



# CONTROL, INCLUSION AND EMPOWERMENT

This report contains the views of 87 people on how much  
influence we feel we have over our lives

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## WHAT IS HUG?

HUG stands for the Highland Users Group, which is a network of people who use, or have used, 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 9 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 be 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.

HUG's aims are as follows:

- ◆ To be the voice of people in Highland who have experienced mental health problems.
- ◆ To promote the interests of people in Highland who use or have used mental health services.
- ◆ To eliminate stigma and discrimination against people with mental health problems.
- ◆ To promote equality of opportunity for people with mental health problems irrespective of creed, sexuality, gender race or disability.

- ◆ To improve understanding about the lives of people with a mental health problem.
- ◆ To participate in the planning development and management of services for users at a local, Highland and national level.
- ◆ To identify gaps in services and to campaign to have them filled.
- ◆ To find ways of improving the lives, services and treatments of people with mental health problems.
- ◆ To share information and news on mental health issues among mental health service user group and interested parties.
- ◆ To increase knowledge about resources treatments and rights for users.
- ◆ To promote cooperation between agencies concerned with mental health.

# INTRODUCTION

The subject of control, including inclusion, rights and empowerment, has often been raised at meetings of the Highland Users Group since it was established in 1996. Much of our work is based on the premise that people who have a mental illness often experience a lack of control over their lives. However until now this has never been addressed as the central topic for discussion.

The Connecting Communities (Information Communication Technology) Project at the Highland Community Care Forum is funded by the Big Lottery to work with HUG for three years to develop ways that we can use information communication technology to speak up and gain control. The Project aims include:-

- Fewer service users and carers will be isolated and excluded.
- Greater numbers of users and carers will get access to better advice, information about services, rights and sources of support.
- Users will play a valued role in developing training.
- Greater numbers of users and carers will experience being included and valued by others and in their own communities.
- Service users and carers will be empowered to take more control of their lives.

There is a full description of the Connecting Communities Project in Appendix 1.

We wanted to look at how we felt at the start of the Project about these subjects. We will return to them at the end of Project in 2007, to see if things have changed.

During May 2005, Control was the topic for discussion at meetings across the network of HUG branches. As usual these meetings involved informal discussion amongst members. In total 87 people (mainly HUG members but some professionals too) were involved. These discussions were then written up for this report. We have also added an appendix describing a workshop HUG members held on active citizenship which we feel is related to this subject.

The HUG reports on Stigma may also be helpful reference documents on this subject.

# INCLUSION /EXCLUSION AND PEOPLE WITH A MENTAL ILLNESS

## ARE PEOPLE INCLUDED IN THEIR LOCAL COMMUNITY?

*"I have a role in the community. I am the community psychopath; I'm quite happy with that role though it took me a long time to accept it. I used to be a skipper of a boat - people still refer to that too".*

HUG members felt that they had a wide range of experiences of inclusion in local communities, ranging from feeling very included, involved and integrated, to feeling very excluded and isolated, often because of mental illness.

For those people who feel included in their local community this is a very positive thing;

*"I find it wonderful people are so supportive."*

There are many different actions that help us feel included, such as people looking out for us, making positive comments, asking if we would like to go out, spending time with us, and friends asking if there is any way they can help;

*"The community look out for me. They keep an eye on whether I have taken the milk in and come to see if I am OK if I haven't."*

Those of us who felt included were almost unanimous in the feeling that this inclusion was due to people knowing us as individuals, rather than just as someone with a mental illness;

*"In my small community I feel included. They know me and not my illness."*

A few of us who felt included had feared that telling people about our mental illness would result in exclusion; we initially made friends who didn't know about our illness. We were later surprised by how understanding people actually were.

Some of us (particularly in smaller communities) felt that once we were open about having a mental illness it made us included as we then had a clear role;

*"As a newcomer I made friends who didn't understand about mental illness. My illness has now brought me into the mainstream and helps us to draw attention to people like ourselves".*

For some of us, our experience of inclusion has varied over time. Whilst we are not automatically excluded, sometimes we feel on the edge and not quite a part of the community. Factors that caused this related both to us and our illness and to the community itself:-

How we look: *"Outwardly I look very well; so people presume I am."*

How long we have had a mental illness: *"Early days -these are more difficult."*

Who we have told: *"Only the people I work with know I have an illness; they are pretty good".*

How long we've lived here: *"If you are already a part of the community then it tends to be OK, but if you want to join in a new community or group then you don't know what to say."*

Where we live: *"Depends on the community, some are quite supportive".*

Who we know: *"We can be very isolated except for contact with support workers. It is a very lovely place but can be lonely, especially for men."*

We feel that though some of us may be included in our local community this does not happen enough, or to the extent that we would want;

*"We are allowed for - but they (the community) don't have to like it."*

However the majority of us (in many of the meetings this feeling was unanimous) feel that people with mental illness are definitely not included in their local community, and indeed can experience dramatic exclusion.

## HOW ARE PEOPLE WITH A MENTAL ILLNESS EXCLUDED FROM THEIR LOCAL COMMUNITY?

There are a variety of experiences of exclusion amongst members of HUG, with the majority of us experiencing exclusion directly attributable to our mental illness at some stage in our lives.

Many of us who live in small, often rural, communities felt excluded by the very nature of a small community;

*"I was brought up in a crofting community; of course I faced stigma."*

Where someone without a mental illness might describe their community as close, with everyone knowing everyone else and neighbours enquiring after each other, this was often very different for those of us with a mental illness. Community can mean exclusion as everyone's history is known, we feel excluded by gossip, and people pry;

*"When you go into the local shop they ask how you are and what you are doing, they should know, not ask, as you are often not doing well and have nothing to do. You can't answer their questions or justify what you are doing with your time."*

Sometimes we are excluded by people's reactions and attitudes towards us. People look at us strangely;

*"Like we are a Rottweiler who might suddenly bite them"; "as if we have horns",*

and make comments about us;

*"Who is that weirdo?".*

Sometimes people do not believe in mental illness. We are lectured and then told that it is all in our mind. People don't understand; we are told to give ourselves a shake, get a job. There can be a 'pat on the head' syndrome.

Some of us faced exclusion in our working lives, either through strange reactions from employers when we give honest answers to interview questions relating to absence from work due to mental health problems, or to the extent that people would not employ us because we have a mental illness. Sometimes we feel that talents which might otherwise be recognised are not accepted because of our mental illness.

Those of us who have experienced stays in Craig Dunain and / or New Craigs hospital, often feel that this has strong links to exclusion;

*"Before you go to hospital it can function as a joke and threat. Watch out or they will haul you off to the Craigs".*

Once you have been discharged then your local community treat you differently;

*"When you come out (of New Craigs) they look at you to see if you have a third horn".*

Some of us feel that if you go to a psychiatric hospital then the exclusion will be really desperate, and that your life is over as you knew it. We did not feel that this exclusion had changed with the closure of Craig Dunain and the opening of New Craigs. There was a suggestion that the hospital should have been given a completely new name as the stigma still sticks.

