



## ASPECTS OF THE NEW MENTAL HEALTH ACT

This report contains the views of 66 HUG members on issues relating to Named Persons, Advance Statements, Advocacy and Tribunals.

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## WHAT IS HUG?

HUG stands for Highland Users Group, which is a network of people who use mental health services in the Highlands.

At present, HUG has approximately 305 members and 13 branches across the Highlands. HUG has been in existence now for 8 years.

HUG wants people with mental health problems to live without discrimination and to be equal partners in their communities. They should be respected for their diversity and who they are.

We should:

- ◆ Be proud of who we are
- ◆ Be valued
- ◆ Not feared
- ◆ Live lives free from harassment
- ◆ Live the lives we choose
- ◆ Be accepted by friends and loved ones
- ◆ Not be ashamed of what we have experienced

We hope to achieve this by:

- ◆ Speaking out about the services we need and the lives we want to lead.
- ◆ Educating the public, professionals and young people about our lives and experiences.

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

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## INTRODUCTION

In preparation for the implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003 HUG members were consulted in May and June 2004 on particular aspects of the new provisions.

Part of this was to inform the Scottish Executive of our views regarding Named Persons and Advance Statements in order to influence that part of the Code of Practice for the new Act. These two provisions took effect in October 2004. The rest of the Act will be implemented from April 2005.

In addition, views were sought in relation to Advocacy and the introduction of Tribunals.

The booklet "The New Mental Health Act - what's it all about?" written by SAMH was distributed to all our members and found to be very useful.

The consultations provided an opportunity to increase awareness about the new Act. Many of the 11 meetings were held in drop-in centres and information was left for reference.

On some occasions staff were present during the discussions and they contributed to the debate.

Some feedback was given to the Scottish Executive at the end of July to help with their consultation.

## **NAMED PERSON**

This was a new concept to many people. Sometimes it did not seem easy to explain this idea and the role of the Named Person.

### **Is having a Named Person a good idea?**

It was felt to be good that we would be able to choose who was to receive information about us and our treatment. Having access to a person nominated by ourselves to participate in the decisions being made about our care was regarded as a step forward. People acknowledged that sometimes when you are ill it is extremely difficult to take things in.

Although having a named person seems like a good idea, people shouldn't be forced to have one. There is a problem for people who have few relatives, or anyone close they can trust.

Some people may not want one because they are very private.

We felt that when well you should certainly be able to choose a named person.

It sounds like a good idea but would it be practical in reality?

We were worried about increasing the number of people who know we have a mental health problem.

### **Who would we nominate?**

The relationship we would have with the named person was seen to be very important. Individuals who had been sectioned were aware that it changes the relationship with their next of kin. It changes the role of the person you trust. There was concern that this could also happen with the Named Person – such a change in role could be unhealthy to the original relationship.

When we are ill and feeling vulnerable it is easy for trust to be misplaced. We often lose trust in most people. Therefore it could be hard to find a named person.

A problem might arise if the Named Person was to get too emotionally involved, depending on who was nominated.

We wondered how we would know if they were on our side. What if they weren't? Then perhaps advocacy would be better.

Some people thought it might be better to choose a professional. It could be your GP or your support worker. Sometimes a worker may see or know an individual more than the family or next of kin. We felt that the family is often told what they want to hear. As service users we often trust CPNs because of the relationship we have built up with them.

However, although we might want a named person we might not want them to know everything about us.

It can be good if our next of kin knows about any mental health problems, but it is important that we feel we trust them. Our next of kin may not be the person we regard as our carer or partner.

If you don't nominate a named person, then information goes to your next of kin. It was made clear that under the new legislation you can say who you don't want as your "named person" which pleased us. Also that there are safeguards for a named person to act responsibly.

We recognised that there might be problems within the family if it wasn't a family member who was chosen to be the Named Person. Some of us would choose a relative to be our Named Person, but we felt it was vital that they did not have the power to section us. We were concerned that any power they may have could work against us. We did feel that it was an opportunity for relatives to gain a better understanding and insight into our difficulties. It was good to be offered the chance to involve a relative or friend in ongoing consultations. We do know that carers have a problem getting information.

### **What might be the difficulties of having a Named Person?**

We felt that it would be important for a Named Person to have information and training for their role. They would need to know a lot about mental health and be prepared to get into awkward and exhausting situations. They would need to know what might be involved.

When we are ill we may think that the Named Person was working against us. Often we may "deny" the possibility of another episode of illness and not nominate someone at a time when we are well.

