range of individuals from different backgrounds and cultures. It should cater for and acknowledge difference as well as making general statements.

Changes to legislation should reflect the changing circumstances of people affected by mental illness and try to avoid media and public views that are based more on prejudice than the realities of peoples lives.

2.2. EQUALITY

Many people with a mental illness can, as a result of their illness and the attitudes of the public and media, live their life on the margins of society. They may be segregated from other people. People may be suspicious of them and feel that they can treat them in ways that they would not treat other people.

HUG wishes that people with a mental illness have the same rights and opportunities as other people and that they can become full citizens of the society of which they are a part.

There should be a set of basic civil rights that apply to all members of society. It should mean that discrimination whatever the person's illness disability, gender or race is not permitted to happen.

People with a mental illness have a multitude of talents and experiences, which can become hard to use once they become ill. They should have the opportunity to use them.

2.3. RESPONSIBILITY

Many people, (including those with a mental illness) can for a time find it hard to exercise responsibility. When people can no longer cope they should be able to relinquish control and expect society to care for and look after them without judgement. In some cases society should assume responsibility when a person cannot look after him or herself or is a danger to others.

There is often an assumption that rights and responsibility are inextricably linked. However, as few rights should be lost as is possible when an individual puts themselves, or is placed, in the care of the state.

Whilst members of HUG do not want people to have special rights because of mental illness they do want an acknowledgement of some of the situations that people may find themselves in:

“The actions of some people with a mental illness can infringe the rights and wishes of other people. There needs to be a degree of tolerance for this where these actions are not completely within the control of the person.”

2.4. REGAINING RESPONSIBILITY

Most people who go through a time of not coping will recover and find that they want to resume the lives they ‘left’ or to stop feeling dependant. They should be helped to achieve this. There is a feeling that for many people with a mental illness that they are helped to function but not given the opportunity or means to regain or achieve their full potential as they recover from mental illness.

2.5. DIFFERENCE

Society needs to acknowledge ‘*difference*’. It needs to acknowledge that diverse and unconventional lifestyles or beliefs are not necessarily wrong.

3. IS THE DETENTION AND TREATMENT OF SOMEONE WHO IS MENTALLY ILL JUSTIFIED?

The majority view on this is that if someone is mentally ill and has become a danger to themselves or other people then it is justified to both detain them and to treat them for their illness even if this is against their will:

‘Sectioning is not justified if it is used as a way of controlling or removing from society people who are different. It is justified if it is used to protect and keep people safe.’

There were two other views expressed:

If we can justify detaining someone who is mentally ill because they are almost certainly going to harm themselves or other people then we should be able to do the same thing to anyone else in a similar situation. The key thing that is being sought is the safety of the person and other people. It is the action that is about to be carried out that is important not necessarily the fact that someone is mentally ill.

The other view was that it is very wrong and very arrogant for a person or a society to decide what is in someone’s best interest. That to force someone to do something against their will or to lock them up and detain them is immoral. No person should be able to sit in judgement of another person in this way.

4. BEING SECTIONED – WHAT IS IT LIKE?

4.1. THE GOOD SIDE.

Some people have, in retrospect, greatly welcomed being sectioned and believe that the fact that they are still alive is because of this.

“People may get worse and worse with their illness and may not know that they are ill or be able to ask for help. When help finally arrives and the right medication and support is given people may find a way out of their illness.”

Some people have seen sectioning, sometimes even at the time, as a way of getting to a place of safety and security that they couldn't themselves access and felt relief that they were being sectioned.

Some people have said that the main benefit of being sectioned has been to provide relief from the trauma that their illness was putting friends and family through.

4.2. THE BAD SIDE.

The very act of being forced into a situation you don't want to be in (often when you can see no reason for it) can be one of huge trauma.

People can feel betrayed, abandoned, angry, despairing and confused.

The process can appear to consist of being locked up and 'drugged up' without anyone explaining anything:

“Its awful, you don't know what you've done or why you are there, the way that you are cared for is not the way forward.”

