



HIGHLAND USERS GROUP
SELF EVALUATION ~ FUTURE PLANNING
SPRING/SUMMER
2009



HUG at
Highland Community Care Forum

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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 380 members and 14 branches across the Highlands. HUG has been in existence now for 12 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, and 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.
- Challenging stigma and raising awareness and understanding of mental health issues.

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

In HUG we find it is very important to keep a record of how our members view us and what they think of the work we are doing.

By constantly checking that the way we work and the way we plan our work is ok we can try to ensure that we keep our activity and efforts in line with the wishes and desires of our members.

In the spring and early summer of 2009 we met with our members across the Hug network of branches to find out their views. There we held a series of meetings in our network of branches, using semi-structured interviews with groups to discover their views. This was not an independent evaluation as we do not have the resources to do this but it is a form of self reflection and a way of testing out our activity.

In total we met with 87 people across our network.

IS HUG AN EFFECTIVE VOICE FOR ITS MEMBERS?

There was almost unanimous agreement across our network that HUG is an effective voice.

The reasons we had for this were:

It is a way of gaining the views of a wide range of people:

"It's the view from people with a mental illness. It puts it's point to others like doctors and nurses and MP's and others. They know what's going on; they have their finger on the pulse."

"It's mental health users giving feedback."

"The focus on consultation and getting as many views as possible."

"You only need to read one report to be aware of the quality of the research and the feedback and contact with other agencies."

It also is welcomed because it passes on a range of views rather than a 'party line'

"Representing the variety of views gives it credibility."

It is an organisation that gets results for its members:

"It is not just talk it is action"

"It can pass on messages without us having to face them [officials]"

"I have seen changes in attitude and things are different to what they used to be. We have the ear of people up to government level and have influenced policy and legislation."

"We did; issues got resolved and nothing was done until we raised it."

"It's a great outlet; look at all the people we've met through hug and the increase in services across the area. Services and staff are now much kinder and sympathetic."

By joining together it unites people and creates a movement that is more powerful than if people were to work separately:

"It's more powerful than on your own."

It helps people give their views but without putting them in situations where they may feel acutely uncomfortable about expressing them:

"I could confront someone but I wouldn't know where to go. I would go to bits on my own"

It creates a connection and a feeling of community and shared visions:

"I read the Diagnosis report; as a new member it gave me feedback of actual people and a broad spectrum of views. It was really good to see quotes; it gives me something to connect to and does it really well."

It provides a range of differing opportunities:

"I really like the writing classes. I would really like to see more people join."

It is a successful and well known group which gives people a good feeling:

"The profile we have acquired is very high and we are listened to and taken seriously."

By empowering its members it increases people's sense of self worth:

"It helped me and I can now help other people"

However there is room for improvement and better joint working. In Argyll where we hold joint meetings with the local group, Acumen, members were not sure how it had benefited people locally and felt (unsurprisingly) that Acumen would be a better first port of call for local issues. There was a view that people needed to know that local issues can be passed on at NHS Highland level and that Acumen understood how to pass on regional issues to HUG and HUG local issues to Acumen.

WHAT DOES HUG DO THAT IS PARTICULARLY GOOD?

Members were very pleased that it gave them a "voice" and was able to influence and contact people that they felt they wouldn't be able to.

They were pleased that it involved a lot of people and that there was always something different to discuss. It wasn't a discussion of the same things all the time.

"Play the corporate game; take the professionals on, on their own ground, with research and credible evidence."

"Everything; everyone is involved, it is ongoing; different topics every month, way ahead of the game in constant consultation. It is all up to date."

"It gets people meeting each other and you can express yourself about things that you wouldn't want to talk about with non members."

"There's a lot of banter"

People were pleased that it gave an honest and realistic picture of people's views.

They were very pleased with its awareness raising activity and work with young people.

In addition the support that fellow members give to each other (especially when people were unwell) was welcome.

The fact that it achieves things was remarked on:

"Everything; anyone can talk a problem but to do the activities that changes things regenerates you."

"It is gradually getting in to circles of people who have never given it much thought before."

The national and international work was appreciated as were the speeches that members and workers give.

The whole area of our work in challenging stigma was seen as especially good.

"Schools stuff is brilliant. Stuff in schools is always needed; it's worth it for this alone"

"It brings awareness of different situations and what it's like to have a mental health problem."

It is also a way of making connections with people, stopping isolation and ensuring that people are not hidden as a result of illness or stigma.

WHAT COULD HUG DO BETTER?

Many people felt that HUG was already doing a great job and couldn't do anything better.