Some practical issues were raised:

- ◆ How would this work during the first episode of illness?
- ◆ How easy would it be to change your Named Person?
- ◆ How would we deal with disagreement?
- ◆ What would happen if the Named Person moved away, become ill themselves, or were unavailable?
- ◆ Could one Named Person act for several people?
- ◆ What would happen if we fell out with the person we had nominated?
- ◆ How would we feel if it reverted to our next of kin who would then be able to get all the information we would get?
- ◆ What would happen if we wanted to change our Named Person once we became ill?
- ◆ How would such people and we ourselves deal with the new role that they had taken on in our lives?

## ADVANCE STATEMENTS

The concept of an Advance Statement was known to many people. Sometimes we described it as being like a living will.

### Are these a good idea?

When we are well, being able to write down how we would want to be treated is a very good idea. We would feel that we still had some element of control – at least indirectly. When we are ill, it is very difficult to make decisions. Often when we are better we forget what it's like to be ill. Each time we are ill it's not quite the same.

However, how do we deal with people who change their mind when they become ill? Sometimes we are very irrational when ill.

Advance Statements would need to be respected. We can often feel ignored by professionals, such as doctors, so would Advance Statements really have any effect? There was a high degree of scepticism expressed.

However, it was recognised that sometimes they would need to be overruled as long as there was a clear procedure to be followed. All decisions made should be justified and well documented. On a positive note, we felt that it could lead to improved accountability of professional involvement in decision-making, and could empower us as service users.

We felt that it is a pity this concept is only applicable to those under the new Mental Health Act. It should be applicable to all illnesses.

It's important to include in our advance statement that we still want to be taken seriously and listened to when we are unwell – i.e. listen to us even when we are saying different things from what's in our advance statement.

### What should be included in an Advance Statement?

We would want to include our views on medical issues. These might include preferences for the gender of the staff treating us and being responsible for our care. It may be even more specific about our choice of Doctor or Consultant. We may have particular dietary requirements. Often we may find alternative therapies beneficial and would wish these to be pursued. Unrealistic requests could be problematical although we would want to include recognition of positive aspects that would help our treatment.



Previous experiences would influence the content of our Statement. We would want to be able to state that we did not wish to be prescribed certain medications, giving reasons. Side effects we have experienced would provide evidence for our choice. There may be medications we have found extremely beneficial. We would want to note those and also the dosage that we can tolerate.

ECT works for some people and they may wish to request it.

A section on how we behave when unwell, and the response we would like was suggested. For example, we may go very quiet, but might still wish to have visitors because we get very lonely. Also, even when very withdrawn we may still want someone to look in on us and ask if we'd like a coffee.

We understand that Advance Statements cannot include anything which is illegal, such as euthanasia. However, we would want to make it clear what procedures we would find acceptable to sustain our life. For example, we might wish not to be kept alive by artificial feeding. We appreciate that there could be very difficult ethical issues.

We feel it is important to record non-medical matters in Advance Statements. Our illness affects all aspects of our lives and additional worries about practical things can impair our recovery. We may wish to state who we might trust with the key to our accommodation; who would look after our pets or even water our plants. We often feel strongly about who may be informed that we are ill and would want that to be recorded and respected.

Reference to any strongly held religious beliefs and the importance to us of spirituality would help to guide the way we may be treated as individuals. When we are ill it may be very difficult to articulate these feelings, even though they are very important.

Some of us have great difficulty with our personal finances when we are ill. We might wish to have someone granted Power of Attorney. We understand that may require use of the Adults with Incapacity legislation, but could it be included in our Advance Statement?

## **What help and information would we need to write an Advance Statement?**

We would need help with drawing them up and the pros and cons of what to say. This help might come from our GP or more likely our CPN. We should have advice from someone who understands the principles. We may need access to our

medical notes and people who have been involved in our treatment. We would also need information on new treatments and advances in medication, particularly if our last episode of illness was some time ago.

Our previous treatment, whether good or bad will have significant influence on what we write. Things will happen that we cannot plan for. A situation might arise which bears no relation to what we were anticipating when we wrote the Advance Statement. This might result in the Advance Statement being overruled. However, we should know the type of circumstances which could lead to an overruling and the procedure which must be followed.

It would be helpful to have a "prescribed" form. We need to be offered help to make our statement as forms like this can be very hard to complete. There must be a variety of formats for those with particular communication needs. Some of us may wish to have an advocate with us while drawing up an Advance Statement.

We need to be sure that we created them of our own free will and not when under pressure. We must not be unduly influenced when writing our Advance Statement – e.g. by views of family or society. They should encompass our individual beliefs and acknowledge our potential. How we see ourselves in the future can be coloured by how we see ourselves now. We may have little expectation of our ability to work again, and this may be the view given by professionals. Some of us have proved those predictions wrong by gaining and maintaining employment.

We need to know how we can make changes to our Advance Statement.

How do we tell whether we are in our right mind or not? This varies and may vary with different subjects – some things we can make rational decisions about and others not, at the same time. Who would decide, and how, that we are mentally well?

