



'INCLUSION'

OUR MENTAL HEALTH SERVICES AND THE WIDER COMMUNITY

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**Highland Users Group can be contacted through Graham Morgan,
Highland Community Care Forum, Highland House,
20 Longman Road, Inverness IV1 1RY**

Telephone: (01463) 723557 / Fax: (01463) 718818

email hug@hccf.org.uk

www.hug.uk.net

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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 342 members and 13 branches across the Highlands. HUG has been in existence now for 10 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 groups and interested parties.
- To increase knowledge about resources, treatments and rights for users.
- To promote cooperation between agencies concerned with mental health.

INTRODUCTION

For many years members of HUG have talked about how hard it can be to be subject to the lack of understanding that surrounds mental illness, and how hard it is to be excluded from many of the aspects of daily living in our society that so many other people take for granted.

The vast majority of our members are unemployed, many of us have few friends and many of us don't have close relationships. We often have little to do and sometimes little to look forward to. We may believe that we are likely to spend the rest of our lives on benefits, find the thought of going on holiday an unlikely prospect and can be faced with ignorance and misunderstanding from much of the rest of society.

We have been trying to challenge this for many years through the work of our 'Stopping Stigma: Raising Awareness Project' which works with our members to educate young people about mental health issues, deliver mental health awareness training to professionals and others, produce training and educational DVD's based on people's personal testimonies, encourage accurate reporting in the media and use I.T. in a variety of ways to improve understanding and change attitudes.

We have already produced a report entitled 'Control, Inclusion and Empowerment' (2005) which looks at this subject in some detail and which is available from the HUG office or our website (www.hug.uk.net).

Many of us would say that we have been excluded, either by the people and culture that we are a part of, or by our own internal stigma and awkwardness that sometimes makes it hard for us to mix with so called 'normal' people.

Over the last few months the idea of 'inclusion' has been a topic of much conversation, especially in light of Section 26 of the 2003 Mental Health Care and Treatment (Scotland) Act which promotes the provision of wellbeing and social development for people with mental health problems.

However, although we are often excluded, and can be angry about this we are not always sure what it would mean to be 'included' or sure about how we would like it to happen.

We have been hearing rumours that when we take into account the ideas of 'inclusion' and its connection to social justice and equity, mental health

facilities which are exclusively for the use of people with mental health problems may be regarded as inadvertently preventing the inclusion of people with mental health problems.

So, for instance, instead of getting food at a drop-in centre why not go to a café? Instead of studying for new skills at a mental health training centre why not go to the local college? Instead of socialising in a resource centre why not make new friends in our own neighbourhoods? And, instead of going on outings just with other people with mental health problems why not go out in the ways that everyone else does - join the ramblers, go to an art class, go to the cinema?

Whilst not entirely clear about where these rumours came from we gained the distinct impression that drop-in / resource centres and other dedicated mental health facilities or user-only gatherings were coming to be seen as part of the problem rather than a source of help or support. In effect they were creating their own mini ghettos that were discouraging us from joining in with life again.

We decided to look at this subject in our bi-monthly round of meetings. We met in the early summer of 2006 and held discussions in our 13 branches across the Highlands. In total 92 people participated in the meetings.

Most of these meetings were held in drop-in centres, Training and Guidance Units and people's houses so the majority of the comments of our members refer to these places.

ARE MENTAL HEALTH FACILITIES EXCLUDING US FROM SOCIETY?

This is a very complex question. It is true that most facilities are exclusively for people with mental health problems (although most drop-in centres, whilst concentrating on people with severe and enduring mental health problems, are accessible to anyone in distress and certainly do not require written evidence of illness for their use) but this does not mean that they stop us from joining in with the wider world.

Going to a mental health facility is, for many of us, a deliberate attempt to mix and socialise and participate.

It is something that we may look forward to all week but equally may be something that we have to 'psych' ourselves up and get the courage to do.

In mental health facilities we are able to mix with people with a shared experience and common understanding of what we are going through. We do not have to explain ourselves and can cry or get upset and know that people will understand what we are experiencing.

We gain company, comradeship and advice in such places. We trust each other and offer each other support and comfort in a way that we don't get in the wider community.

We are encouraged to do things together and will often gain the confidence in such places to go out into the wider world where we can do things either alone or in company.

Mental health facilities are a way of joining in and a means of getting us away from an isolated existence which too many of us spend alone in our homes. They are also a form of security, rich in understanding of our situation. Whilst some of us rely on them for our daily activities, others use them as a reserve to return to when we are ill and cannot cope with ordinary living in mainstream society.

Many of us feel that we have so many common issues and similar experiences that we are, in effect, our own mini community which provides mutual support and shared understanding to each other.