However suggestions for improvements included:

- Provide more training to trainee professionals
- Become better known and recruit more members (for instance via widespread publicity in places like doctors surgeries)
- Have more contact with health professionals outside Inverness
- Keep in better contact with groups outside Inverness
- We maybe cover too much ground and could do better focussing on specific achievable areas of work. Maybe have themed areas of work.
- It could host occasional parties and socials
- Members could raise funds themselves and contribute to the cost of tea and food.
- If it had more resources it could reach out more to young people and go into more schools
- It could better anticipate changes in government policy and the impact it will have.
- It might do better to concentrate on its stigma and awareness raising work
- It might do better if it could help members with their confidence and openness
- It might be good if it could give money advice and help people access grants

STRENGTHS, WEAKNESSES, OPPORTUNITIES & THREATS

WHAT ARE HUGS STRENGTHS?

The main strength remarked on by most people was its membership:

"It's people, It's membership, it's unity."

"The range, from all different walks of life, with people at different stages of recovery across the whole area."

"A family group; all in the same boat."

"Together we are united."

"Camaraderie"

"Equality"

"Talking about our own illness and how it came about to people who understand"

A number of other strengths were also mentioned, by being a group there is more chance of being heard, we support and help each other, people can get advice and issues are kept to the forefront.

"It gives us an identity towards society, it decreases isolation."

By being independent we can speak out in the way our members want:

"We are free with what we say; we are more powerful than statutory organisations."

A key strength is that our voice is that of our members:

"Our lived experience."

"Very talented members who do lots of work"

Knowing that we have an effect is a great strength:

"Feeling our views are taken seriously"

"Good reputation"

The atmosphere in which we work is also strength:

"Good atmosphere, we work together and are not too stiff and regimented."

WHAT ARE OUR WEAKNESSES?

Some people were very happy with what we do and felt we had few if any weaknesses but other people identified the following weaknesses:

- We are not powerful enough
- Keeping a strong local presence in every part of the Highlands especially rural areas.
- Graham, one of the workers, is important to the success of the group. If he left there could be problems
- We need more discussion meetings [branch meetings]
- Funding insecurity
- The use of numbers; the involvement of 6 people in a meeting may actually mean that they are feeding in the views of many more. So a low turn out does not mean a lack of success.
- We are maybe trying to achieve too much; have we set ourselves an impossible task?

- Our strength is our unity if we had dissent and division we could collapse.
- Change occurs too slowly
- There may sometimes be too much pressure on members
- It is difficult to get everyone together

WHAT OPPORTUNITIES DO WE HAVE?

This question was mainly interpreted as being about what we could do in the future:

We had a variety of views which included having more of a say within what can be very 'dry' business meetings.

Other issues were:

- Developing a social firm
- Having social events
- Lobbying for user run drop in centres
- Making sure that government has to listen to us
- Making employers listen to us
- Changing the attitude of some health professionals
- Promoting the importance of holidays
- Influencing legislation
- Influencing policy at a national level
- Providing more education on psychosis
- Increasing our links with VOX (the national user voice)
- Getting more funding because mental illness is increasing
- Increasing our presence in local areas and include people in remote areas by outreach
- Using the local media more as well as other media sources
- Promoting creative writing and other forms of creative expression
- Involving members more in shaping the future of the group
- Generating more funds and hold fundraising events
- Using the wide range of talents we have within our network
- Making the members set the rules of the group more
- Being environmentally aware
- Doing things that promote good self esteem
- We should concentrate on what we do already and remove any weaknesses
- Showing what we have to contribute to society
- Getting into further education to raise awareness there
- Helping councillors recognise the value of the voluntary sector and of users
- Stopping stigma in the family
- Helping put Tag on a par with conventional training units
- Having a HUG MSP

WHAT THREATS DO WE FACE?

Few threats were mentioned except for one which was mentioned in every group.

This threat was having funding which was secure for HUG, which we doubted was the case.

Other threats were:

- If Graham gets ill again
- The need to have more young people involved
- Being over regulated by our funders
- The need for support for HUG members who are speaking out publicly
- Lack of support from employers about the need for healthy workplaces
- The effect of stigma on members

OUR YOUNG PEOPLES' WORK

We have been working for a number of years with young people. We do this by taking HUG members into schools PSE classes where young people can hear directly from them. We have also taken a play called "stigma" round most of the Highland schools over a period of four years. In this time we reached between 5-6000 people. We have provided creative opportunities for self expression and awareness raising using drama, film, music, art work and other creative mediums. In the past we have established peer education courses and also feel good days in school.

WHAT ARE THE KEY MESSAGES WE WANT TO GET ACROSS TO YOUNG PEOPLE?