How would someone write an Advance Statement if they had never been ill – but had some reason to draw one up? (perhaps because of illness of other family members).

It would be helpful to have a guide to a stay in hospital available with an Advance Statement.

### **Where should they be kept to be accessed?**

There should not be too many copies. We should have our own and they should be in our GP notes, together with our nomination of a Named Person. We may wish

our Named Person to have one. They could also be kept on a database at the hospital.

How would we indicate that we have an Advance Statement drawn up? It could be by a "message in a bottle" or symbol on a bracelet.

## **Should an Advance Statement be offered to us? How should we find out?**

We should be asked as soon as we become involved with services. There must be good publicity and information about this right.

## **Witness for the Nomination of a Named Person or making an Advance Statement**

There was overwhelming agreement that the witness to the signature should be someone who knows us and has knowledge of mental illness. We did not want to increase the number of people who knew we had a mental health problem.

It would be important that the witness saw us on a regular basis in order to determine our "competence". Some of us have fluctuating symptoms (sometimes from day to day) so we would need someone who could see the signs.

Many felt that a CPN would be a good choice for this role in that they are likely to have formed a trusting relationship with us. They are also professionally trained in mental health issues.

Others involved with our care with mental health experience would be staff in drop-in centres, or support workers. These are people who would be aware of our behaviour and attitudes and so have insight into our "competence".

The "qualification" to be a suitable witness should rest on the ability to make a decision, not status.

For one person their choice would be the psychologist who they see regularly.

A few people thought their social worker would be appropriate.

The GP was also suggested as appropriate to be the witness. However it was frequently said that many of us do not have a good rapport with our GP and we would not wish to ask them. We wondered whether GPs would charge for this service.

Obviously some people have good relationships within their family and would wish their next of kin, carer or a close relative to be the witness.

Mental illness can be very isolating with relationships difficult to maintain. For many with few, if any, friends or relations this isolation can result in contact with only a very small number of professionals. We were concerned about those who may be homeless and who would not move in the 'right' circles. How would they find someone to act as a witness?

What about those becoming ill for the first time?

We wondered whether the witness should be someone who can currently witness a passport application. Would a solicitor charge to witness a signature?

There are particular difficulties in many rural areas. Could there be a list of "rational people" for a particular geographical area?

# ADVOCACY

## Advantages/disadvantages

Under the New Act everyone with a mental disorder will have the right to independent advocacy. This provision of advocacy was welcomed. We feel that advocacy is a good thing that really can help.

We acknowledged the fact that it can be hard for many service users to articulate their true feelings, and that everyone needs to be listened to in relation to their individual needs. Advocacy, therefore, was considered to be a very important service. It was pointed out that many forms of advocacy are already ongoing and suggested that the best people to fulfil this role are those who have specific experience. Some felt that people who work on a voluntary basis are most effective, whilst others felt that it makes no difference whether or not an advocate is paid for their work.

Advocacy enables us to articulate our feelings at the time. It's a bit like a good interpreter – who states our views and wishes.

It's crucial if we are incapable of speaking – it may be the only voice we have.

We recognised that some people will need this more than others. They may not have the education; they may not have a loud enough voice.

Would some people use Advocacy when they didn't need to? If so it could be disempowering. Some people are able to help themselves. We need to emphasise the need to self-advocate too.

However, it must be unbiased. We need to be confident that the advocate won't take anyone else's side other than our own.

Advocates would need to have knowledge of mental illness.

It is sometimes thought that advocacy may increase antagonism. It is perceived as confrontational and that as a result people will be treated badly – this may create an 'us and them' atmosphere. This needs to be addressed through training. The early and appropriate use of an advocate can reduce confrontation and prevent an issue becoming a complaint.

But patients can be frightened of doctors and may feel they are not being listened to. Advocacy could be very important for them.

Independence is important – you can't rely on a nurse to do this - however an increase in advocacy may take funds away from other services.

The advocate needs to know the person so they can speak for them if they clam up. Someone had a very helpful experience of using an advocate at a benefit tribunal. However, someone else refused the help of an advocate because it felt like another professional.

We wondered how you advocate for someone with dementia. It is also difficult to advocate for a person who's very high (manic).

They should be trained and know how to listen and deal with emotion.

### **Should they be paid or volunteers?**

Our views were mixed on this. They might be good as volunteers but many of us thought they should be paid to do such an important job. They should be paid because they are so valuable – and are professionally skilled. We are aware, for example, of the salaried worker at the Royal Edinburgh Hospital.

Also we are unlikely to have enough volunteers – and people need to earn a living! However, some of us felt that a paid person might exploit us. It was thought that volunteers might have greater loyalty. The provision of an advocate should be free to the person needing one.