We can feel that the facilities that we rely on provide an added dimension to our lives that is very valuable and should not be dismissed.

However, despite this, some of us do worry that we can become over reliant on such places and can become locked into the world of mental ill health to such an extent that it becomes damaging and limiting.

We also, in the main, feel that although we need places just for us, most of us do routinely use mainstream facilities. Some of us may need help to do the same things as other people in mainstream society and we welcome this help when it is provided. Some of us would never use a drop-in-centre but may feel trapped at home. In these circumstances the help that 'outreach' can provide is useful and if we feel up to it, then, help to get out and about can be very attractive.

WHAT ARE THE ADVANTAGES OF USING FACILITIES THAT ARE JUST FOR PEOPLE WITH A MENTAL ILLNESS?

The following is a list of some of the things our members told us:

- They represent a place of our own, security and safety and we can mix with people who know what we are going through.
- We can pick up on the early warning signs of illness in each other and learn from each other.
- We support each other and build up networks that support us outside of the centres. Places where we have a shared experiences.
- They help us get out of the house, are places where we meet our friends and where we enjoy ourselves.
- They keep us out of hospital and are where we can get help from professionals.
- There is acceptance there and we are safe from harassment and the effects of stigma.
- There is access to the basic necessities such as tea, warmth, food and support.
- There are people to talk to and you can spend time there without spending money.
- We feel equal in places like these and we can be open in ways we can't elsewhere.
- They can be a place to get help and can prevent illness.
- They give us a life and a community.
- We can take part in activities together but without pressure.
- They are, in themselves, all about inclusion.
- They provide a stepping stone back in to society.
- They can provide somewhere to go in the evening and to do things together which can be great.
- They stop us getting trapped at home, and they are great places to go to when we are ill and cannot cope with normal society.
- They are somewhere to go without everyone knowing what is wrong with us.
- We can get distraction from our illness and help boost our confidence.
- They are also places to get help, advice and representation.
- We don't feel judged if we feel down or tearful.
- They are often places where although we mix we also feel a sense of privacy.
- They provide a welcoming atmosphere.
- They give us a challenge - we can feel a sense of achievement when we get there.
- We can drop in and out of them as we wish.

- They provide structure, offer hope and give us something to look forward to.

WHAT ARE THE DISADVANTAGES OF USING FACILITIES THAT ARE JUST FOR PEOPLE WITH A MENTAL ILLNESS?

Many of us could see disadvantages to using drop-in centres and other user only places or meetings. It can be tempting to get sucked into a comfortable secure world that in effect stops us participating with the rest of our society.

For some of us this is fine but for others it signals a way of becoming trapped in the world of mental illness and perhaps lowering our expectations or will to see different maybe more productive ways of living.

By relying exclusively on mental health facilities we worry that we can segregate ourselves from the rest of society.

WHAT ARE THE ADVANTAGES OF MAINSTREAM SOCIETY?

Nearly all of us said that, although we use mental health facilities, we also participate in mainstream society.

Many of us feel that is the ideal environment in which to live our lives but reality means that it is sometimes a distant prospect and that, equally, the drop-in centres, Training and Guidance Units and user-only gatherings are so welcoming and helpful in themselves that we use them as our bridge between the mainstream and our own community.

Having access to people who can help us get into the community, whether they be activity or support workers, has been welcomed by our members and simple things like bus passes, Hi Life and One Plus One cards can make a huge difference.

Most of us do think that we should be encouraged and supported into mainstream society but that this doesn't need to be at the expense of facilities that we have a great appreciation for.

WHAT ARE THE DISADVANTAGES OF MAINSTREAM SOCIETY?

There are many barriers to us when we contemplate joining in with mainstream society.

These include our impairment. For example, when we are ill, it can be too much to face people who don't understand what we are going through. We may find crowds hard to cope with and may worry that we will panic in public. We may also find it hard to mix and communicate and may lack the motivation or confidence to join in or get out of the house. Being in the mainstream may in itself create so much pressure for us that we find it hard to cope.

It is also because of stigma or lack of understanding: people may be deeply prejudiced about us or they may just not understand us and therefore avoid us because what we are going through is hard to accept. This can make us self-conscious and may make us avoid normal company. In addition illness can sometimes cause us to do things we regret which may make us avoid other people. Some of us don't feel that we are valued by the rest of society which can make us unwilling to join in. We may also have a strong sense of feeling different and that feeling can make it hard for us to participate.

Some of us feel that we are singled out and rejected by society. If our local community regards us as a threat then it is hard to join in and, if when we became ill we lost all our friends, it can also be difficult to re-establish those connections - especially if institutions in the community such as our churches seem to have rejected us too.

There are also basic barriers to participation. The people we grew up with may be living very different lives to us and may have lost all connection to our own journeys and therefore we lose bonds and connections that others take for granted.