Sometimes exclusion existed even during our stay at New Craigs, in terms of exclusion by the staff. We feel that there is sometimes less contact between staff and patients than at Craig Dunain, where some of us felt more included;



*"In New Craigs the staff remain in a gold fish bowl. It is like a conveyer belt, where nobody is concerned about me. I am not a part of it; just being processed."*

Certain groups of the community are more likely to exclude us, with secondary school children and young adults being the worst;

*"School kids fire 'bullets' – abusive comments such as 'nutcase' or 'nutter' – the comments can result in self harm because of the distress. 'He' makes a point of avoiding the school area when the kids are in the playground."*

Exclusion by this group has sometimes reached the extremes of harassment. Examples include; being spat on, rocks thrown at us, our windows broken, students take off their coats and put them on back to front. This can be worst for those of us who are still in education or who have left recently.

For some of us the worst exclusion is from our own families. We feel that we are strangers, even in a family situation. This exclusion can be caused by a lack of understanding;

*"My mum doesn't understand what my tablets are for. She said to me; "I managed to get myself out of depression so why can't you?", "*

It can lead to hurtful comments and attitudes;

*"My mother-in-law said I should be locked away for life",*

It can involve excluding actions;

*"My sister won't let me talk to her children, or play with them outside because she thinks everyone is talking about me."*

Isolation was probably the most common example of exclusion that we described. This can involve very active and visible exclusion, ranging from being ignored, to people crossing the street to avoid us, to being asked to leave pubs, to being advised to keep off the streets.

*"My neighbour knew me well, but after I went into hospital he never spoke to me again because of my illness."*

*"Once I was on a bus journey where there was a man who was known to be mentally ill and whose condition made him very talkative to anyone who got on. He was well known to be harmless but people moved away from him. They said quite loudly that they didn't want to sit near the nutter".*

*"Excluding behaviour is obvious - if you are in bereavement people cross the street."*

*"Pub owner said; "I'll pour you a pint just now but I want you to drink it and leave. Don't come in at weekends. Some people don't want you to come in".*

*"A husband was asked to keep his wife off the street."*

## WHY ARE WE EXCLUDED?

There are many different reasons for exclusion, which can be grouped into those involving exclusion by our local community and those where we exclude ourselves.

Common causes of exclusion by the local community include:- ignorance / lack of understanding, over protective friends and family, fear of difference, fear of our behaviour, fear of the causes of our mental illness, historical factors, stigma / prejudice, media / misinformation and poverty.

### **Ignorance / lack of understanding**

Sometimes exclusion is a result of people either not understanding or misunderstanding mental illness. This exclusion is based on ignorance and is not necessarily malicious. We feel that there is a societal embarrassment in relation to mental illness, which may be partly due to mental illness often being invisible. We feel things are improving for people with physical disabilities, but not mental illness. The result is that people, including close family, often don't know what to say to us, skirt around the subject of mental illness, and don't know how to cope or act with us;

*"People may lack confidence and self esteem and be awkward about knowing what to do with us".*

### **Over-protective family and friends**

Our friends and family are often overly protective of us and this can result in us feeling and being excluded. They may be protecting us from the stress of joining in with our community, or have an expectation that we are not able to deal with the rest of society or to contribute, and therefore they avoid putting pressure on us and we end up excluded because we don't join in with the activities of our wider community. Sometimes higher expectations would include us more.

Our families may also conspire to keep illness a secret; such as don't tell granny or distant relatives, which is exclusion at its greatest. People can go to a family gathering and on arrival it may be obvious they have problems which can come as a surprise to the wider family.

### Fear of difference

Many of us felt that people's fear of difference leads to our exclusion. As with exclusion through ignorance or over-protective friends and family, fear of difference is not always a malicious act, but may be a natural reaction to the unknown.

The fact that we don't always conform to a norm is enough to single people out as different. Men in particular can be frightened of associating with people who appear different and who have a mental illness in case it damages their reputation;

*"Now we are less ashamed and more open but people are still ignorant and afraid and almost frightened that they will catch it."*

### Fear of our behaviour

Many of us felt that we are excluded because people are scared by our behaviour, or the way they feel we might behave, or once behaved;

*"in small communities people have long memories".*

We may act bizarrely or take a 'wobbly'. Violent incidents in the past can lead to exclusion;

*"Behaviour can be the thing that excludes people, such as drugs or violence; mental illness itself doesn't figure so high".*

### Fear of recognising the causes of our mental illness

Some of us felt that where our mental illness was the result of a specific event, for example child abuse, our exclusion was due to people being afraid to acknowledge that this took place. Recognising our mental illness would mean acknowledging that we were abused and people would prefer to believe that this doesn't happen.

### Historical reasons

People were also reluctant to face up to decisions that were made in the past about the treatment of people with mental illness. Historically, many people went into hospital and never came out. Now that we are mainly in the community they are faced by us, but the history and the legacy of past treatment and attitudes still lingers and influences how they see us.

### Stigma / prejudice

People's negative attitudes towards mental illness were one of the most common reasons given for feeling excluded. This was a more conscious type of exclusion than those above, and therefore more difficult to deal with. There was a feeling that these attitudes were historic and had been passed down the generations, leading to people being automatically prejudiced against people with a mental illness. As a

consequence many felt their communities didn't care enough, weren't interested in mental illness and thought those with a mental illness should be kept in hospital.

### **Media / misinformation**

People with a mental illness are excluded because of the effect of the way they are sometimes portrayed in the media. Many of us felt that this is 'organised' misinformation on the part of the media, as by portraying mental illness in a particular way they sell a story. This is now being challenged by national initiatives such as 'See me', the national anti-stigma campaign. However their impact has not reached some of the more isolated areas in Highland.

### **Poverty**

Many of us felt excluded by our lack of money. No money means that you can't afford to do things that others do, and are therefore not part of the community.

### **DO WE EXCLUDE OURSELVES?**

A few of us felt that our exclusion was not the result of any of our actions, and was solely due to discrimination by other people. We were very much in the minority in this view.

Some of us felt while we may exclude ourselves, this is due to geographical reasons:- choosing to live in a very remote area where we are too far away to participate, or choosing to live on our own, rather than anything to do with our mental illness or discrimination.

The majority of us felt that we definitely play a part in excluding ourselves due to our ignorance about mental illness, the stress of having to work to fit in, our behaviour, fear of local community, for our self protection, stigma / self stigma, symptoms of our illness, historical reasons and our services excluding us.

Many of the reasons for excluding ourselves relate directly to the reasons that our local communities exclude us.

### **Our ignorance about mental illness**

The local community excludes us due to their ignorance and lack of understanding of mental illness. We feel that we also exclude ourselves for this reason. We can be ignorant about our own mental illness. When we first get ill we often have no understanding of it and face our own former prejudice. We remember our own attitudes and assume other people will have these too.

## Stress of having to fit in

As people with a mental illness, we have experiences and behaviour that may be different to those of people without a mental illness;

*"My illness makes me talk too much. Hearing voices is part of my illness. You perceive things differently."*

Because we are aware of this difference we often have to work very hard to try to fit in to our local communities, and find that at times we choose to exclude ourselves as a reaction to this;

*"Need a bit of space – to stop having to wear the mask".*

*"Social situations can be really difficult – have to become another person to cope".*

*"Self stigma – we don't want to explain ourselves to people".*

*"Actively challenge people who are excluding people. Always someone turns up. Having to defend yourself continuously becomes tedious".*

## Our behaviour

We are aware that at times our behaviour can scare people. Some of us feel that people play on their mental health problems and bring us a bad name.

