



## PROGRESS REPORT

**Measuring our Record –  
What we have achieved from early 2005 to March 2006**

**July 2006**

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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 360 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**

The Highland Users Group has been in existence since 1996. We are a group of users of mental health services spread throughout the Highlands and supported by HUG workers who have a strong knowledge and understanding of mental health problems.

The purpose of HUG is to provide a voice for people with a mental illness. We believe that people with direct experience of mental health problems have an expertise that cannot be found elsewhere.

By speaking out, we can influence our own lives and the ways in which services are developed and run as well as helping to educate professionals and the public about the reality of mental illness and what does and doesn't work for us. By speaking out we gain more control over our lives and can be given the opportunity to participate and be involved in changing the way other people view us.

We have a strong belief that people with a mental illness have a history of being excluded and marginalised. In the past this was because many of us were kept in institutions but nowadays is due more to the effects of discrimination, stigma, poverty, lack of opportunities and the sometimes patronising attitudes of some of the professionals that are there to help.

In HUG we believe that this is wrong and feel, that to challenge this, we need to speak out directly about our lives whilst also involving allies in our cause.

We are known as a collective advocacy group but are part of a wider movement that aims to create social justice for our community.

For the last ten years we have been a project of Highland Community Care Forum (HCCF). Whilst we have our own unique voice, our own aims and objectives and membership criteria and our own committee that the workers report to; our infrastructure, administration and management support is provided by HCCF. We are now at the point where we are exploring the idea of becoming independent of, though allied to, HCCF.

We have reported on our activities in the past through a wider service level agreement and through the HCCF annual report. However we are now being monitored through a system that covers all advocacy projects in the Highlands. We have chosen this development to produce our own annual report of progress.

## **WHO IS INVOLVED WITH HUG?**

HUG is open to anyone with a mental health problem living in the Highlands. At present (March 2006) we have 360 members this is an increase of 55 people since January 2005 when we had 305 members.

We do not keep detailed records of all of our members believing that this would be an intrusive and unnecessary act which would not only put off people from joining but would serve to label people who are often trying to move away from stereotyped images.

However inclusion of the wide range of communities in the Highlands is very important to us. We make efforts to be as welcoming and open to new members as far as time and geography permit. This may involve meeting people in their own environments on a number of occasions before they decide to become involved with us.

We know that between us we have experience of the great majority of services in the Highlands. This varies from people who have been treated in the State Hospital to those who have never been formally diagnosed.

When we look at our membership we know that we include people with experience of all of the major psychiatric illnesses, people who have been homeless, people with drug and alcohol problems, survivors of abuse and other traumas, single mothers, gay and lesbian people, people from ethnic minorities, people with physical disabilities and learning disabilities, people in work (including people who work in mental health services). We are able in most areas to include people from remote areas by either visiting them in person or by communicating by phone or email.

We are aware that a lack of records makes it hard for us to record how many of our members may be excluded from society for reasons other than mental illness but are in discussion with our funders over how we can further improve the ways in which people can feel included.

We promote HUG to new members in a number of ways:

- We have posters in various locations
- We display free postcards in New Craigs hospital and drop-in-centres
- We have a new members' pack
- We appear regularly in the media
- We are in contact with a number of enthusiastic workers who refer people to us
- We go out to meet new members
- We communicate by email and through our website

However, the main source of new referrals is by word of mouth or through our regular branch meetings held across the Highlands.

We are presently re-designing the HUG leaflet and members' pack.

**"HUG has become an integral part of my life. In the first place, as an adopted person with no real sense of belonging, HUG has become my family. Since becoming a member 2½ years ago, I feel I really started on my journey towards recovery. As part of the collective voice of HUG I feel this is the first opportunity I've had where my voice cannot only be heard but it can also make a difference towards reducing stigma, discrimination and improvement in mental health services. I feel the work HUG does is vital".**

*Kaye, HUG member*

#### **The HUG Round Table (March 2006)**

This is the committee drawn from each of our 13 Highland branches. The HUG workers provide two monthly reports to it and we discuss issues affecting our members across the Highlands as well as looking at future plans for HUG and policy issues.

We also use the meetings to meet with officials, ask people in to educate us on issues of concern and provide training for our members. We meet once every two months in Inverness.