As most of us are on benefits, many of the activities others engage in routinely are hard to afford and many of us use public transport; because we can't afford a car and we have no driving licence it can be hard to join in and get out to do things with other people.

Sometimes the most basic barrier is that we don't want to join in. What we already have seems better than the mainstream and the things that the mainstream can offer are just not interesting.

Another barrier is that some of us just don't have the ability to get out. An outing from a drop-in centre can help, as can the assistance of a support worker but we don't all have access to this assistance.

Many of us are not in employment which is in itself a barrier to inclusion as it is an experience that takes up the lives of most adults around us. Being unemployed can mean that we lose contact and a sense of connection to those friends of ours who are employed.

There is also a sense that people misinterpret what we need; we would not expect to get help with our mental health in a café but we would in a mental health facility. Drop-in centres and other places where we meet are not just about socialising or training they are also places of therapy and support.

Another barrier is that some of us just don't feel a part of mainstream society and therefore feel little need or desire to be a part of it.

SHOULD WE SHARE OUR FACILITIES?

We wondered whether opening up mental health facilities to anyone who is lonely or distressed, whether they have a mental illness or not, would enhance a sense of inclusion.

Our members were divided on this subject. (In the first place some facilities do not have rigid criteria for their use and all sorts of people from many backgrounds already use them). Some of us felt that wider use would not only enhance our service but would be more vibrant and equitable if anyone in need of some company and support could use them.

Others felt that mental health facilities should, as far as possible, remain purely for people with a mental illness. They cater for a particular group of people with particular needs and run the risk of changing their ethos and character if open to the whole community whether they have mental health problems or not.

CONCLUSION

We hope that this description of what is important to us and what isn't helps advance the debate about inclusion.

Many of us do want to be a part of everyday society and, in many ways we already are, but at the same time there are barriers that stop us participating and without challenging what sometimes seem to us to be immovable obstacles it will be hard for some of us to join in.

Equally everyone in society is a part of sub-cultures and other communities and it is here that we share common experiences and have similar goals and values. These communities may be as simple as being a part of a golf club to as complex and rich as being from a particular faith or ethnic background.

In the area of mental illness many of us also feel that we are a part of a community where we support each other, look out for each other and share similar experiences. We value these connections and feel that for many of us, they enhance our lives rather than hindering us.

In addition the mental health facilities we use are there because we have particular needs that other people don't have. By being able to use them we are helped on our journey to recovery and a fuller life, whether that is found within our own community or by reaching out into the wider world of which we are all a part.

OPENING TALK AT WORKSHOPS ON PEER SUPPORT, INCLUSION AND RECOVERY BY GRAHAM MORGAN (SCOTLAND) AND LARRY FRICK (USA)

AT

A CONFERENCE RUN BY THE INTERNATIONAL INITIATIVE ON MENTAL HEALTH LEADERSHIP - EDINBURGH SUMMER 06

Hello, my name is Graham Morgan and in the introduction to this workshop I will be talking about my personal experiences of peer support, my personal views on inclusion and the views of HUG members on inclusion.

I have a mental illness but this doesn't mean that I live an excluded, marginalised or unhappy life.

I have a rewarding job, a good income, a nice house, a good diet, lots of alcohol! and many friends. I'm married and I live in a small village where I feel welcome.

I have experienced stigma and discrimination through the actions and comments of others, some of whom are very close to me, and often through the cultural activities of institutions such as the press in Scotland.

However I feel that I am welcome in my local communities' activities and, on occasion, join in with them. I don't feel that I am excluded from the local pub, arts activities or any other form of communal activity.

And yet, I still feel apart and always have done. I feel awkward amongst 'normal' people. I hesitate to get involved in most activities. I dread social events or having to talk to neighbours or other members of my community.

Where I do feel comfortable is amongst people who have experienced mental health problems.

I feel a great unease when I disclose that I have a diagnosis of schizophrenia to other people and never know when or whether I should

let people around me know about this. But it is part of the way that I view and define myself so, at some stage, new friends will always be told about it. I have never had a negative reaction when I reveal this to those that I trust but, when I find out that those very friends have themselves had mental health problems, I feel a weight lift from my mind and my heart begins to warm because there I know will be someone who understands my experience, who will be free of prejudice, who will have a shared knowledge and a welcoming connection.

It is among people with experience of mental illness that I feel a true sense of community and belonging and shared vision, values and understanding.

Nearly all my friends, outside of work, have experienced mental health problems and most of my work is directly connected with people with experience of mental illness.

I find us to be a community that is generally non judgemental, accepting, capable of giving and receiving and encouraging. It is among these people that I feel validated and at home and able to flourish and grow and live as I want to.