Our mental illness also makes it difficult to socialise with our local communities; it can be a great effort to get out; we feel that we can't manage in normal company; we lack confidence and worry about joining groups; we worry that we will be seen as weird. The resulting apathy leads to us staying at home; isolated from the community;

*"There are different standards – the expectation is to chat and mix if we can't conform to these expectations then we can feel excluded".*

We feel that we exclude ourselves as our illness makes it hard to communicate, we are not listened to or misinterpreted, and we may misinterpret others.

## Fear of our local community

We exclude ourselves because of our fear of the reaction of the local community if we are open about our mental illness. Ironically, as the local community is scared of us, we too are frightened of the public. Self protection results in us being unable to travel for fear of potential abuse, so we stay amongst users and keep a low profile.

## Stigma / prejudice

We exclude ourselves because we fear being stigmatised by the local community. We are creating a situation of self stigmatisation;

*"Things have changed and we may now be creating our own prejudice by wanting to keep our condition secret".*

Some of us have direct experience of stigma and don't want to expose ourselves anymore. Some of us are concerned about future stigma, so we don't tell our friends that we have a mental illness;

*"If you are already a part of the community then it tends to be OK, but if you want to join in a new community or group then you don't know what to say. You may get unwell and not be around for a time and then become too embarrassed to go back to it and have to explain why you have been unwell".*

We can be defensive which can make people judgemental as they react to our expectation. Our attitudes about society result in us excluding ourselves; a self fulfilling prophesy leading to us being less and less able to take the risk of asking for help.

We may isolate ourselves through fear of stigma, and later discover that when we are open about our mental illness the stigma does not exist. Once we get over our fear of the lack of understanding in the community we find that the community can be supportive. If we ask for help, we generally find it is there.

Stigma varies with different mental illnesses; there is almost an unwritten hierarchy, with depression being much more acceptable than schizophrenia.

## A symptom of our mental illness

Some of us feel excluding ourselves is a result of our illness. When we are very ill we are unable to participate in our communities. It then becomes very hard to do this once we have recovered;

*"We may force ourselves to go out, but that is very, very hard and creates great pressure. We have to force ourselves to meet people, so inclusion doesn't figure".*

Certain mental illnesses seem more likely to result in self-exclusion;

*"We want to hide away - especially with depression".*

Our mental illness can also stop us asking for support;

*"As people with mental health problems we lack the ability / awareness to know that help is there".*

### Historical reasons

We can also feel guilty about what we have been through;

*"If you want to shout and swear, it is best not to do it in public".*

We worry that we have let others down and therefore it can be hard to go back to people when we feel guilty and this guilt increases the longer we stay away. So we exclude ourselves.

Past experiences of ill treatment mean that we have a tendency to isolate ourselves; can't go forward can't go back.

### Employment

We exclude ourselves in employment because we are scared of the consequences of informing our employers. We fear that this will affect our chances of promotion. The pressure of hiding our illness can make it worse.

### Services

The Services and facilities that support us can lead to us excluding ourselves. Attending drop-in centres can feel like hiding from the real world. People with mental health problems may be housed together, in the same areas.

## WHAT IS OUR COMMUNITY?

### The mental health community

For the majority of us, the mental health community is our main community. We feel that this is a strong community, mentioning in particular; drop-in centres, college courses, TAG (*the Training and Guidance Unit*), HUG, and other friends with mental health problems.

*"Here (TAG) is a community. You leave home and come here and don't have to explain anything, here we are open about our difference, we can be ourselves and be more relaxed and more informal, there is no need for a veneer. If you come in and have that look, people know not to say anything or to interfere, they are not tactless, there is no 'pull yourself together' attitude."*

The main benefit of the mental health community is that we are able to meet others with mental health problems; people who are interested in us, who we have something

in common with, who understand, give excellent support, shared experiences and camaraderie. It is a forum where you don't have to explain yourself – so you can. No topic is taboo, there is no embarrassment. We can establish telephone networks, cook for each other and feel at ease with each other. Most of us find it easier to make friends who have mental health problems.

The security we gain from being a part of the mental health community enables us to be more involved in the wider community;

*"Being part of HUG has helped me be an active citizen in community".*

It can be a starting point for our involvement, helping us to cope with the community outside it;

*"'X' gives us supportive, emotional literacy".*

Our experiences of exclusion within the mental health community sometimes related to drop-in centres which despite being greatly valued may sometimes:-

- not be accessible when we are really ill, as it is then difficult to go anywhere.
- cover a huge range of conditions leading to some people being uncomfortable there.
- include everyone (which is good) but the open door policy means you don't know about people's backgrounds - there could be abusers present, as well as victims of abuse.
- Other problems with the wider mental health community are that:
  - being a part of such a community can be a sign of self-exclusion.
  - once you are in the community, it can become difficult to participate in mainstream society.
  - we are vulnerable and closure of any service would destroy the community that uses it.

**The other communities that we use**

Many of us had a number of different communities, often described as being concentric or overlapping circles of community, and including:-

- **Geographical** – where you live; people you are familiar with; where there is the hustle and bustle of ordinary living; where you know everyone; where you lived as a child. For example:-
  - Thurso – *'the same one that everyone in Thurso has'*



- Gairloch – *'everyone knows everyone'*
- Ullapool – *'lots of different communities - pub, incomers, artists, locals. I fit into the artists' community but nobody knows what I have been through.'*
- Groups with similar interests – *'have become my mini-community'*
  - The church
  - The leisure centre
  - The bookies

**Work** – *'without this there would be a feeling of being useless'*

- keeps us occupied and going – keeps connections with the community – weekends are awfully isolated.

- Friends and family

However, many of us felt that we were definitely not a part of the wider, mainstream, community. We should be included in it but we aren't.

Some of us use both 'mental health' and 'mainstream' communities. We need different communities at different times. When we are ill we need a place where we feel safe, this is often the mental health community. When we are better we feel able to reach wider groups and gain a wider circle of friends. This can be very positive and helps us meet more and more people. However, if we get ill again we can withdraw to the mental health community where we feel safe.

For some of us becoming mentally ill has led to us making lots more friends, both from the mental health community and the wider community.

Some of us struggle to recognise any kind of community. We feel that as individuals we are our own communities. We find that our experience of mental illness means that we are always on the edge or outside community;

*"My own experience makes me extremely self-reliant – an island – my own community".*

#### **WHERE DO WE FEEL PARTICULARLY INCLUDED?**

*"Only because of organisations like HUG have I found a safer space to be in".*

For many of us the mental health community is the place we feel particularly included. This community can take many forms; in particular drop-in centres, Community Mental

Health teams, HUG meetings and being a member of TAG. The reasons these places include us are associated with both the premises and the individuals there.

The premises, in places such as drop-in centres, have to be a suitable size to give us personal space, and also room for communication. We have to be able to rely on their existence, and feel that we have some ownership over it. It is our space.