Some of the attitudes are still:

“Never mind all these questions you are just here to get better”.

This can cause people to lose hope and belief in themselves, it can make them lose all trust in the professionals caring for them and mean that they stop co-operating with treatment.

For some people the fact that they have been sectioned can mean that they become even more ill despite having treatment given to them.

The whole process of being sectioned can polarize attitudes in an already fraught situation and lead to a, them and us feeling. Because control has been taken, staff can be seen as enemies who are coercive and authoritarian and they may actually conform to these perceptions which only serves to aggravate the situation.

Some members of HUG said that once someone has been sectioned it is more likely for them to be sectioned again in the future in situations where other people might not be. This can also lead to further hostility.

Being in hospital, which would ideally be a place of sanctuary and treatment, can also come to symbolise a new phase in someone's life in which assumptions about a persons capabilities and status change. Hospital can come to be a place where people find themselves:

"...Going in circles with no way back to the life that you've come from."

"You can never get rid of what has happened and there is always the fear that you will go off the rails again.... Hospital can be hard to cope with. It can in itself be damaging... there should be alternatives to it."

The attitudes of people around a patient can just reinforce feelings of negativity:

"Everybody, by the fact that they are human, possesses dignity. There is a judgement that for a person with a mental illness their quality of life is inferior to others and that this justifies paternalistic attitudes and manipulation."

4.3. BEING ABLE TO MAKE INFORMED DECISIONS

One of the key factors which justifies detention and treatment against someone's will is the fact that when a person is in that state and is ill they are not always able to make decisions and choices about life that accord with their normal beliefs and wishes.

Members of HUG have recounted actions that they have carried out when ill that they deeply regret doing and say that they would have preferred intervention rather than being left to themselves. For some people the right to treatment outweighs the civil liberties issues of being left to pursue their own course. In fact being treated and being brought back to their familiar reality can sometimes be more in tune with someone's civil rights than being left to their own devices when ill.

However mental illness and psychosis do not often mean that a person has lost all capacity to make decisions even if sectioned.

Members of HUG were very familiar with situations where, for instance, delusions such as having a belief in having their thoughts read or of feeling completely worthless had a huge influence on their lives whilst at the same time they could make everyday ordinary decisions on a multitude of issues.

How a person could work out what parts of someone's beliefs and wishes were in accord with what they would ordinarily want was a mystery to members of HUG and yet very important. If a way could be found to discover what someone would want when ill, but cannot express or be believed because of their illness, then treatment would be much more in tune with an individuals needs and wishes.

Some suggestions were however made:

1. Do not assume that seemingly irrational, destructive or strange decisions are always a result of illness.
2. In many cases good common sense will tell people that the views being expressed by someone are more a function of illness than anything else.
3. Finding out the views of people who know a person well such as carers, friends, relatives and professionals is often a very good way of insuring that a persons 'previous' views are respected.
4. The use of advance directives (see 21) could ensure that, as far as possible, the views of people who have been sectioned or lost some of the ability to make informed choices is respected.

4.4. WHERE SHOULD SOMEONE BE DETAINED OR TREATED? IS THE COMMUNITY AN OPTION?

For the vast majority of people the point at which they may be sectioned is often the point where they have lost huge parts of their ability to function with any sense of confidence or safety in the community.

In this situation the majority of people need and sometimes want a place of security, safety and comfort where they can be sure of treatment and asylum. Hospital remains the place that most people see as being able to provide this and any other alternative would be greeted with great concern.

There was also the thought that, if someone can function in the community, albeit with support, then they are 'rational' enough to make their own decisions about what happens to them and probably well enough for any use of the Mental Health Act to be more of a means of control than as a means of providing assistance.

However there were people whose experiences provided evidence to the contrary:

People who are on long term sections but have become a great deal better can find being in the community a much more pleasant option than staying in hospital (although for some there is an ever present fear of being 'lifted').