In mainstream communities I don't feel this - I feel awkward and ill at ease and stunted and restricted and unable to express myself or feel a part of, or even to want, to be a part of it.

I have in many ways rejected the mainstream community in favour of a community of my peers, because that is where I feel most comfortable and at my best.

In the last year I was a patient in hospital and received great support from the staff but also turned naturally to my fellow patients for support. I remember the days and nights spent walking round in circles in the corridors of the ward. I remember the camaraderie and acceptance and the small gifts we made to each other. I remember the visits my peers continually made to see me and encourage and support me and, although many things contributed to my recovery, I think my fellow users played a great part - they inspire, motivate me and make me feel that I can truly be myself.

For me, my fellow users and ex-users make for a vibrant and dynamic community and although I know I can be a part of mainstream society

and, in many ways am already, it is in this small community that I feel most welcome.

I would ask the questions though:

- Does this restrict my life?
- Does it marginalise me?
- Does it make me close my life to the vibrancy and the multitude of different communities that the world is composed of?
- Have I, in the need for connection, denied myself the very connections that could lift me away from what other people could perhaps see as an inward and sometimes negative circle of experiences?
- Should other people, in the name of inclusion, be busy making me break what may be seen as dependant and negative bonds in the name of more positive inclusive and mainstream connections?

Maybe it is time to break from a definition of myself which may be seen as bound up with illness and to reach for a wider world.

I don't know the answer to this and would love to hear your views. I do know though, that my peers have kept me going and supported me at critical periods in my life where no one else, with the exception of my son and wife, could help.

In HUG, which I work with, we have just finished a round of meetings involving 92 people where we have looked at the subject of inclusion.

They are less exclusive than me and although the meetings are not all written up the main points they make are:

- The places where we meet, such as drop-in centres employment centres and each others houses are communities which blossom with the support we can offer each other. We use them sometimes, just when we are vulnerable, and at other times day after day and month after month – it is here we feel welcome and supported.
- We don't want these user only places to go because someone somewhere thinks that they are marginalised unhealthy ghettos - for many of us they are the only contact we have with other people outside of a solitary existence.
- This doesn't mean that our members don't want to join in - the majority do. Most of us use mainstream facilities routinely already,

some of us need support to do so and wish to get it - sometimes from workers and sometimes through the support we give each other in such places and often through our own initiative.

- And yet we know there are many users who would never dream of going to places with other users and who prize their independence and autonomy and others, unfortunately, who have neither the solace of user only places or mainstream services and who live twilight lives at home with neither the confidence nor the motivation to join in.

I would ask:

- ➔ Is a drop-in centre its own worst enemy?
- ➔ Is a 'user only' community a celebration of diversity or an insular way of defining our lives?
- ➔ Are users the best supporters?
- ➔ Are we our own community?
- ➔ Should we be encouraged into the mainstream, is that a visible demonstration of the need for equality and respect and inclusion, or is it a sign, yet again, of people deciding what is in our best interest without asking us first?
- ➔ If we are our own community; do we need our own community spokespersons and how is that person and community defined and elected and given the power to speak, and how big a community do they represent? Remember the 'one in four' – can we really claim to speak on behalf of all those people?

Extract from a debate on Inclusion taken from the HUG message board

If you are a HUG member and want to access this board please go to the HUG website: hug.uk.net and follow the instructions to register.

I have a problem with the mainstream

To me mainstream means conventional. A much higher level of conformity is required to fit into the mainstream. To some people (with or without a mental health problem) this isn't too much of a problem. The problem arises when your personal lifestyle and lifestyle choices, interests, etc. fall outwith the mainstream. Sometimes this is referred to as non-conformity, counter-cultural, idealistic, etc.

Society is comprised of a wide range of people. Mainstreaming us all will not make the problems disappear. Tolerance and understanding of people, especially of people who live outwith the norm needs to be far greater.

Diversity should be greatly encouraged not suppressed!

The solutions to better mental health services can be found within mental health service users themselves. Service users must be actively engaged in **all** levels of delivery, policy and decision making of services. Local, regional and national. A 50/50 ratio of service users to professionals would be ideal. This works for a user-led service in Aberdeen. Meetings don't happen unless this ratio is satisfied.

In addition, I strongly feel that mental health service users should be provided with adequate training, funding, support, advice, etc. with the sole aim of setting up their own mental health services serving their needs and local community.

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. The report can be supplied in large print or on tape.

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:

Graham Morgan
Highland Users Group
c/o Highland Community Care Forum
Highland House
20 Longman Road
Inverness
IV1 1RY

Telephone: (01463) 723557
Fax: (01463) 718818
E-mail: hug@hccf.org.uk
www.hug.uk.net