Our members in March 2006 were:

CAITHNESS WEST:	David, John
CAITHNESS EAST:	Garry, Billy
SUTHERLAND:	Gordon
EAST ROSS:	Andrew
MID ROSS:	Fiona
INVERNESS:	Margaret, Keir
NAIRN:	John
BADENOCH AND STRATHSPEY:	Pam, Catriona
LOCHABER:	Ronnie, Jackie
SKYE AND LOCHALSH :	Marja Liisa, Helen
WESTER ROSS:	David
NEW CRAIGS PATIENTS COUNCIL REPRESENTATIVES:	Frank, Alison

We also keep aside four places for interested HUG members to participate as observers.

### **The HUG Workers:**

In 2005/2006 the following people worked for HUG:

Graham Morgan:	Advocacy Project Manager
Emma Thomas (part time):	Development Worker (Education & Training)
Karen Maclean-Yuille (part time):	Development Worker (Media & ICT)
Debbie Berry (part time maternity cover):	Development Worker (Media & ICT) November - present
Martin Russel (part time maternity cover):	Development Worker (Media & ICT) September – October.
Kaye Boyack (work placement):	Editor of the HUG newsletter

We also relied on core HCCF staff for the expertise and organisation which helped keep us running smoothly:

Sheena Munro:	Executive Director
Mary Rawlins:	Finance Officer
Isla Cuthbert:	Administrator
Marina Patience:	Clerical Officer
Susan Mackenzie (part time):	Clerical Assistant (until January 2006)
Brian Hill and Anne McDonald:	Connecting Communities Project

### **Other Links:**

We also work closely with the NHS Highland, Highland Council, voluntary organisations and the Scottish Executive to help achieve a better life for our members and people in a similar situation.

The impact of our activity is sometimes hard to quantify, especially of our campaigning and lobbying work. We often hear of the way people have reacted to our voice, months and even years later and can rarely single out a single change as being solely due to our influence. Change usually occurs because most people agree to its need; at times HUG can only say that it has been the catalyst to change. However, we also have clear evidence of significant changes and improvements in services and attitudes initiated by HUG and the work of our members.

This means that it is important to us that we maintain good relationships with service providers, the community, as well as our elected politicians and the media whilst keeping in mind the need for a strong and independent voice.

**"HUG has given me the opportunity for constructive involvement with other users in advocacy, creating better understanding of those with mental health problems, including preventing stigma for which there is still much work to be done. It's helped prepare me for the working**

**environment. HUG presents to the public a unified image of users as individual people with positive capabilities and the capacity for positive input into society. I have met professional people from much further afield and, when I mentioned HUG to them, they have told me that they have heard about us. It is great to be a member of an organisation that is not just contributing locally but nationally and internationally.”**

*Pauline (HUG member)*

## **THE WAY WE WORK**

HUG works as a team with all the workers and many of our members being involved in a wide variety of activities. We have two broad focuses to what we do:

- **Speaking out about and lobbying for change.**
- **Speaking out to challenge stigma and discrimination.**

The main areas of activity for 2005 – 2006 can be found in the following pages.

### **Speaking Out and Lobbying for Change**

We find out our members' opinions on a range of issues by meeting them across the Highlands and involving them in discussions on the areas of their lives that are important to them.

This gives us a variety of views (and we are at pains to include the whole range of opinion our members have) on Local, Highland, National and International issues.

We then try to use our members' experiences and wishes to inform service delivery and policy development in the following ways:

#### **1) Producing Reports on Areas of Concern to Our Members:**

We try to hold 6 rounds of meetings a year with every branch of HUG on topics that our committee have usually already agreed and approved. This means that we hold a total of 78 branch meetings each year. These meetings are based around one or two set discussion points, workers' reports on the last two months' activity and a chance to hear of any issues of concern to members of each branch.

The main discussion topic will be based around a series of questions and prompts to find out people's opinions. These are developed by the HUG workers but influenced by discussion with HUG members and outside agencies. Notes are taken of each meeting and then combined into a report that distils our views, concerns and ways of improving the situations we are in. This is approved by our Round Table committee and then distributed amongst our membership and the wider mailing list of people with an interest in our views and those who may be able to respond positively to our message.

Each report usually involves between 70 and 80 people with mental health problems who attend meetings held throughout the Highlands with the exception of the far North West where we have no members who wish to meet.