The section can also provide a feeling of security. Some people have described being released from a 'Section 18' after being in the community for a long time and having some feelings of regret that this has happened even though they resisted the section itself.

A section in the community can be seen as some sort of half way house between hospital and the community.

For some people the process of being sectioned and returning to hospital can become extremely frequent, so much so that the hospital, instead of being seen as a temporary asylum, comes to be a refuge to be sought whenever life goes wrong. It can become some peoples focus instead of the

community. For these people (if properly done) the use of intensive support possibly accompanied by some form of community section could act as the point at which a cycle of admission is broken.

One of the HUG branches is based in a nursing home. Residents found it to be very much better than hospital. It was relatively small, homely and there was an attitude that everyone was *'in it together'*. Such facilities were seen as, in most cases, being very good alternatives to hospital when a stay is likely to be long term.

However the option of treatment in the community, whilst it may give rise to greater freedom, is not always easy:

'Life itself is risky. We act in different ways in different environments and with different illnesses. There are no set answers. To cope in the community can be very good but can also be as hard as coping in hospital.'

"Being in Craig Dunain and under a section can be terrifying. It can wreck your life and make you lose confidence in everything. Although being sectioned {in the community} would also be unpleasant, at least you are in your environment, around those that you trust and are still doing ordinary things. It could be a lot better than hospital."

4.5. SHOULD IT BE POSSIBLE TO REFUSE TREATMENT WHEN ON A SECTION?

Almost invariably, the answer to this question was that, whatever its rights or wrongs and whether or not it is effective, people should be able to refuse electro convulsive therapy. However there were some people who thought that as a last resort it may be justified despite a lack of consent.

Generally the use of advance directives should be a way of providing an answer to this question.

When someone has first been admitted they should not be treated against their will, if on a 72 hour section, because they have no right of appeal to it . It would be too cumbersome to provide a mechanism that allowed the right to appeal to a 72 hour section.

There was also a view expressed that if a decision is made to start a course of treatment against someone's will then there should always be a second opinion to confirm that this is appropriate.

Even if it is possible to impose treatment the patient should always have the process explained and be given the chance to have their point of view taken seriously.

4.6. SHOULD IT BE POSSIBLE TO FORCE PEOPLE TO TAKE THEIR MEDICATION WHILE IN THE COMMUNITY?

There is the thought that taking medication would stop many people relapsing but it should be remembered (see the HUG report on medication) that people rarely stop taking their medication without a reason.

There are conflicting views here, for some people, being forced to take medication would stop them co-operating and would be felt by them, and those around them, to be an infringement of their rights.

Other people, especially those who have gone manic and then stopped their drugs, have wished that there could have been some way of intervening to stop the damage that was occurring to them and around them. This intervention would often be one that requires them to take their medication.

Again the use of advance directives was mentioned here.

4.7. SHOULD A PERSON BE TREATABLE IF THEY ARE TO BE DETAINED UNDER THE MENTAL HEALTH ACT?

In mental health the concept of treatment is both fluid and elastic. The idea of a cure is for many people very far off, in fact, for a large number of people just being able to cope is a great advance in treatment.

Treatment may mean being able to be persuaded to drink a cup of tea or to be able to get out of bed or to go for a walk. The concepts of getting better are diffuse and intangible for many people.

When people are told that there is nothing that can be done for them it is often seen as the final insult in a series of distressing encounters.

Some people who are judged untreatable can be at some of the extremes of self harm and disarray. It may well be true that they will not get better but once help is withdrawn then it can be likely that they will get 'worse.' For some people prison or becoming homeless becomes a very real possibility when they are given up on by the people and services around them.

"The implication that someone is untreatable is that there is nothing that we can do. We need a change of vocabulary. It is a negative term that is not relevant to our lives. No one can guarantee what will happen to people. If someone is not likely to get better we should look not at failure but at what can be done to make life as good as possible.