For volunteer advocates, we wondered whether there could be some sort of creative "reward" scheme (creative in the sense of avoiding problems with benefits). Perhaps the training that advocates undergo could be recognised. An example would be the RELATE training, where the recognition of being trained is in itself a "reward".

We were concerned about the actual availability of trained advocates in time for the implementation of the new Act in 2005.

The advocate should be paid in order to get more people and make it more attractive.

### **Who should be an advocate?**

We know how important it is to be able to communicate with the advocate. So is it desirable for the advocate to have had a mental health problem? What sort of person should they be?

The advocate needs to be independent and willing to listen in order to say what you want to say. They should have experience of the mental health system and behave as your "friend" in the sense of doing something the way you would want to do it yourself if you were able.

We must be able to trust them. They must have an understanding of confidentiality. It is sometimes easier to talk to a stranger.

They might be a relative of someone with a mental health problem.

Some members also pointed out that some support workers already fulfil the role of advocate, which is good in that there is no need to reiterate 'old ground' because the worker is already aware of the background.

People who work alongside you can give added weight because they know the system. However, a separate independent person may be needed depending on the issue.

Although drop-in centre staff would be known to users to behave and act independently, they would not be seen to be independent. Often the character of the person is far more important – someone you know and trust may be just the person you need to be your advocate.

Important characteristics were felt to be:

- ◆ Personality
- ◆ Someone on your side
- ◆ Someone who understands the system
- ◆ Someone who believes in you
- ◆ Someone who instils confidence and trust
- ◆ Someone who helps you find your own voice
- ◆ Someone who is unbiased

Advocates should have training in issues of mental health, and good communication skills

More accessibility to organizations such as Advocacy Highland would be helpful, as would the opportunity to build a trusting relationship with the potential advocate. It was noted that there appears to be a lack of resources in this area of support, and that all such help should be free of charge.

It is important that you meet them face to face. Advocacy workers may accompany you as your support.

## Where should they be based?

The base for an advocacy service needs to be accessible; it needs to be contactable in a whole variety of ways.

They should have bases in drop-in centres; health centres; social services - wherever service users go; and be there or available when you arrive in hospital. Part of the project could be based in the hospital.

## What do we mean by independence? How important is it?

It is very important that advocacy is independent from service providers. Even if the actual funding comes from services/agencies, Advocacy services need to be able to support someone who wishes to speak out against that funder's provision.

Independence was seen as a way of working. Some workers do act on individual's behalf - they do speak up for people. What's most important is what people do and how they behave, rather than structures.



## TRIBUNALS

These will replace the work of the Sheriff Court where someone may go re Section 18 of the current Act.

We felt that this is a definite improvement, and would be less intimidating and intrusive than going to court. We thought that tribunals would be more accessible, which is good. For some people having the tribunal in the hospital would be so much better than the Sheriff Court. We wondered where else they could be held.

The Tribunals are meant to be less intimidating – although the person will still be “judged”. It was felt that although Tribunals will more accessible to patients, they might be unduly weighted against the user, who would need more professional help and support and good representation. Who would pay for this? Would legal aid be available? Money can buy you good representation.

We felt that emphasis should be put on being a voluntary patient.

There was experience of the Sheriff Court, which had been very negative – the carer only being contacted on the day of the hearing.

How would it work if there is a “criminal” element to the issue?

What about the accountability of the Tribunal? Would accountability be to the Mental Welfare Commission?

If the psychiatrists for Tribunals in Highland are to be from out of the area, where would they come from? Western Isles? Aberdeen? We were concerned whether there would be sufficient doctors to take on this role.

One HUG member was not convinced that the Tribunals were a better system than the Sheriff Court. Her experience had been that in order to appeal/revoke a Section, she had felt it necessary to employ a lawyer (at considerable personal expense). This did result in her appeal being successful, but she felt that you needed the power of the judicial system to challenge the psychiatrists. Without this legal weight the individual patient is powerless or at least at a huge disadvantage.

## CONCLUSION

The new provisions regarding Named Persons, Advance Statements, Advocacy and Tribunals were broadly welcomed by our members.

However, there were significant concerns raised about the practicalities and resources required for these provisions.

The concerns included:

- ◆ Whether there would be sufficient awareness by all staff who should be knowledgeable in time for the implementation
- ◆ Whether there would be the personnel to meet the Advocacy and Tribunal requirements
- ◆ Whether the scepticism felt about the possible overruling of Advance statements would prove to be justified

We are continuing to work and support the implementation of the New Mental Health Act. We appreciate and acknowledge the work of others who are striving hard likewise.

Chris Evans October 2004

## ACKNOWLEDGEMENTS

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

*(Please feel free to photocopy this Report)*

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