Some of us had experienced feeling excluded even when we are somewhere which we feel should be an 'appropriate place' for us to be (such as a Psychiatric Hospital), along with others with a mental illness. We feel that there can be segregation between different mental illnesses. It is our common experiences that result in inclusion, rather than just the blanket label of mental illness.

People in mental health organisations (both staff and other users) make us feel included by spending time with us, giving us an opportunity to contribute, showing us we are valued, not waiting till we ask for help, being understanding about how we are;

*"If you were in tears in a café or at work, you wouldn't be included. In TAG you are".*

For the majority of us the things that make us feel included are not exclusive to the mental health community, but are to do with being accepted, understood and feeling valued and useful. They are about people rather than premises.

We feel included when enjoying ourselves the way everyone else does. For example when we are spending time with someone, a night out, enjoying ourselves with friends, attending groups such as drama, going for a drink, going for a walk or playing football.

We are included when we spend time with people who understand and value us as individuals - generally family and friends. They make us feel included by being sensitive to our moods and inviting us to share activities with them. Sometimes this can include professionals such as our doctors. One of us has had the same doctor for 30 years and he has become as much a friend as a professional.

For many of us, feeling that we can make a useful contribution is essential to our feeling of inclusion. Examples of this are:- making a DVD of our personal testimony for training, holding a sale of work, being asked to work, having our musical talents recognised, helping others.

*"Employment has helped in making friends and has helped trusting relationships to be built up. Being known as a hard worker has helped me establish a good reputation".*

Money was mentioned as an important factor in inclusion. We feel included when we can afford to participate in activities and see friends.

## DO WE FEEL MORE COMFORTABLE AROUND OTHER PEOPLE WITH A MENTAL ILLNESS?

Many of us were very definite that we feel much more comfortable around other people with a mental illness;

*"The madder the better"*

Through our mental illnesses, we have often had very similar experiences and this means that we can understand and relate to each other. This gives us something to talk about and makes us feel that we are not alone. We identify with people who have similar concerns, such as being anxious. We can find it comforting to be with others who are experiencing more severe mental illness than ourselves.

We support and help each other. We find that other people with a mental illness are more caring and that we have a natural shared empathy;

*"You don't tell me what to do. You help me to help myself".*

Ease of communication is one factor that makes us more comfortable with others who have a mental illness. We can talk openly about our illness;

*"You don't have to guard your tongue",*

This helps us feel better. We don't have to pretend that we do not have a mental illness and therefore don't face unreal expectations from each other. Many of us feel that we are non-judgemental towards each other;

*"You don't have to watch yourself in case you give yourself away."*

With each other we feel a sense of safety and sanctuary.

Others felt that they do not see much difference in how they feel between being with others who have a mental illness or those who do not. The people who we are most comfortable with are those who are kind, decent, honest and understanding, regardless of their mental health.

Some of us felt that we are less comfortable being around others who have a mental illness particularly when their illness has resulted in violent behaviour.

There can be stigma between different mental illnesses. Some of us feel more at ease with those who have depression than those who have schizophrenia.

## DO OUR NETWORKS REACH INTO MAINSTREAM SOCIETY?

We have a very varied opinion on whether our networks reach into mainstream society. Some of us feel that this is the case. We mentioned the HUG network in particular.

Sometimes it can vary. When we are well we make links through our networks to mainstream society, for example through an outing with our drop-in centre, or by speaking at a conference with HUG. However, when we are ill, we can come away from day to day life and feel we need to stay in the mental health community.

Most of us had experienced our networks as being separate from mainstream society. We feel we tend to exclude ourselves or form our own sub-culture.

Those who are unaware that they have poor mental health may not be able to join in the mental health community, which may be the only one available to them. They can end up very isolated and lack the support we can offer each other.

## WHAT DOES MAINSTREAM SOCIETY THINK OF US?

*"There are malicious people out there - their ignorance does not excuse the way they are, even if educated about mental health they will still be like that".*

We feel that there is a section of mainstream society with an automatically negative attitude towards mental illness. Their common associations with mental illness are words such as 'nutty', 'crazy', 'off her bloody head', or with violent acts which they see as our fault, not as a part of illness. They link mental illness with groups such as paedophiles;

*"Sick of all these paedophiles and schizophrenics living next to us".*

They are judgemental about mental illness and feel we have brought it upon ourselves.

These negative attitudes often result in malicious actions towards us. In particular from children, who 'take the piss' out of mental patients, and can be cruel to our children;

*Children at school ask my children; "are you going home to that woman", and say; "your mother is off her bloody head".*

Nurses working in psychiatric hospitals were also occasionally mentioned as a group who are prejudiced against mental illness; actions mentioned included ignoring us when we are out of hospital;

*"You do not see me, you do not speak to me. I do not exist when you are in the community".*

The attitude of the media towards mental illness remains a problem, and may have got worse. We feel we are an easy target for the media as we make a good story;

*"Schizo maniac doesn't take medication and kills someone".*

Documentaries, plays and media articles can be very negative about mental illness and we feel that there is a tendency to try to make links between mental illness and violent crime and paedophilia. The language used by the popular media does not help.

*Radio 1 DJ comment:- "to the nut house".*

Fear is another common reaction from mainstream society. This can be due to a pre-conceived idea of mental illness, or being afraid of what they don't understand. Some of us felt that society's attitudes depend on whether we fit the mould of someone with a mental health problem. If we are empowered people (society) can find that threatening.

However, some of us also felt that mainstream society does not think a lot about us, largely due to ignorance. People can be very stand offish. They jump to conclusions and are uncomfortable with us and feel that they do not know how to speak to us.

The ignorant attitudes of mainstream society result in actions such as:-

*"They don't understand that we can't have too much pressure so when we say we can't see them on a particular day they may take offence and stop the friendship".*

*"They see us get ill and are accommodating to start with, but when we don't get better quick enough they can write us off as a waste of time".*

*"You have to justify yourself".*

Mainstream society can see people with mental illness as a burden. There is an assumption that we can't do much, and that we could snap out of it if we chose. Words used to describe us are 'scroungers', 'wasters' and 'lazy'.

Some of us feel that mainstream society's view varies, both in that it is generally changing for the better, and varying between individuals.

In the general change for the better we are finding that while there is still ignorance, education is improving this. People are talking about mental illness more, there are more good programmes on the television covering mental illness, and the work of groups like HUG in schools changes things.

Changes vary between individuals. There is more interaction between us and mainstream society. Some people are more understanding than others.

*"Attitudes can change, especially if we become more open ourselves. However, if we are open about it there is still alarm - imagine saying; "I'm feeling fluey today", at the bus stop. That would be fine. Now imagine saying; "I'm feeling really manic today"."*

We find that the prejudice is generalised against us as a group, but when we are seen as individuals it tends to be OK. Once people meet us they are much more understanding and see us just as a people.

Many of us had experienced increased curiosity from mainstream society. We felt this was connected to the portrayal of mental illness in the media;

*"on 'Women's Hour' every week."*

As a result of this there seems to be a desire to understand mental illness;

*"People stop me in the street, they want to understand and ask the right questions, but don't seem to get it. I am the Celebrity Bi-Polar!"*

Some of us felt that things had changed so much that people with a mental illness are now completely accepted. We are mainstream.