It would be interesting to compare the philosophies of the Mental Health Services with those of services providing palliative care or of the hospice movement: respect for the individual; providing a good environment and looking to a life that is as good as possible are paramount. Whilst elements of this can be seen with people who are deeply damaged by mental illness other elements can be seen to be lacking - not getting better is not in itself a reason to give up on someone.

4.8. PEOPLE WITH A PERSONALITY DISORDER.

Many people have been diagnosed as having a personality disorder. Some are a danger to other people but many are no threat to others and experience lives of great distress. HUG believes that there should be greatly increased research into helping such people and that they should at least be given the dignity of treatment even if it is only aimed at showing that there is some care around them.

In the words of one of the HUG branches:

“These people are written off for life. The stigma could not be worse. The attitude is, that’s you for life, don’t ask for any help or expect any improvement.”

There should be an acknowledgement that constantly reinforcing the alienation and exclusion of some people who have a personality disorder only serves to reinforce the ‘antisocial’ behaviour that they may have. All people, including people with a personality disorder, need to see the possibility of a way out and to have hope.

For those that are a very real danger to other people or themselves, it is important that they have some sanctuary. They have not chosen the feelings and thoughts that they hold and yet it is said that they cannot be treated.

A place of sanctuary was suggested as a far more humane option than prison or the streets and hospital was seen as inappropriate if they cannot receive medical treatment.

However building new places to house people with personality disorders who present a very real threat to themselves or others, could further ‘demonise’ this group of people. If there is no cure, then many people could expect to spend their lives in such places. Having gone far along the road of removing the stigma of the present Victorian institutions that still exist, any new facilities for people with personality disorders will quickly take on that image.

There was a view that there are some people with personality disorders who are very hard to associate with, they can be very anti-social and can be completely excluded from the communities that they live in because of their attitude and actions. The one thing that might help them would be friendship, trust and love and yet this is the one thing that they are unlikely to get.

Some members of HUG refused to talk about people with a personality disorder saying that they did not know anything about the lives of such people and did not want to be associated with them.

4.9. THE USE OF THE COURTS FOR SECTIONS AND APPEALS

Going to the courts was seen by most people as reinforcing feelings of wrong doing, a them and us atmosphere and a feeling of criminality.

This is reinforced by the everyday use of words such as being “let out on pass” or “parole” when in hospital .

The feeling of HUG is that the association between being detained because of illness and that of criminality should be avoided.

There were a number of suggestions:

- ◆ The justice system: this is the best place to be sure of a fair hearing. People should still have the opportunity to have their case heard in court but there needs to be a great deal of effort put into educating the public that the justice system is not always about wrong doing.

- ◆ A panel system. This could operate in a similar way to a children's panel. Efforts should be made to ensure that expert opinions from both points of view could be represented to a panel of lay people. The presence of a local mental welfare commissioner or an advocate would be a way of ensuring that the user's views are safeguarded.
- ◆ There was also a feeling that users were less likely to be listened to and respected in court than psychiatrists who will tend to obtain an immediate respect for their position and expertise that may be denied a patient.

4.10. THE TREATMENT OF OFFENDERS

People with a mental illness can commit offences just like other people and should experience the consequences of this. However offences can be committed purely as a result of a mental illness in which case the person needs treatment not punishment. There is also an in between area, where a person commits an offence and this is influenced by their illness, in which case what should happen is less clear.

In all these situations it was thought that the person's situation, circumstances and illness should be clearly understood before any action is taken.

This was illustrated by the example of a person with a mental illness who after months of harassment and persecution by the local community finally 'cracked' and committed criminal damage to property for which he was imprisoned. The opinion of members of HUG was that this was extremely unfair as anyone subjected to similar torment would be likely to act in that way.

4.11. PRISON

The use of prison to cope with people who committed crimes and were mentally ill gave rise to a number of views:

One view was that the existence of prison is an indication that society creates rules and regulations that people will inevitably break. People are not in themselves bad but they cannot always meet the expectations of society. Society's response is not to look at how to change things for the better but how to dispose of people who will break the status quo.