### **Issues Addressed By Our Reports:**

The following is a list of the reports we have produced since 2005 with a description of the impact that they have had:

**1. Single Sex Wards** – the views of HUG members on the need for single sex wards in New Craigs Hospital.

Number involved: 69

#### Impact:

**"I would be grateful if you could pass on my thanks to the members of HUG who have been involved in this report. Input from this group is recognised as valuable across the whole of the NHS in Scotland."**

*Andy Kerr, Minister for Health and Community Care*

**"Many thanks for these informative reports. They highlight complex issues and I hope to have the chance to discuss the main findings with New Craigs managers in the near future."**

*Gill Keel, NHS Highland*

The desire to have some form of single sex provision has been raised repeatedly with service providers/managers at our Round Table meetings and throughout the year. Whilst our concerns are acknowledged and respected, the present configuration of New Craigs makes structural changes impossible. We have been heartened by specific measures put in place to help vulnerable patients feel more secure.

We will have a follow up to this report available later in 2006.

**2. Smoking and second-hand smoke** – the views of HUG members on smoking issues and in particular smoking and people with mental health problems.

Number involved: 85

#### Impact:

**"Our Director of Policy has asked me to tell you that he thought the report was excellent; very useful and thorough."**

*Scottish Association for Mental Health*

**“..[THE REPORT] is of the high standard produced by HUG; balanced, broadly representative and fair.”**

*Dr Chris Macgregor, Clinical Lead Mental Health Services, NHS Highland*

The report was sent to the Scottish Executive and used in a conference on the subject. A worker and HUG member attended the New Craigs sub-committee on smoking. We joined the Scottish Executive committee on Smoking and Mental Health (although we haven't been able to attend any meetings yet). Members in Caithness lobbied MSPs. We helped disseminate the experiences of a drop-in-centre which had already become non smoking. The general theme of the report was that smoking needs to be permitted in some areas for people with mental health problems. This runs counter to public opinion and will not succeed in its aims. We will be looking at the impact of the ban in Summer 2006.

**3. Psychiatric Hospitals** – the views of members of HUG on psychiatric hospitals and what they should provide, whether or not we need them and what they are like.

Number involved: 73

Impact:

**“I commend this report it is an excellent document.”**

*Jackie Agnew, Service Manager, New Craigs Hospital*

**“I welcome the latest in a series of excellent reports by the Highland Users Group. I will now be asking the Health Minister and NHS Highland what action they will be taking in response to the many issues raised in the report.”**

*Mary Scanlon MSP*

**“I have read it through and have found it absolutely excellent. It provides a detailed balanced commentary on so many aspects of hospital care. I could not think of anything that had not been covered.”**

*Dr Chris Macgregor, Clinical Lead Mental Health, NHS Highland*

The report was an agenda item at three meetings of the New Craigs management meeting (mental health and learning disabilities) and has influenced our voice when discussing issues over the need for transfers of hospital resources if community services are to be financed properly.

**4. Positive Futures - Employment and Mental Health** - a report on a conference on employment and mental health - the barriers people with a mental health problem face when seeking employment and solutions to these barriers.

Number involved – around a 100 people attended the conference.

Impact:

**"I hope to see some progress in this important area."**

*Dr Chris Macgregor, Clinical Lead Mental Health, NHS Highland*

**"I found it easy to read and well presented. Well done to those that compiled it – not an easy job."**

*Lorna Beaton, Highland Workstep Consortium*

The report reinforced the arguments of the Employment Working Group and helped with the eventually successful efforts of this group to obtain funding for a worker. Two HUG workers attend the meetings of the group with the occasional presence of 3 other HUG members.

**5. Employment and Mental Health** - the issues we face when looking for employment.

Number involved: 83

Impact:

We were visited by a worker from the Scottish Association for Mental Health to discuss the report and consider joint work on the subject. As a result of this meeting a HUG member gave a presentation on incapacity benefit to 30 MP's and 3 cabinet ministers at the Parliament in Westminster as part of a wider delegation.

We joined a SAMH group looking at how users who also work in mental health services can be best supported, and it was also the subject of a 3-page feature article in Mental Health Today magazine.

**6. Medication** – the views of HUG members on medication – what we think of it, the information we get, the people who provide it and other issues.