We had mixed feelings about mainstream reaction towards us. Many of us feel the reaction of the establishment to mental illness is very important.

*"I want people to think that I am intelligent; to like me."*

Others feel that it doesn't matter what society thinks of us;

*"I don't care (now). For the great bulk of my life I have seen so much, experienced so much, my inhibitions have fallen away."*

We feel that most people are touched by mental illness and exclusion does happen, but with one in four people experiencing mental health problems at some point, it impacts on virtually everyone. Exclusion is created for no reason. How can we exclude people because of a condition that affects everyone?

## WHAT DOES MAINSTREAM SOCIETY THINK OF MENTAL HEALTH SERVICES?

*"The stereotype is of places [mental health services] in the back of beyond, all hidden away and hard to get to. Their shame makes us ashamed and encourages us to hide too. We should have bright, cheery, open, explicitly mental health services on the High Street. It is very frustrating; so much more could be done if we could be open."*

There is a great deal of stigma about using services and the services themselves. Most people have a negative image of mental health services connected mainly with psychiatric hospitals, of which they are fearful. They use words and phrases like 'asylum', 'people locked up against their own will' and 'being sent to the loony bin.' People often associate mental hospitals with prisons;

*"Have you been in Cornton Vale? No, I have been in a locked ward of a psychiatric hospital and that was enough for me".*

In the Highlands the main association was with Craig Dunain, and is now with New Craigs. We feel that there was a huge stigma about Craig Dunain, and that this still exists for New Craigs. People know about New Craigs but some of them still picture the image of Craig Dunain.

Other than psychiatric hospitals, another general image of mental health services can be of people being hypnotised on psychiatrists' couches.

Many people do not have any impression of mental health services. They are uninterested as they feel it is irrelevant to them. They are often unaware of the services that are available and what they do. If they gave it any thought we felt they would be likely to prioritise treatment of physical illness, rather than mental health.

Others think that we are very well looked after, and that the services are good. They do not feel that there is any stigma around mental health services.

GPs' views about mental health services were mentioned in particular. Some of us have experience of GPs who appear to be nervous about mental health issues and would prefer to pass on our case rather than take responsibility;

*"GPs want to pass us on to New Craigs"*

Others have doctors who don't seem to accept mental illness, for example depression.

However some of us felt that people are now much happier to go to their doctor with symptoms of mental illness, whereas in the past they wouldn't have sought help.

## HAVE ATTITUDES CHANGED OVER THE YEARS, AND IF SO, WHY?

*"Two generations ago anyone with a mental illness was excluded. One generation ago there was a lack of understanding and uncertainty about what to do with us. Now people are much more interested and want to help".*

Most of us feel that society's attitude to mental illness has improved slowly over the years, particularly at a national policy level and in relation to children's attitudes;

*"Now kids just pass by (the Haven). They used to shout".*

There is much more awareness of mental illness, which has led to increased acceptance. Mental health has become part of our common vocabulary. This increased awareness is largely due to more of the public knowing people, both friends and family, with mental illness. We feel this increase is due to several factors:-

- A greater number of mental illnesses being discovered / recognised.
- More people suffering from mental health problems.
- More people with mental illness living in the community rather than institutions.

Changes in the way services are provided was one of the most commonly mentioned causes of improvements in society's attitude to mental illness. This included:- more people living in the community, nicer hospitals, more drop-in centres, doctors getting more mental health training, and (for some of us) the change of name from Craig Dunain to New Craigs;

*"Changing the name from Craig Dunain made a big difference. New Craigs has lost the loony bin attitudes".*

There was a suggestion that to improve things further there should be New Craigs Open Days.

Improvement in the attitude of society to mental illness is also due to improved education of the public through campaigning and awareness raising by mental health groups;



*"Less ignorance in mental health – education, education, education".*

National campaigns such as 'See me', and publicity by people in the public eye, are making a difference. The work of HUG in challenging stigma has contributed to society evolving. We feel that the work of HUG in schools has changed children's attitudes and demonstrates that education of children in mental health issues should be a part of the curriculum. Some of us feel that it would be better if education of children happened earlier and primary school children received mental health education. This may be frightening to some but they often have an insight anyway and just don't realise it. It could bring them comfort.

Some of us felt that improvement in society's attitude to mental illness is due to us learning to believe in ourselves. This has led to group action such as the campaign by the users of Gardeners Cottage in Nairn to keep their facility.

We felt that society's attitude to mental illness can sometimes differ depending on which mental illness is being discussed. Some illnesses, for example depression, are more acceptable than others. People who don't have a recognised mental illness can find it more difficult to deal with issues around stigma and their own attitudes.

Others felt that there has been no improvement, prejudice still exists, the media exacerbates this by portraying peoples with mental illness in horror roles; and the result is that people still see us as dangerous.

# THE RIGHTS OF PEOPLE WITH A MENTAL ILLNESS

## HOW AWARE ARE WE OF OUR RIGHTS?

*"We know our rights to be human."*

Many of us feel very aware of our rights. This has been gaining over the years, and we are now more aware than ever before. For some of us this has come about through particular events:- 'been to court and won', 'had our rights taken away - which made us aware of them'. The Scottish Executive's Mental Health Act pamphlet was specifically mentioned as something which is full of descriptions of our rights.

Though we have a good awareness of our rights we don't feel that this is always the case for the rest of society, who have not moved on in perceiving disability as including mental health problems.

However, though we have an awareness of our rights, we have problems getting them upheld:

- Sometimes we are too submissive. We can't turn round and say 'no'.
- Sometimes what we want is not respected - even if we think it is a right.
- Sometimes we are treated like children and this can be hard to challenge.

Getting our rights upheld is closely related to how we feel about and portray ourselves. Improvements in confidence and self esteem make it easier to access our rights.

Support can be crucial in getting our rights respected. Many of us felt our rights are stronger if people in official positions are involved as supporters. Having a supporter makes us feel more assertive, which gives us personal confidence in our rights. Services we mentioned in particular were advocacy services (including the old Citizens Advice Bureau Advocacy Service) and lawyers.

Some of us were uncertain about our rights. We find it difficult to find information, take it in, and work out which information we need because there are lots of different policies. If we are very ill then our perceptions of our rights can change.

Some of us feel unaware of our rights, or know others who are unaware. There are times when we feel this is more likely to occur:-

- When we first experience mental illness.
- Long-term hospital patients.
- When we are ill we can be so ill that we stop being aware of our rights.

There are also certain areas where we feel particularly unaware:-

- What to do if you disagree with treatment.
- Rights contained in the new Mental Health Act.
- The obligation on society to support us.

There are also areas where we may be aware of our rights, but disagree with the policies that are in place to deliver them:-

- Benefits trap.
- Confidentiality. We should be able to choose *what* should be told and to *whom*.

Sectioning is clearly an area which closely concerns our rights. Many of us fear a section because we lose rights. We worry that sectioning is getting a bit fierce, and need to be sure that voluntary admissions to hospital are the preferred option. However, others have had the experience of building a more trusting relationship with professionals, especially the psychiatrist, which has made this less scary.