There was an equally strongly expressed view that those people who commit offences should be punished for them; that there are some fundamental barriers that no religion or society should permit; and those people that transgress should be punished and excluded.

People who are in prison and are mentally ill should be able to receive treatment for their illness. Being in prison may not be the best place for this treatment to be carried out.

Some offenders feign illness in order to be transferred to hospital where life is seen as easier, this is resented.

4.12. THE POLICE

HUG is in the middle of a discussion about the actions of the police when dealing with people with a mental illness. One of the key factors in reducing the inevitable confrontation or fear that occurs when dealing with the police is being known by them and being able to trust the person concerned (being able to see behind the uniform). This has in some cases greatly helped the process of being sectioned in a way that is unlikely to occur in some of the cities. Other issues will be covered in a later report and will include: a discussion on whether a police station is suitable as a place of safety; the role of the police in obtaining evidence from victims of crime with a mental illness; and issues to do with harassment, exploitation and the prevention of suicide.

4.13. HARASSMENT AND DISCRIMINATION

The stigma of mental illness and the ignorance of many people about it is of great concern to members of HUG and a subject that they are trying to challenge.

At its extreme the attitude of other people can lead to physical and verbal harassment.

Where people are being harassed there should be the certainty that the police will act to protect the user and adopt the zero tolerance approach used with other groups of people.

It should not be possible to discriminate against people and it should be possible for people to learn to remove any prejudices that they may have about people with a mental illness.

Again a few views were expressed:

If discrimination and prejudice could disappear, then life would change dramatically for many people. However using the law to achieve this is wrong, it is a blunt instrument that will only fuel resentment if it is used to tell people how to think - forcing someone to give up their opinions is wrong and counterproductive.

Equally the use of the law to protect people was thought to be extremely important.

It should be possible for there to be education and training about mental illness for everyone, especially in schools.

This training, though realistic, should be gentle and aimed at bringing people along together. It should not be about blame but about learning and change.

People should be taught about practical things - about human actions and relationships; respect for life; and positive attitudes and respect for our own mental health as well as seeing and getting help for those early signs of mental illness. This should be a part of the school curriculum.

(This may be a little idealistic in some areas where traditional attitudes to mental illness, such as it being a sign of sin or even of possession, can lead to exclusion and avoidance).

The media consistently gives a negative image about people with a mental illness, it should be held to account for this.

4.14. THE MENTAL WELFARE COMMISSION

Some people who had been sectioned did not know about the mental welfare commission and what it was meant to do.

There was quite a strong feeling that little would happen when trying to get help from the commission. One person described how a 'very nice man' would visit and how they would have a cup of tea but that it would be obvious that there was no chance of change.

There was a feeling that was occasionally expressed that the commissioners were more allied to the professionals than the users.

There was also a recurring theme about the time that it took to get help from the commission.

In contrast a few people had very positive experiences with the commission describing them as both approachable and helpful.

It was suggested that there should be local commissioners to ensure a quick and accessible service. It was also requested that some way be made to ensure that the commission reacted to things that were likely to happen rather than to things that had already happened.

4.15. ADVOCACY

Everyone should have the right to someone who will help them represent their views about their lives and treatment. (People who have already experienced this often have a great deal of praise for this type of service).

This advocacy service should be especially available to those people who are excluded from speaking out due to the severity of their illness or due to the exclusion they face from society. There should also be a service that is based locally and can also be used by anyone who is resident in a psychiatric hospital.

People should have a legal right to advocacy services and possibly these services should have some legal powers. There should be a way of making advocacy services accountable for what they do.

Everyone should have access to collective advocacy groups.

4.16. THE ROLE OF CARERS

In the vast majority of situations people would like those people that they are close to, to be as involved as possible in the decisions that are being made about them .

They tend to have a unique insight into the life and the needs, wishes and lifestyle of the people that they love and care for and can educate professionals in matters that the user may not be capable of doing at the time.