Number involved 73

Impact:

**"This is an excellent piece of work which your organisation can feel proud to have produced. It will be used to inform the development of these services."**

*Mary Morton, Acting Chief Pharmacist, Primary Care NHS Highland*

**"This is a very substantial piece of work which we very much appreciate....which should enable us to improve the service we offer to people with mental health problems across Highland".**

*John Cromarty, Chief Pharmacist, Highland Acute Hospitals NHS Highland*

**"We have in the past made service delivery changes based on the content of a HUG report and I envisage further change will be a consequence of this report."**

*Tom Shaw, Principle Pharmacist, Mental Health NHS Highland*

**"The NHS Highland Area Drug and Therapeutics Committee wanted HUG to know that they were very impressed with the report which raised many interesting points. They found it well written and constructive."**

*The NHS Highland Area Drug and Therapeutics Committee.*

In addition there were three press articles in specialist publications as a consequence of the report. It was also the subject of a presentation to psychiatrists and others by a HUG worker and three HUG members

**7. Control Inclusion and Empowerment** – the views of HUG members on how much influence we have over our lives.

Number involved 87

Impact:

**"I think this is really for me the most interesting and thought provoking report to date..... lets talk about this further"**

*Dr Chris Macgregor, Clinical Lead Mental Health NHS Highland*

**"We have read the report and thought it was very powerful and informative and one that we will be able to use widely to inform our ongoing work on inclusion and equality and diversity."**

*Charlie McMillan, Director of Policy, Scottish Association for Mental Health*

This report was created with the help of the Highland Community Care Forum Connecting Communities Project and may be used as a baseline against which we hope to measure changes in the future.

**8. Drama, Young People and Mental Health** – an evaluation of the Eden Court "STIGMA" play (in partnership with HUG and the Department of Child and Family Psychiatry)

Number of young people involved in the evaluation – 950

Impact:

The report has been the subject of a feature article in the magazine Mental Health Today in April 2006 and we are still awaiting more written feedback but have had an increasing number of queries from people outside Highland

interested in learning from us. We have now received funding that will allow us to perform the play again in 2006.

**9. Stopping Stigma: Increasing Awareness** – celebrating the last three years' work of the Communications Project.

Number involved - 72

Impact:

We are still awaiting written feedback

It was a successful piece of work in its aim to both disseminate information about the Communications Project (in accord with requests from the Scottish Executive) and, as a part of our efforts to gain local funding to keep our anti stigma and awareness raising work going.

**10. Occupational Therapy** – a focus group looking at occupational therapy as a part of the College of Occupational Therapies development of an Occupational Therapy Strategy.

Number involved - 12

Impact:

The report has been used to help guide discussion at the away day of the New Craigs Occupational Therapy Department. We await further feedback.

**Learning Points from the Reports:**

We have learnt a number of lessons that could help us improve on our reports:

- It is hard to get feedback quickly on their impact. It is important to us that we let our membership (who provide all the material for each report) know what has happened as a result.
- After the release of a report and some discussion in the following weeks we start work on the next one. It may be that the release of a report should signal the start of activity rather than the conclusion of an enquiry.
- We have begun to look at some of the reports that we worked on in the past. In some ways this is heartening as the new reports have been different to the old ones but also discouraging in that many of the issues remain the same.

HUG members' views:

**"I go to the branch meetings and there is a great deal of participation from each branch. It is an ideal way of obtaining different peoples views from living in a rural area to living in a city. Reports are accurate and professionals read them, they find them very very important and it educates them."**

**"From my experience as an American, this a very unusual thing that you do - going out to invite user input on their issues and making reports on their answers. In this way HUG becomes a conduit on users views with an impact on; policy, reform and protest. The fact that the reports are then picked up by government, officials, practitioners, fellow users and journals strengthen the network of advocacy from local to international. I find the meetings open, vocal and respecting. I wish they were better attended by all the users in the community. I think once a user had attended one meeting they would realise how effective they are – I am impressed with the level of commitment intelligence and passion reflected in user opinions at the meetings."**

## **2) Talks and Workshops**

HUG has given many talks and facilitated many workshops locally, at a Highland level, and nationally over the years, mainly by the HUG workers but also by members. These talks educate, inform and contribute to policy issues as well as sometimes inspiring people.