The following are the key messages we thought were most important to get across to young people recorded in order of the frequency with which they were mentioned in the meetings (A being most frequent and D least frequent)

- A
- Awareness of stigma (don't do it , don't let it damage you, or self stigmatise)
 - That they or someone they know may get ill at some point

- B
- Recognise that mental illness is natural and is an illness
 - The effect of language and behaviour

- C
- The early warning signs of illness
 - That people can recover, get better or become stable
 - Helping them understand what it is like to have a mental illness
 - The myths of mental illness
 - Stop bullying and poor behaviour
 - Where to go for help and support
 - That they are not alone
 - To promote equality issues
 - What the risk factors and preventative factors are in suicide
 - That young people can get ill

- To seek help for illness
- Not to be scared of mental illness
- To raise awareness of psychosis
- To raise awareness of what triggers mental illness
- Mental illness controls you ; you can't control it
- How bad it really is
- What lack of insight is
- What it feels like when you are first getting ill
- Dealing with guilt and family
- The facts of mental illness
- Describing the wide range of illnesses
- The importance of respect from family – don't let people put you down everyone has a role to play and a way of contributing
- What the different treatments are
- Everyone's behaviour affects someone else and impacts on their mental health
- The help a teacher can give
- To accept it
- Stop the resentment
- Be truthful honest and open
- The illness that you can't see
- There is life after mental illness – even happy life.
- There can be advantages to mental illness
- We are not ill all the time
- Celebrate the talents of those with a mental illness
- To be non judgemental
- Mutual help and support
- Education that hospital doesn't have to be terrifying
- What the new hospital is like
- Not to be frightened to get help
- Mental health is as important as physical health
- Make it part of their world
- There are likely to be young people with a mental illness in their class
- Learn to trust each other
- Draw and describe emotion
- Not to be embarrassed or ashamed of illness
- Anti violence message
- The need to be treated well by the family

WHAT TECHNIQUES CAN BE USED TO GET THE ABOVE MESSAGES ACROSS?

The following is a list of the different methods that we hoped would keep young people engaged and interested again the most frequently mentioned ideas are labelled A and the least frequently E:

- A
 - Drama; Including interactive drama and plays young people participate in
- B
 - Personal testimony
- C
 - DVD of our experience

D

- Question and answer sessions including direct questions of users
- Role play
- Young people giving testimony in person or recorded
- Real stories
- Find out how they would like it presented: directly from them

E

- Recreate hallucinations such as voices
- Cartoons via projector
- Get to them at their level
- Make it something they identify with
- Use volunteers
- High profile people going into schools
- Show the science behind our experience
- Show young people a real mental health consultation
- Use stories in that occur in literature
- Poetry and prose
- Make it part of the curriculum
- Use physical activity as a medium
- Show we are all precious
- Use episodes from soaps
- Workshop format
- Multiple choice quiz
- feel good days
- Taster sessions in different therapies
- A game to test what they know
- Music
- Colourful information packs
- Peer education
- Internet and other IT techniques
- Explain medication and how it works

HOW IMPORTANT IS OUR WORK WITH YOUNG PEOPLE?

We were clear that this area of work is very important to HUG and may indeed be one of the most important areas of work we do.

We felt that they would be the next generation of people who can help us and also the next generation of people who will get ill.

"It is very important to get to them at the right age before their minds are made up; when their minds are open."

"They need to know what it is; to realise that they have it"

"Very young people can have problems and more and more of it is coming to the surface."

We also thought it would be good if drugs and alcohol and their connections to mental illness were included and that if young people revealed personal experience we were sure that they could get help for this.

It was also said that we need to target other groups such as the elderly

MENTAL HEALTH AWARENESS TRAINING

HUG's mental health awareness training is based around the personal testimony of our members whilst using DVD's, quizzes and group discussion as a framework to deliver safe and sensitive sessions to help other people gain an insight into our lives and what does and what does not help us.

We asked our members which groups of people would be best to target our training at in the future (A represents the most frequently suggested group and G the least frequently mentioned group):

- A
 - General practitioners
- B
 - Teachers
- C
 - Police
 - Benefits agency staff
- D
 - Psychiatrists
- E
 - Social services
- F
 - Psychologists
 - Mental health officers
 - Nurses
 - Housing staff
 - Community psychiatric nurses
 - Churches/ministry
- G
 - Community mental health teams
 - Trainee workers of all sorts
 - Anyone in the NHS (receptionists cleaners, everyone.)
 - Hall keepers in West Ross
 - Youth workers
 - Shop assistants
 - Accident and emergency staff
 - Sports groups
 - Financial services
 - Employers
 - Councillors
 - Politicians
 - NHS managers

THE HUG NEWSLETTER

We asked our members what they thought of our Newsletter. Most people thought it was very good and very interesting and informative. It was an honest and truthful publication that people could pick up a lot from. It had articles that people could relate to and promoted comradeship.