However there are carers and family members that would not act in the interest of a patient and may even go so far as being abusive to that person or even be considered by the user to be responsible for the fact that they got ill in the first place. There should be safeguards against this, perhaps the user should be able to make the decision about who their principle carer is or, if they are too ill to do this, then perhaps the use of advance directives would be a solution.

Some families will not act because of the stigma of mental illness and need education about it, other families may be so traumatised that they don't know what to do.

Where it can be demonstrated that the decisions made about a patient's care and treatment will have an appreciable affect on the carer then they should have the right to have a say in what is to happen.

4.17. CARERS AND CONFIDENTIAL INFORMATION

If the user gives permission, either when ill or through the use of an advance directive, then information should be shared with the carers.

4.18. CARERS AND CONSENT TO A SECTION

If a carer were to have a legal role in giving consent to a section, then an unfair burden may be placed on their relationship with the user. They should have a say in what happens but not be one of the final decision makers.

There was however a different view to this:

To be sectioned is a frightening and confusing process, but if it is carried out with love, by the person that you trust, then the whole thing can be smoother and less frightening. Any backlash that may come later on will be lessened because the person who carried it out is clearly a person with your own interests at heart. In contrast, to have a relative stranger involved in the sectioning process at such an emotional and personal time could feel like an intrusion or even a violation.

4.19. THE MENTAL HEALTH ACT AND VOLUNTARY PATIENTS

There was agreement amongst members of HUG that voluntary patients have felt a degree of compulsion to act in ways that, at the time, they don't want to. This can vary from being subject to a vaguely paternalistic expectation to overt intervention and instruction. In this situation there is a feeling that people have fewer rights than people on a section.

People may also, due to the severity of their illness or their perceptions about the place they are being treated in, find it very difficult to work out what they want to happen or to articulate their wishes .

It is important that voluntary patients also have access to the use of advance directives as well as access to an advocacy service.

There should also be consideration given to the training issue that this perception raises.

4.20. RIGHTS TO SERVICES

There was agreement that users should have rights to services:

- ◆ There should be a level of service below which health boards, trusts and councils cannot go, although what this should be we couldn't decide.
- ◆ Some ideas were that, everyone should be able to be admitted to hospital if necessary and equally, there should be guaranteed rights to crisis care and respite care. There should also be guarantees to the help that a 'home help' may provide after discharge from hospital.

There was also discussion about legislation and services . There is a degree of skepticism that there will be any investment in mental health services This was also reflected in a belief that any new legislation would have, as one of its motivations, making savings in the amount of money available for services helping people with mental health problems.

This gave rise to discussion about 'rationing' . To be able to say that one person will benefit from or deserve help and another not, takes away the mutual giving of dignity and respect. How can the distress that someone experiences because they have a 'severe and enduring' problem be ranked as more important than the distress of someone with a 'minor' illness or even desperate social problems?

Some people who have to make frequent use of services may benefit from some form of contract about the services that they can expect. (For instance, a guarantee to a certain amount of time a year in hospital when they feel they need it), This statement of faith in the judgement of the user and the guarantee of services can decrease uncertainty and give more autonomy to the user which may reduce the possibility of crisis arising.

4.21. WHO THE MENTAL HEALTH ACT SHOULD APPLY TO

Again there are diverse views:

The main view was that the mental health act should apply to people with a mental illness.

Whether it should also apply to people with a learning disability or people with dementia members did not know except to say that making laws specific can make them more in touch with the individual concerned and that therefore legislation should be as close to the client group as possible.

The other view was that legislation that applies to one group of people because of who they are and not what they have done, is in itself divisive and will encourage segregation and negative attitudes. Legislation should concentrate more on principles that apply to everyone rather than particular sections of society.

4.22. SHOULD THERE BE SPECIAL PROVISION FOR PEOPLE FROM ANY ‘MINORITY GROUPS’?

By the end of this round of talks we agreed that all services should be accessible to all sections of the population.