A number of talks have been given over the last year by HUG members and workers:

1. Talk about HUG at a users' conference in Stirling.
2. Talk on the patient view of clinical governance by a HUG worker and HUG members in Highland.
3. Presentation given at Care Programme Approach conference by a HUG worker and HUG members in Highland.
4. Talk on inequalities in mental health at Inequalities in Health seminar by a HUG worker and a HUG member in Highland.
5. Talk on a user's view of the Mental Health Act at training event for Mental Health Tribunal members in Highland. A copy of the talk was then circulated to all Tribunal members.
6. HUG worker and 3 HUG members gave a talk on HUG to 70 Social Work students in Aberdeen.
7. Talk at Inverness Children's Forum by HUG worker.
8. HUG worker gave a talk on user involvement at a British Council seminar in Edinburgh involving representatives from 14 different countries.

9. Talk on HUG by a HUG worker to a variety of NGO's (Non-government Organisations) in Poland as part of the Grundtvig 2 programme.
10. Two HUG workers gave a talk on user involvement in a rural area at the Mind Annual Conference in England. Delegates exchanged contact details as a result.
11. A HUG member gave a presentation in Inverary on HUG as part of the reconfiguration of Argyll and Clyde Health Board.
12. A HUG member gave a presentation at Westminster as part of the lobbying over Welfare Benefit Reform
13. Talk by HUG worker to a variety of agencies in Portugal as part of the Grundtvig 2 programme.
14. Talk on HUG by a HUG worker to members of 'ADEM' the user voice in Catalonia, Spain.
15. Participation on opening panel and question time by HUG worker (also speaking as a member of VOX) at a conference organised by Pavilion Publishing in Glasgow.
16. Talk by a HUG member on the Mental Health Act to volunteers at Advocacy Highland.
17. Talk by HUG member on advance statements to members of the East Ross Community Mental Health Team.
18. Talk by HUG member on advance statements to members of the Lochaber Community Mental Health Team.

Lessons learned:

It is hard to get anything other than anecdotal feedback about the impact of our talks.

A small number of people are regularly asked to give talks by name so it is hard to encourage new people to get involved in speaking at events such as these.

We could provide more training to members interested in this area of expression.

A HUG members view:

**"Up until January I was not confident on the impact of personal testimony on policy. Then I gave a speech at Westminster before MPs and cabinet ministers. The overwhelming response was that service user experience was more instructive than all the presentations by voluntary organisations although we still need the information provided by voluntary organisations. We also need their clout and their passion. When all is said and done it comes down to a very simple thing and that is the experience of the individual service user which is what we are all fighting for."**

### **3) Raising Local Issues**

At each round of HUG meetings we ask if there are any local issues that need followed up. Most groups raised a number of concerns which we then tried to pass on to the appropriate people at regular meetings or by letter. We have agreed that we need to pursue these issues more vigorously next year.

In a few areas we helped users campaign on issues of particular concern to them. These included:

- **The future of the Gardeners Cottage in Nairn:** this Drop-in-Centre is due to be demolished with the re-provisioning of the local hospital.

Action taken:

- We continued to publicise the DVD that we helped make to illustrate members' concerns and distributed it to local MSP's and showed it to the Community Planning Partnership in Nairn.
- We publicised members' concerns in our newsletter and bulletin.
- We liaised with local workers and officials over possible new premises.
- Two HUG members visited possible new premises.

Impact:

We received a commitment from NHS Highland that the service clients received would not be lost even if the original premises were lost.

Alternatives to the Gardeners Cottage were identified but had to be abandoned. Users of the centre have usually been kept informed of developments.

- **The Travelling Day Hospital - East Ross:** this hospital was closed for a year due to staff changes.

Action taken:

- We raised the concerns of users over its closure with officials.
- We helped make literature about developments more user friendly.
- We participated in visits to see other day resources.
- We publicised our concerns in our newsletter and bulletin.
- A HUG member kept in touch with workers developing the new service.

Impact:

A new service has now reopened.

Users were initially happy with this service and we have informed the Community Mental Health Team about this as well as concerns that have developed since.

- **The TAG Unit in Alness:** these premises were seen as inadequate and unhealthy by the clients.

Action taken:

- o Clients to wrote to officials with their worries.
- o We wrote to officials ourselves.
- o We publicised clients concerns in our newsletter and bulletin.
- o We invited local MSP's to visit the premises. Representatives from each main party met with clients and raised the issue with the Health Board and Social Work Department.