"I didn't know about the variety"

"Great; comprehensive, with all the different stories, you can express yourself so freely"

The parts that people particularly liked were the poems, personal testimony and news of what has been happening. Some people said that they liked all of it. One group said that they did not like the recipes.

We asked what new themes or areas there were that we should concentrate on in the future and came up with the following (A most common C least common):

A

- Personal stories

B

- Cartoons

C

- It is ok just as it is
- Jokes
- Recovery stories

D

- Feedback from members
- Local authority news
- Funding news
- The Recession and its effect on mental health
- Music
- Topical themes
- Problem page
- Doodle pad
- What different therapies there are
- News from different groups across Scotland
- Articles about different diagnoses
- competitions
- art work
- success stories and stories of when things go wrong

There was also a suggestion that the design could be improved on and that it could be produced on DVD for those people who have difficulty with reading.

Over the years the newsletter has become longer and longer as members contributions have increased. We asked if it was becoming too long. In two groups, members

thought that its length could be off-putting but in the other groups people said that although it was long and sometimes took some time to get through that they were happy with this or would even prefer it a bit longer.

DVD PRODUCTION

We have been producing DVD's for a number of years now; sometimes responding to national commissions by producing DVD's on the Mental Health Act, Employment and Mental Health First Aid and sometimes by producing more specific DVD's such as on Recovery or Medication.

Many HUG members had not seen any of the HUG DVD's and said that they would like to. They also said that charging for DVD's could make it too expensive for them to see them.

They said that we should send free DVD's to the main drop in's and TAG Units as well as wards of the hospital in order that people could have a chance to see them. They also asked for us to produce cheap versions that they could get for little or no cost saying that the cost of duplicating a DVD without graphics or accompanying resources was relatively cheap. Alternatively they should be available to borrow.

We asked what sort of DVD's we should produce in the future and came up with the following ideas (A most common, C least common):

A

- About each illness
- What it is like to have a mental illness *
- Celebrating the talent and creativity of people with a mental illness

B

- Employability/showing we can work *
- Services and people we can approach for help and advice
- Recovery*
- Mutual support/caring for each other/self help
- About New Craigs Hospital

C

- The experience of young people with a mental illness
- The frustrations we have
- Medication*
- What it is like to see a psychiatrist
- Alternative approaches to mental illness instead of medication
- Anger management
- Assertiveness
- Prejudice and how to deal with it
- How to handle stress
- Mental health and its connection to physical health
- Pet therapy
- The help we get from friends and family
- Activities people can do in New Craigs
- What to do in crisis

- Confidence building
- What stigma is like
- The police – using role play to show what it is like to be involved with them
- Self harm*
- What it is like to be diagnosed
- Signs of mental illness
- Sexual abuse
- About HUG itself

**(We have already produced a DVD on these themes)*

THE HUG WEBSITE

The HUG website (hug.uk.net) is now quite old and in the opinion of staff, needs updated. It is kept up to date as far as posting new reports, newsletters and talks goes but most other pages have not been modernised for some time.

Most of our members had not been on the HUG website. This was for a number of reasons:

1. They did not know it existed.
2. They did not know the address.
3. Many did not have access to the internet or were frightened of the internet .
4. They felt no need to access it as they already had enough information.
5. It had in the past been out of date and they saw no reason to visit it again.

The views some people had of it were that it was often a bit out of date and a little boring. However some people said it was easy to find and had a nice page layout and others said that it was fine or even quite good. Some people also said that it was well organised and easy to follow.

The sort of things that would make the website more attractive would be - having news features and creative spaces for arts and photography.

If face book, u tube, my space and user led social networking featured on it , it might be more accessible.

It could have a section that gave people contact details of where to go for services and advice and information about mental health in the Highlands.

It would be good to have colour and pictures on the site as well as personal testimonies, stories and poems. It would also be good if there were more links to other good websites. It would be nice to see pictures of staff and members on it and ideas for places to go to for cheap meals and so on.

If there were DVD's to download on it that would be useful.

It would also be good if it were simple and accessible enough for children to use it. It would be nice to see some humour on it too; we could also have news from the branches which might also be welcomed.

The better the website becomes the more likely people will be to visit , as news about it would spread. Leaflets that advertise it might also help.

THE MEDIA

We attempt to get 12 articles in the media every year including the equivalent of three feature articles.