Illustrations of the way this might occur were that people should have the choice of single sex wards in hospital and same sex workers.

There was a feeling that parents with a mental illness were not well catered for and that the structure in which services were provided made families very vulnerable to break up, especially single parent families.

Other groups have particular needs, for instance, deaf people should be guaranteed the use of an interpreter and not made to rely on relations to help them communicate - and people with physical disabilities should also be able to access any mental health service that they may need.

4.23. IMPROVING THE PROCESS

GENERAL:

Whilst legislation is necessary, HUG believes, that there are a number of things that could be done to reduce the need for the use of the mental health act.

‘THEM AND US’

If it were possible for people to gain the feeling that everyone involved in the process was trying to improve things, the aura of suspicion and lack of co-operation that can be encountered could be reduced and as a result the mental health act might need to be used less often.

There is a feeling that professionals can often think that they know best and yet feel threatened by users whilst telling them what to do.

Equally users, especially young people and people with drug and alcohol problems, can feel a suspicion of professionals that stops them from co-operating. This is fueled by the stigma of an illness that people don't want to admit to and to the mythologies of treatment which do not exist nowadays. Illness and lack of motivation can also fuel this lack of co-operation.

Issues of class, culture, race and gender can further mix the waters so that the wish of a new patient to get better and a new worker to help them get better can become quickly and hopelessly entangled as soon as both enter the institution or service. The cultures, bureaucracies and beliefs of the different groups can make it impossible for people to trust each other and work together.

Ideally we should be able to respect the expertise of professionals, whilst they should respect our individuality and the views that we have about our treatment.

4.24. HEALTH PREVENTION AND PROMOTION

Members of HUG remain convinced that if there was appropriate information and education then people would accept or seek treatment earlier with no feelings of secrecy or shame. If people could get help earlier there would be less need for later interventions.

If people had the right to choose treatment that is appropriate to their circumstances then later problems could be avoided (however making a choice when ill or ignorant can be very hard to do).

There is a need for help in learning the basics of emotional literacy which so many people lack. There is also a need for people to gain a knowledge of how to deal with those parts of life that are bound to adversely affect mental health.

Equally it is important that people know the warning signs of serious illness in order that they can seek help early (there is feeling that although lack of insight into illness is a very real problem that it is exacerbated by the stigma of illness).

4.25. SEGREGATION AND INTEGRATION

Many mental health services are restricted to people with a severe and enduring illness. This makes them inaccessible to most people and creates an image of apartness and difference that only serves to reinforce prejudice and exclusion.

Services in the community, even if biased towards people with a severe illness should still be accessible to people who just need somewhere safe to go to and someone to talk to. Hopefully they would one day become prominent parts of the community, regarded as an asset for that village, town or city. Somewhere people naturally use instead of being marked with a discrete plaque on a door whose entrance signifies a new phase in someone's life.

4.26. EMPLOYMENT

If mental health services could give positive messages about employing people with an illness this would give a good message to the community and also to people experiencing the illness.

4.27. LISTENING TO USERS.

People can often know when they are getting ill and yet find it impossible to gain admission to hospital. If routes to hospital were made better for those people with the ability to 'self assess' then more extreme measures could be avoided later on.

4.28 BEING TOGETHER

The words of one group describe the importance of 'being in it together', which can lead to confidence and the discovery of coping strategies.

"People, perhaps all of us, put on brave faces. People do not see what we are going through or understand that the face that we show the world is often a pretence. We need to stop being told we look fine when we are the opposite. It is such a relief to be in the company of people in a similar situation."

4.29 MAKING CONTACT

Lack of motivation is a major problem - if ways were to be found of overcoming this many problems could be avoided.

4.30 MAKING THE SECTIONING PROCESS EASIER

Whatever is done the process of being sectioned will always be a traumatic process for the majority of people. The removal of freedom and choice when a person's sense of identity is also at risk cannot be anything other than traumatic.

There was a plea that, if possible, people have some advance notice that they are likely to need admission to hospital so that they can get used to the idea.