## HOW DO WE GET INFORMATION AND ADVICE ABOUT OUR LIVES?

There are a number of places where we look for information and advice:-

Mental Health Services including, the Community Mental Health Team, drop-in centres, psychiatrists and advocates. We get information from New Craigs, where we can pick up leaflets.

Other places we mentioned were LIGs (Local Implementation Groups), Disability Advice Line, New Craigs Patients' Council, and the Disability Rights Commission.

Many of us find the internet a very valuable source of information. However we have concerns about the information that is on it, about the fact that it is unrestricted and may be provided or used irresponsibly. Examples included:- being able to find out how to kill yourself, discovering a website advertising 'Miss Anorexia USA', and adverts for unprescribed medication. Some good websites have a facilitator with a recognised qualification, and boundaries established to protect people.

HUG itself is a resource for information and advice, from the Newsletter, Website, meetings, Round Table, and the HUG staff. Some of us are on various committees through HUG and these give us information and advice too.

We also obtain information and advice from the same places as the general public:- libraries, family and friends, Citizens Advice Bureau, GPs, the Media, including TV and newspapers, each other, Service Points, Teletext and solicitors.

Much of the information and advice about our lives is out there and relatively easy to get, but there are a number of crucial factors in relation to accessing it:-

- You have to be in the system before you get the information. We find it difficult when we first have a mental health problem to know where to go.
- You have to be confident and know what questions to ask to get the information. You cannot be shy about asking for information.
- You have to translate jargon.
- You have to make an effort to get information and really search for it.

Some of us had experienced, and still experience, problems accessing advice and information. There are gaps in the information we are given. Our friends and relatives can't help because they don't know where to turn. We are unsure of what is good information, and we are given information but do not read it.

#### **DO WE NEED SPECIALIST HELP IN ACCESSING INFORMATION?**

Some of us felt that we do not necessarily need specialist help from an expert in mental health. What is most important to us is the attitude of the person providing the help; that we trust them, they know what they are talking about, are able to describe things in layman's language, and are kind and understanding.

However, many of us felt that specialist help is necessary for both us and our carers. We often don't know what is wrong or going on with our mental illness and our diagnosis can change over time. We need someone who has specialist knowledge of mental illness to explain things to us. In order to access services we often need a specialist referral. In our experience, self-referral can result in rebuttal, as services are not always geared up for enabled, empowered people with mental health problems. We feel we need specialist advice on how to present ourselves and get information.

#### **WHO SHOULD PROVIDE INFORMATION TO DO WITH OUR LIVES?**

The people who provide us with information should be people we know and trust, ideally with a background in mental health. For many of us these are staff working in the mental health field including:- staff in drop-in centres, psychiatrists, CPNs, support workers, and social workers.

We would like to have nurses to welcome us at the door of New Craigs and let us know what to expect on admission.

The Citizens Advice Bureau is an excellent source of information and support, particularly with benefits claim forms. Some of us feel they should have specialist mental health outreach services.

Other sources should be:- each other, the internet, books, library, our GP and others who are professional on the particular subject.

Problems accessing information include bureaucracy, lack of time, lack of experience and confidentiality issues.

## CONTROL

*"No one can be in control. It is affected by chance and upbringing and environment. The most we can have is the feeling of being in control".*

Some of us, a minority, felt that we are largely in control of our lives.

The majority of us feel that we experience varying levels of control dependant on; how well we are, how long we have been ill, our medication, the relationships we have with the people who support us, and our knowledge of the 'system'.

Many of us feel that we have no control, and are often powerless. This lack of control is a result of a variety of factors including:- our illnesses, having to negotiate the system to receive support, and poverty.

For many of us lack of control is a direct effect of our illness. Our illness makes concentration very hard, makes us feel socially inadequate, and we feel we lose some of our abilities. The more ill we are, the less awareness we may have of our illness;

*"No control at all – gay abandon, can't finish things. Illness makes it hard for me to have control - Hop, skip, jump and accident".*

*"Mental illness can take away control. As you learn to live with it and accept it, you can regain some control. As I have grown up with my bi-polar I have gained ability in educating my life through self management and exercise".*

Some of us are able to negotiate and work with the system to receive the treatment and support we need to get well. However, this can mean that we have to remain ill to qualify for help. We had many examples of this including:-

- Self-harm to get help.
- Accommodation dependant on me being ill and being on benefits.
- Supported accommodation – you sometimes need to stay ill to keep your house.
- Benefits - husband and wife who both have mental illness and are recovering, have to get jobs at the same time or lose too much benefit.

Some of us feel that poverty is a very significant factor in the amount of control we have. Many of us are unable to work due to mental illness and the resulting lack of money limits what we can do. We are unable to pay for some of the support we need, i.e. we have to contribute to respite care, without which our condition can be exacerbated.

*"War veterans can access respite care. We need a trauma survivors' centre".*

We felt that these feeling of lack of control are not confined to those of us with a mental illness but are experienced by society as a whole;

*"Everyone has a life that has problems that they need help with. We can work together to make our situation better. We are all interdependent on each other".*

## DO OTHER PEOPLE MAKES DECISIONS ABOUT US?

We had many, many examples of situations when other people make decisions for us, or try to.

**Hospital** was the most frequently mentioned place where other people make decisions about us. This ranges from sectioning when some of us feel we have lost all right to make decisions and can feel that 'punishment techniques' are used;

*"If you are bad, they stick you in the locked ward".*

There may be restrictions on visitors occasionally or some of your personal possessions may be removed or what seem like everyday decisions may be taken away from you. Other people (friends and family) also make decisions about when and whether they will visit, regardless of our views;

*"Once you go to New Craigs you lose all control because 'they' think you are batty".*

Medical Professionals make many decisions about us;

*"The attitude of the medical profession in general is to make decisions for us."*

This varies depending on the doctor concerned, but many of us had been in situations where we felt the professionals had more control of our lives than we did. This is particularly so when we first become ill because they have much more knowledge about our condition and medication than we do;

*"What we don't have is the knowledge that they have, and they don't always share it. This gives them power over us. How do we know that we can put our trust in people who have such power?"*

We need a partnership where we both listen to each other. They need to listen to us as carefully as we listen to them.

Others who make decisions about us include the Government, particularly relating to benefits, local Council decisions, and our families.

Some of us felt that it was not the case that other people make decisions for us. We make decisions by using particular methods of support:- advocates, support workers, and witnesses.

There are times when, due to our illness, we are unable to make decisions, Advance Statements are another effective way of being able to have a say in decisions;

*"My Advance Statement gives me control over other people's control".*

Sometimes having a certain amount of control can make a big difference and avoid us feeling steam rolled.

A few of us felt that the experience of mental illness had made us much more aware of and determined to speak up for our rights, compared to when we were free of illness;

*"Probably less at risk of being taken advantage of than when I wasn't ill; then I would just let it pass by".*

## DO WE EVER WANT TO HAND OVER CONTROL?

There are certain times when we feel that we need to hand over control, when we don't want autonomy or responsibility, and having decisions made for us can be a luxury.