Outcome:

New premises are still being sought but seem more likely to be found.

Increased space in the current premises has been made available but we have just heard that it is possible that the entire space may need to be vacated in the near future with no alternatives identified yet as possibilities to use in the interim.

- **TAG Inverness:** these premises need to be relocated very soon due to the redevelopment on the Craig Dunain site.

Action taken:

- o We have repeatedly raised this issue with officials in meetings and by letter.

Outcome:

New premises are still being sought.

- **Resource Centre for Mid Ross:** the drop-in at the youth café is now in too much demand. There is a call to develop a permanent centre in the area.

Action:

- o We have become partners with NSF (Highland) and the Mid Ross Community Mental Health Team in a project to develop plans for a new centre.
- o We have agreed to try to gain user views and support for the project.

Outcome:

The project has only just started.

Lessons Learned

We need to become more organised in raising local issues and in supporting our representatives to do so. Setting aside some dedicated time for this may be one way of doing this.

We need to be more creative in the way in which we pursue issues.

Many of the issues raised locally have been repeatedly talked about for a number of years and yet little has changed. Developing solutions together is very important- it is very tempting to blame local officials for delays and yet this is not always the most productive move.

In some cases there has been media publicity about the issues we are following. This can be an incentive for change. However we need to decide when media coverage is a productive as opposed to a negative action.

#### **4) The Friday Forum**

The Friday Forum is a gathering held on many Fridays throughout the year at the HUG offices between 11.00 and 3.30 pm. It is attended mainly by HUG members from Inverness but has regular visitors from Caithness, Skye and East Ross.

The work carried out is variable but includes:

- Commenting on the entrance to New Craigs.
- Reviewing the old Mental Welfare Commission website and commenting on and meeting with the person responsible for redesigning the new site.
- Hosting a visit by users from Falkirk.
- Responding to requests for information from students.
- Responding to requests by researchers on subjects ranging from self harm to stigma to crisis services.
- Providing stories on recovery to the Scottish Recovery Network.
- Discussing healthy living with New Craigs Pharmacy Department.
- Responding to a consultation on public involvement.
- Developing articles for the newsletter.
- Discussing the values of HUG.
- Contributing to a national user message board.
- Answering questionnaires (e.g. on medication) and consultation documents. (e.g. advocacy standards, review of social work services ,advocacy monitoring tool Incapacity Benefit proposals).
- Looking at inequalities in health.
- Discussing and visiting the proposed community woodland at Craig Dunain.
- Acting as a focus group at two meetings looking at priorities in mental health.
- Ranking the recommendations of the Medication Report into priorities.
- Recruiting members to attend meetings and conferences on HUG's behalf, including Scottish Parliament Committee Enquiry on disability issues, Medium Secure Unit option appraisals, Art Angel's event and Scottish Association for Mental Health art awards.

- o Reviewing publications - e.g. a series of booklets on self harm and other mental health problems, Scottish Recovery Network booklets.
- o Meeting people interested in the work of HUG.

In a day's meeting at least three key topics will be addressed but they have not all been recorded so far. Time is also spent talking, getting to know each other and trying to make the time spent enjoyable and fun.

#### Lessons Learnt

We have been surprised by the number of people willing to travel long distances to come to these events and will need to make sure that we can continue to pay people's expenses for attending.

We have not recorded all the things that we do and need to find some way of doing so.

We need a balance between focussed work (which can become too much for some of us) and enjoying each others company which can detract from our wish to use our time productively.

HUG member's views:

**"The Friday Forum has variety each week - it is held with active members of HUG who contribute to making a difference. I look forward to going to them, feeling that I am useful there. The forums cover a lot of ground and are also a way of meeting your friends."**

**"This was my first introduction to HUG. Instantly I had both a family and a vocation. Friday Forums are informal, relaxed, welcoming venues. It is a place for keeping up to date on the latest issues in mental health advocacy, participating in information exchanges, giving opinions and responses as well as being a social occasion. I like the fact that we have regular meeting time to address issues as they come up as well as knowing what opportunities to attend and participate in different activities will be coming up in the future."**

#### **5) The HUG Bulletin**

This is an occasional bulletin aimed at raising current issues in mental health with officials and then Counsellors, MP's and MSP's. It has been sent out twice but its effect is not yet fully known:

**"I must commend you for their clarity, the use of straightforward language and the balanced approach they take to the problem being addressed."**

*Dr Ken Proctor, Associate Medical Director, Primary Care*

### Lessons Learnt

We need to be sure that asking our elected officials to speak on our behalf is a way of enhancing our voice rather than a mechanism that clogs up the work of our officials.