For some people it is important for doctors to take over responsibility and control of the situation. People can get into situations where they need help or hospitalisation but cannot take the final decision or admit that is what they want.

Most people said that the first few days in hospital were times of pure trauma and confusion. Explanations of rights, where they were, or what was happening and the procedures and rules of the ward could not be grasped. However, at some stage, most people will want some understanding of what is happening and what their rights are. If at that stage they wish to appeal against what is happening then they should be assisted in this and encouraged to do so.

One of the HUG groups said that although sectioning could be antagonistic that, if possible, people should be sectioned with love and dignity by a psychiatrist whom they know and trust. A parallel was drawn a few times of when a parent imposes their wishes on a child but because the child feels safe with the actions of their parent there is little recrimination afterwards.

As much effort should be made as possible to ensure that people become happy with their treatment or at least inclined to accept it. Without some form of co-operation it is unlikely that there can be any advances in a person's condition. This requires both the professional and the user to gain respect for each others views. The use of the Mental Health Act does not stop this being needed.

Perhaps some form of contract could be drawn up between the user and the doctor. An advance directive should be offered when a person is due to be discharged from hospital and should form a part of a person's aftercare.

Compulsory treatment often involves medication, perhaps it would be a good idea for people to be told to at least try some of the talking therapies that may be on offer in the hospital.

Where a person is originally in hospital voluntarily and, having refused treatment, is sectioned then it can be very hard for the person concerned to regain any of the feelings of safety and sanctuary that can be so important for recovery.

When people are very very ill it can be helpful for there to be a degree of segregation from other patients which will help both the person and those around them.

A key element that removes the damage of being sectioned is 'human contact' and prior knowledge of the person. People need to be talked 'with' and not 'at'. Explanations are vital even when people don't take too much in at first.

Wherever people feel threatened then confrontation can occur.

Proper rehabilitation facilities can also prevent readmission or the need for sections.

As has been said before, a key element which will minimize the damage of a section is to have a trusting relationship with the professionals involved in your care and yet the very act of sectioning someone can remove all the trust and faith that has been built up.

There needs to be a genuine acknowledgement that whether under section or not, users are equal to professionals.

4.31 ADVANCE DIRECTIVES.

The use of advance directives became a central theme of the HUG meetings. It is thought, by HUG, to be a key tool in safeguarding the wishes of users and in giving a clear direction to professionals providing treatment to people where the validity of the users' ideas may be questionable.

It gives direction where previously none could be obtained with certainty and, equally, acknowledges that most people with a mental illness have an expertise about what helps which cannot be gained elsewhere.

When people are well they should be able to put down their wishes about how they would want to be treated if they became ill again.

These wishes should be respected and in some cases be legally binding.

A person's ability to make an advance directive should be assessed before it becomes binding.

Where a person is trying to stop a potential intervention then this wish should be respected.

Where a person is trying to request an intervention whether from a professional or a friend then this should be agreed with the person or service concerned.

An advance directive could also give powers to people to call in services if someone is getting ill, or for information to be shared with particular people.

An advance directive should not be able to transcend the legal or moral values of the society of which a person is a part.

The directive should be witnessed and a person nominated to try to ensure its instructions are being carried out.

People should have the information that they need to create such a directive.

There should be a cooling off period to reconsider the directive before it comes into force.

Perhaps there should be room to grade things, for instance, there may be some things that a user would never want to happen and others that they would prefer didn't happen.

It is important that changes such as those that occur with time would allow such documents to be overruled in the interests of the user and those around him or her.

4.32 RURAL AREAS

In rural areas, concepts such as choice whilst still valid can also be impossible to provide. Admission to hospital can be a long and lengthy process and access to professionals when needed impossible to obtain. Confidentiality and anonymity are also almost impossible to achieve.

4.33 ACCOUNTABILITY

There was a feeling that it is hard to bring professionals, especially doctors, to account for their actions especially for such intangible things as their attitude. This should change.

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

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