We asked our members what they thought would be newsworthy topics and gained the following feedback (A most frequent C least frequent):

A

- Direct testimony

B

- Stories about recovery
- Success stories despite illness

C

- Information about HUG
- Articles tied in to new legislation
- Articles tied in to Council activity
- Publicity about our work in schools
- Employment
- The prejudices and myths around stigma
- Local issues
- A day in the life of people with different conditions
- Celebrity stories
- Add our story to current storylines that are happening
- The way health professionals deal with illness
- Coming back from war zones
- The reality of PTSD
- Our talents and things we can celebrate

There was a feeling that we could make much better use of small local media outlets. Phone in debate and discussion programs may also be an area we could get involved in.

THE HUG REPORTS

We produce between 4 and 8 reports a year in HUG. These reports are about issues of importance to HUG members and are laid out and written in as accessible a manner as we can manage.

We generally felt that they were well written and easy to read and most people said that they read them. Some people felt that there were too many to read them all thoroughly and some felt that although they would be accessible to professionals that they might not be accessible to all members.

"The only mail I open straight away"

"They have two audiences; very useful for professionals and academically acceptable; maybe not so good for ordinary people on the street; too complex and academic..."

When we talked about improving the reports many people said that they were fine as they were but other suggestions included:

The reports are produced in quite a basic way. If we had more money then they could benefit from graphics, more visuals, a better front cover, smaller blocks of text, the use of colour and larger font size.

Some people said that they were quite formally written and could usefully include suggestions of:

What people can do personally to help themselves in each report with coping strategies, self help ideas and personal testimonies.

If we could include quotes that show how they have been received that would be helpful too.

Some people said that it would be too expensive to improve on their design and that as long as they remained clear and easy to read they would be ok. Some people said a glossy cover would be good as long as the contents remained as they are and others said that the reports look both professional and economical which is important for the way HUG is seen.

We discussed offering the reports in various formats; Email form to our membership, in hard copy to those who like them in this form and as a précis for those who do not want the whole report.

In this way we will save on the cost and we will also become more environmentally aware; we can no longer afford to produce more than four hard copy reports a year.

BRANCH MEETINGS

The HUG branch meetings are where we hold the discussions that lead to the HUG reports and also where we report on our activity to our members.

We felt that the meetings were usually good and nicely informal but sometimes people regretted that more people did not manage to attend.

We thought they could be improved and may attract more members if we did the following things:

- Send out more letters and information about what will be discussed and where and when they will be held.
- Realise that it can be hard for some people to participate because they are shy and lack confidence.

- Realise that it can be difficult to attend your first meeting if you do not know anyone already; a buddy system may help.
- We should meet whenever there is a local issue that needs dealt with
- Transport difficulties can make it hard for some people to attend
- We felt that it would be good if everyone knew that there was no need to speak if they did not want to contribute.
- We need to make sure everyone has a chance to speak but that no one feels made to speak.
- We could sometimes have a social type of setting with refreshment; these would possibly encourage more people along
- We need to be sure that there are smoke breaks if needed
- Changing the venue occasionally may mean they are more accessible to rural areas.
- It would be good to have an event with a conference and social activity so that everyone could get together.
- We could phone round the wards for New Craigs meetings
- When people are ill they may not be up to meetings
- It could be good to encourage members to share their news at meetings and to get more local feedback at meetings.
- It might be good to invite people from outside the area to come to meetings
- It could be good to have more meetings
- Make staff more aware and inspired by HUG and its meetings
- Make sure no one ever feels that they have to come to a meeting
- Put news from the meetings on the website
- Reach out to people who do not go to the doctor for their mental health
- Answer members' questions in the newsletter.
- Bring some of the DVD's to the meetings
- We could alternate meetings so that we meet in each others houses

"We get our say and air our views and know that they are taken forward."

"It is a marvellous organisation; everyone should join, It has given me so much."

"Keep coming out to us"

THE ROUND TABLE

This is the committee that gives direction to the HUG project. In many ways it is the HUG steering group or management group.

A fair number of people had not heard of the Round Table but most were not very bothered by or interested in knowing more about it.

Some people said that it was like a secret and some people said that it should have an AGM.

There was also a call for members to be aware that if they raise issues with Round Table members that they will not be identified as a result of this.

CONCLUSION

The views given to us will be very useful in planning our future activity. It is good to know that we are still very much appreciated by our members, to have highlighted areas that need improving and to know that the views of our members are in most cases in line with the views of our workers.

We will distribute this evaluation amongst our Email list, to the HCCF Board of Directors which has overall responsibility for HUG and to the HUG Round Table to which our workers are accountable and lastly to our funders who monitor our activity.

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

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