We need to be sure that the bulletins are as accessible and accurate as they can be in order that they inform and educate our MP's and MSP's rather than proving to be just another email or piece of paper in their 'in tray'.

## **6) Attending Meetings**

In order to get our voice heard it is necessary to attend meetings across Highland and beyond. This is perhaps one of the least popular ways (to our members) of expressing our opinions but is a key way of contributing to and keeping informed about current services and future developments.

We attend many meetings, the local ones primarily by HUG committee members and the Highland ones by a HUG worker with a HUG member as well.

The nature of such meetings is that there is a degree of formality and an expectation of a prior knowledge of the subjects under discussion which can put some of our members off. However we have also generally found the professionals at such meetings to be welcoming and keen to hear our views.

### Local Meetings

In each area of the Highlands there are meant to be Local Implementation Groups to help develop local services. We try to have a HUG involvement in these:

CAITHNESS - HUG members attend these meetings when they are called (which is infrequently at present).

SUTHERLAND - Two users attend these meetings but there is no HUG involvement at present.

EAST ROSS - Two HUG members and a HUG worker have attended one or two of the only meetings to which they have been invited.

INVERNESS - Four HUG members are willing to attend meetings but have not, until recently, had dates for the meetings.

NAIRN - A HUG member is willing to attend meetings but has not been invited.

BADENOCH AND STRATHSPEY - Two HUG members have attended when meetings have been held.

LOCAHBER - Two HUG members attend meetings.

SKYE AND LOCHALSH - One HUG member attends meetings.

### **Highland Wide Meetings**

- Mental Health Network Group - a HUG worker attends these meetings and HUG has a standing agenda item at each meeting. HUG members have not been invited to participate.
- Mental Health Operations Group - a HUG worker and member attend these meetings.
- Mental Health and Learning Disabilities Management Group - a HUG worker and member attend these meetings.
- Care Programme Approach Management Group - a HUG member (and more recently a HUG worker) attends these meetings.
- Choose Life Group - a HUG worker attends these meetings.
- Employment Working Group - two HUG workers and some HUG members have attended these meetings.
- Perinatal Mental Health Group - a HUG member attends meetings when possible.
- Alcohol Related Brain Injury Group - a HUG member would like to attend these meetings but they are not held at a convenient time.

## **7) Attending Service Development Groups**

### Short Term Groups:

- Safe Houses - a HUG worker and HUG members attended meetings over the possible development of safe houses.
- Psychiatric Emergency Plans - a HUG worker and members attended meetings about these plans and commented on draft documents.
- Tobacco - a HUG worker and member met to discuss NHS Highland's policy.
- The Environment at New Craigs - a HUG worker and members met to discuss security safety and the physical environment.
- Craig Dunain Community Woodland - a HUG worker joined the management committee temporarily. HUG members visited the site twice and were consulted over possible developments.

### National Groups:

- National Advisory Group On Mental Health And Wellbeing - a HUG worker attended these meetings.
- 'see me' Management Group - a HUG worker attended these meetings.
- VOX (a group developing a national user voice) - a HUG member and later a HUG worker attended these meetings.

- National Mental Health Nursing Review - a HUG member attended very early meetings.
- 21<sup>st</sup> Century Social Work Review (CITIZENS JURY) - a HUG member attended these meetings in a personal capacity.
- Open University Social Work Course Review - HUG members attended these meetings.

## **8) Working Internationally**

- HUG worker attended an international conference in Milan on the user movement.
- HUG hosted a visit by a worker from the Ukraine.
- HUG participated in the Grundtvig 2 project involving teams from Czech Republic, Poland, Romania, Portugal, Spain and Scotland. A HUG worker and HUG member visited Spain, Poland and Portugal. Two HUG workers and a member helped host the Scottish visit. HUG members participated in a series of focus groups developing materials on active citizenship, employment, social roles, empowerment and leisure and recreation.
- HUG publicised a series of feature articles in their newsletter highlighting the mental health situation in Ghana.