Principally this happens when we are ill. Then we want to hand over control as we feel that we can't cope alone, we don't care what happens, we can't look after ourselves, can't think straight, have no energy and the stress gets too much. When this happens we need care to heal and get well;

*"You just want looked after".*

Hospitalisation can be very welcoming;

*"Didn't know what was good for me; needed therapeutic support; not capable of knowing what to do next, but liked to think that I did know best. I will always need support".*

Sometimes we want to hand over control because our illness has resulted in us becoming unsafe and at risk;

*"I'm important that someone will hold me and stop me falling".*



*"Mostly I know what's good for me. At times it goes beyond that and I need help".*

Though we may want to hand over control, the way in which this is handled can have a huge impact on the outcome. We should be able to hand over control when ill, but should be listened to. Our thoughts should still modify the decisions. A gentle approach can be much more effective than dictatorial;

*"Nurse did a brilliant job of challenging my delusions. An outside perspective very gently challenged all I was thinking and made me get better more quickly".*

When we begin to recover we need to regain control.

Some of us couldn't think of any time when we would want to hand over control;

*"That is the worst that can happen. We need to have the hope that we can have a say".*

The thought of losing control makes us feel angry. As a minimum, we need choices and to have a say.

## WHEN MUST WE HAVE CONTROL?

There are certain times when we feel that having control is crucial:-

- When we are well, living ordinary lives, we should have as much control as anyone.
- When we are looking after our children.
- When we are at risk of being taken advantage of.

We felt that with certain professionals, for example psychiatrists, it is important that we have a feeling of control as some of them appear arrogant and think that they know better than us.

There are certain stages of our illness when it is vital that we feel in control, these are largely around the time when we are starting to get ill, and then again when we are starting to recover.

## WHAT DOES IT FEEL LIKE NOT TO HAVE CONTROL?

We had very mixed views on how it feels to not have control; both very negative and very positive.

The most common feeling on not having control is to be frightened, or even terrified;

*"The idea of having treatment forced on me or having to go into hospital is my biggest fear".*

Others felt lonely, lost, imprisoned, punished, frustrated, threatened and angry. Feelings on loss of control were very passionate;

*"I would kill myself if they took my control away",*

*"Everything (bad) that has happened to me has been through letting go of control over what I wanted".*

Some of us had good experiences of having control taken away from us. We felt that though it is scary, it is necessary at times. We may already feel that we have lost control of ourselves;

*"When you are psychotic you can lose control and do wrong things and put yourself in jeopardy".*

Sometimes we feel that we have to actually lose control before professionals understand our situations properly. The process of having control taken away by professionals can be reassuring occasionally and result in us feeling understood.

For it to be positive, it is very important that this process is handled very sensitively. Often then the most important factor was being listened to;

*"I was first sectioned because I would harm myself. My second section was almost requested because I felt so exposed. I was happy to have control taken away, but it was important that I was listened to during the sectioning meeting".*

The language used is very important. To say "I would really rather you went in voluntarily", instead of saying "You have been sectioned" makes a big difference. We should be sectioned with love.

## HOW DO WE GET CONTROL BACK?

Recovery helps us to get control back; often sleep and time helps. We need to get well and get a logical perspective.

Speaking up also helps us to regain control, particularly if it leads to being listened to and having our opinions respected. Joining together with other people who have had similar experiences makes us feel that our voice is heard amongst the safety of a lot of users. The strength of being part of a strong group, 'People Power', helps us

regain control. We felt that politically, mental health service users and friends could swing any election. One suggestion was setting up 'The Nutter Party'.

**Support** is vital in gaining control. It is important that our insight into our illness is acknowledged, and we are listened to when we ask for support. Self-referral should to be taken at face value. Support to act for ourselves, such as by a relative or an advocacy worker, helps us regain control.

*"My wife made me stand on my own two feet. She said that to get out of hospital you square it with the doctor yourself. She had every confidence that I would".*

*"I got control of my life when 'X' took it over".*

**Other** means to regaining control are medication, education, advance statements, rebellion (break a section), and just exhausting the system;

*"They get fed up and throw you away."*

## WHAT DO WE MEAN BY EMPOWERMENT?

Some of us had very little idea what the word empowerment means and indeed some of us had little interest. However most of us did have a clear idea of what we felt it meant.

To us, it is about being in control of our own lives and about regaining personal control having lost it in the past. It is also about being able to regain power over our lives and being able to exercise this power rather than having someone else tell us what to do. Connected with power is having the freedom to choose and make decisions about our lives and the freedom for us to choose how we see, view and define our own lives.

Empowerment also involves having appropriate information provided on which we base our decisions and being able to speak up and being listened to when we try to get our point of view across. In order to be listened to, empowerment also places an obligation on those around us to respect us and to recognise that we also have a personal knowledge and belief about our condition and life that needs to be listened to as much as the views of experts.

It means a feeling of autonomy and not being treated differently to everyone else.

## IS EMPOWERMENT A GOOD THING?

For most of us empowerment as an idea is very important, for some of us it is vital and a really important factor in our health and well-being.

Some of us were less certain, feeling that empowerment was important but not imperative, and a few of us had reservations about it. We felt that if we have autonomy and express our own feelings of personal power that we will not easily fit into the mental health system and may suffer as a result. In addition a few people resisted the idea of 'being empowered'. It smacked of the idea of being done to and changed by outsiders rather than through our own free will.

## **HOW DO WE ACHIEVE EMPOWERMENT?**

First of all we need to want to be empowered and once we want it then other beliefs come into being. We need to have a life that matters to us and to believe in ourselves. We need to be able to cope and look after ourselves. This involved us behaving and being respectful, responsible, honest and direct. To do this we need to be able to talk on an equal footing. It involves a lot of hard work about feeling better and having the impetus come from us in the first place.

Then we need to educate ourselves which includes knowing the system, knowing our rights and getting the right information to make our own decisions and choices.

This process is often gradual and means that it can take time and space with the possibility of a gradual healing and the need to learn to heal.

The work of groups such as HUG can be a big influence on our own personal empowerment and the culture that supports the idea, but such groups do not appeal to everyone and don't represent the whole solution. It would be good to learn from other disability groups who may have got further ahead than us. We need to learn to help each other and to take individual and collective responsibility to achieve the change we want.

Despite this, we did feel that empowerment can be very difficult especially if we are suffering from illness. Simple things such as a lack of money can hinder empowerment and the attitude of professionals can be crucial. Sometimes they are our route to empowerment and on other occasions they are the main barrier that we face.

## **DO PROFESSIONALS HELP US ACHIEVE EMPOWERMENT?**

We had mixed views about this. Many of us felt that the actions of our helpers were instrumental in helping us regain power over our lives and improving our sense of wellbeing. Yet others felt more cynical. We didn't feel that professionals helped in this area and that they tended to hold onto their own power at our expense. The fear that we had of their opinions and actions in the face of more assertive activities from us made some of us resist the idea of empowerment.

## SHOULD PROFESSIONALS HELP US WITH EMPOWERMENT?

Most of us agreed that professionals could play a vital role in this area of our lives. They can help us reach our goals especially if they give us information, are respectful, treat us genuinely and help us believe in ourselves. It should be a routine part of their jobs and would help us regain our own power, stop us being dependant and also helps us with our recovery. However not all professionals have the skills or understanding to help us with this and despite their best efforts until we take ourselves seriously, no one else can help. We can also help each other in this struggle.

## IS THERE ANYTHING WRONG WITH RELYING ON OTHERS?

The last area that we looked into was the idea that we should all aim for independence. As usual we had a wide variety of views:-

Some of us felt strongly that relying on others was not a good thing. We have no one to rely on and are alone and need to stand on our own two feet. Independence is very important and becoming dependant on others can take away our individuality.

Being dependant is a big risk. It can lead to institutionalisation and makes us reliant on support workers (amongst others), but we will ultimately need to live without their support. It can make us very exposed and puts us into the risky situation of relying on people who may let us down dramatically.

For many of us there are pros and cons in having to rely on other people. Whilst we need to be able to do things for ourselves and live our own lives it is also important to acknowledge the effect of others on our lives. There is a fine balance between being healthy but relying too much on other people, and relying purely on ourselves.

The majority of us were keen to make the point that there is nothing wrong with being dependant on each other. We all rely on each other; none of us are separate islands. In fact the idea that we rely on each other is a natural part of our common humanity. Something as simple as doing the shopping involves relying on and trusting many people. The idea of independence has its attractions as long as it doesn't detract from the mutual dependence we all have in relationships and everyday living. In fact the possibility of depending on other people can be key to our very survival. Trying to make us overly independent may not always be sensible thing to do, just as it is not always wise to rely too much on other people.

## CONCLUSION

Members of HUG had a wide variety of things to say on the subjects of control, inclusion and exclusion.

A sad reflection on people's reality was the following quote:-

*"It's a bit like a pack of wolves; the pack will fend off outsiders and the weakest wolf can be turned on by the pack; some of us are loners."*

Some of us felt that we are the outsiders and the weak members of the pack and that this brutal reality will never change.

In contrast other members saw change as a reality that was drawing ever closer.

They said that stigma is a result of difference. It is ever present and allows the weakest to be picked on and abused. However they did not see this as permanent and cited other oppressed groups who had created a change in attitude by celebrating and enjoying difference. Instead of trying to fit a conventional but unattainable norm they felt comfortable and happy with their own experience, culture and community and refused to allow their difference and diversity to be something they were ashamed of. They felt that with this attitude we could grow and believe in ourselves much more comfortably.

This report graphically describes some of the harsh realities people with a mental health problem face. Discrimination, abuse and stigma are a daily reality for many of us and the cultural attitude that so many of us hold about mental illness means that even if we don't suffer direct discrimination, we may be so embarrassed and ashamed that we exclude ourselves.

The reality of our illness also means that exclusion comes to be a routine part of life. For some of us the effort of mixing and putting on a front of coping is just too much to cope with.

However we do feel that this situation is changing for some of us. There are many members of HUG who feel that they live in supportive communities with little exposure to stigma, and equally there are many of us who feel that the impact of anti-stigma initiatives and a growing awareness about the subject of mental health issues by the public is causing a change in attitude towards us.

## CONNECTING COMMUNITIES (INFORMATION COMMUNICATION TECHNOLOGY) PROJECT

This Project is an extension of the Connecting Communities 3-year Lottery Funded Project which finished in June 2004, and builds on the experiences and strengths gained during the past 3 years. It runs from October 2004 to October 2007.

### Aims:

- To support and enable a wide range of service users and carers to contribute and communicate their experiences through video and audio. This allows beneficiaries to speak out using video or audio media, which can then be used in training courses for nurses/social workers.
- To use ICT to develop telephone conferencing for carers to break down isolation and provide advice, support and information.
- To create on-line bulletin boards, instant messaging and chat facilities for people with mental health problems and pilot use of web cams to facilitate communication and break down isolation.

### The need for this project

The inclusion and involvement of service users and carers takes time. This project is a continuation of the Connecting Communities Project, which was aimed at including more users and carers and supporting them to have a louder and more influential voice. Through discussions, the Highland Users Groups have identified their preference to use video as an awareness raising and support tool for mental health service users. They have also identified the need to use ICT as a means for support and inclusion. People First members collaborated on their first video with students in Thurso. They identified bullying by young people as an important issue for them. People First groups now do similar work in other parts of Highland and also produce educational material about their lives in order to influence services and public perceptions of people with learning disabilities. The Highland Carers Project have identified the need for support mechanisms to combat physical and psychological isolation through discussions with carers.

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## APPENDIX 2

# ACTIVE CITIZENSHIP

### WHAT DO WE MEAN BY IT?

- § Taking part
- § Volunteering
- § Feeling a member of society regardless of how you are seen by it.
- § Having enough mental health to feel pleasure in helping another person- giving up your seat, holding a door open for someone else.
- § Getting a buzz from being involved

But we can feel that we are not able to do this because of illness

You should be valued and looked after and accepted for who you are and helped to become an active citizen through support and encouragement

- § Being a part of our local and broader community
- § Going to church is being an active citizen
- § Being a member of hug is being an active citizen
- § Being involved in community groups
- § Attending a class to learn new skills
  
- § Feeling that you have a stake in the world you're in
- § Having responsibilities
- § Helping each other – advocacy and peer support
- § Kind words
- § Giving to charity and others
- § Having something to believe in
- § Spirituality – (bible “without vision the people perish”)
  
- § Acting to help each other; turning words into action.
- § Being able to accept other peoples gifts
- § Receive graciously
- § Accepting other people as individuals regardless of any labels
- § Accept everyone is unique and special
- § Accept everyone unconditionally.

Looking after ourselves and valuing ourselves first

See the ten commandments and any equivalent from other religions



Accept that giving back has joy as its own reward  
Join to help people gain the rights they might not have

Treat others as you would like to be treated by them

Respect for yourself and others  
Have the confidence to give and make connections  
Dare to connect.

Have the confidence and freedom to vote  
Use your right to vote

Acknowledge every persons human rights

Celebrate the life we all lead.

## **BARRIERS TO CITIZENSHIP**

Stigma  
Discrimination  
Illness  
Mental ability  
Motivation  
Articulacy  
Wellness  
Confidence  
Other peoples attitudes  
Status  
Class barriers  
Cultural barriers  
Wealth  
Poverty  
Isolation and social networks  
Homelessness  
Institutionalisation  
Medication  
Dependency on other people  
Lack of vision  
Insight  
Lack of opportunity  
Lack of education  
Exclusion by society  
Societal misconceptions

Lack of social support

## HOW TO HELP US BE MORE ACTIVE

Having resources and an income and expenses

Being able to afford the things you want to do.

Being helped to believe in our abilities

Having programs to improve understanding and change attitudes to mental illness

More opportunities to get involved in things that seem meaningful

Results to our activity

Positive feedback to activities

Being encouraged

Information

Help to develop skills

Change in culture

Availability of messages to inspire

## 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.*

*However if you use this report or quote from it or use it to inform your practice or planning please tell us about this first. This helps us know what is being done on our behalf and helps us inform our members of the effect their voice is having.*

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

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