### Lessons Learnt

It can be hard to keep motivated to attend committee meetings despite acknowledging their importance and being made welcome by officials. It is not always possible to gauge the views of HUG members on the subjects being discussed, although the HUG reports and Friday Forum meetings provided both a policy bedrock and a means of rapid consultation.

It would be useful if we could expand the network of HUG members who are ready and capable of attending such meetings.

HUG members' views:

**"At times when I have been extremely well I have attended Management meetings and L.I.G. meetings accompanied by another HUG member. There our voices and values were both appreciated and documented and listened to in our position as HUG representatives."**

**" it's a privilege to be able to have user input in the New Craigs Management Committee when we can comment on policies and activities directly affecting fellow service users. During the monthly meetings we are kept abreast of issues and conflicts regarding service users and management. Although just active observers I still feel our opinions are respected recorded and taken into consideration."**

## **9) Attending Conferences**

HUG workers and members attended a series of conferences and other events throughout the year where we learnt from other groups and professionals, passed on information about ourselves and occasionally held information stalls about HUG.

A HUG members view:

**"I love conferences because you get to meet all aspects of a particular issue or cause. I very much like the workshop parts. It's a great opportunity to network and to learn and upgrade your skills. It's also a great way of renewing your passion when you find yourself among like minded people."**

### **Speaking out to challenge stigma and discrimination**

We have recently published a comprehensive report describing the achievements of the Communications Project over the last three years (Stopping Stigma, Increasing Awareness, February 2006) which is available from the HUG office.

This section is therefore a brief glimpse into last year's work.

## **1) Work with Young People**

### **Peer Education**

A pilot peer education project, involving twelve 5<sup>th</sup> and 6<sup>th</sup> form students was established in Millburn Academy in 2005 which met with HUG members and researched the issues around mental ill health, concentrating on self-harm, schizophrenia and eating disorders.

The idea behind this project was that we would help the pupils to learn about a range of mental health issues by encouraging them to raise their own awareness and understanding of a range of mental health issues and hear directly from HUG members and professionals. Whilst we as workers pointed the pupils in the right direction, they were very much encouraged to take ownership of how they wanted to educate themselves and to choose specific topics of interest.

### **The impact:**

Apart from educating themselves they were keen on educating their fellow students and produced materials by which they could then educate their peers on

mental health issues, including a school website, posters and a collection of video clips and interviews.

They have also participated in HUG awareness raising sessions in the school (as part of the Personal Social Education curriculum) and given a presentation as part of a regional seminar on young people and mental health.

The young people who took part in this project have been very positive about their experience as have 3 HUG members who met with them and who found them enthusiastic, very respectful and extremely eager to learn.

A new group has now been established to continue the work over the next year.

### **Awareness Raising via Personal Social Education (PSE) Classes**

Over the years HUG has had increasing requests to go into schools to talk about mental health. These can be one-off sessions or, more often, part of a series of classes that ultimately reach a whole year of students.

A HUG worker (usually accompanied by 2 – 4 HUG members) has provided awareness raising sessions to 4<sup>th</sup> – 6<sup>th</sup> form pupils in Millburn Academy and Charleston Academy.

#### The impact:

Around 200 young people have had a chance to hear directly about mental illness from HUG members. Feedback from teachers and young people has been positive, with pupils commenting that they have a much greater general awareness of mental health issues and are more understanding (and will be less stigmatising towards) people experiencing mental health problems, including young people their own age.

### **“STIGMA” Play**

With recent research showing that 1 in 15 young people use self harm to manage distress, the Eden Court ‘STIGMA’ play has been a core part of the schools’ annual calendar for the past 4 years. The play, which is interactive and based on forum style theatre, explores some of the issues for young people around mental health, particularly stigma, self harm and depression. A workshop follows, in which the pupils suggest different, more positive/helpful, outcomes for the main characters and looks at how to get help and the fact that people can recover from mental health problems.

This play, with accompanying awareness and information sessions via the PSE curriculum, is a partnership between HUG, Eden Court Outreach and the Department of Child and Family Psychiatry.

Directly linked to the play are training/awareness seminars for a wide range of professionals (although school-based staff are key targets) on the issue of young

people and self-harm. The aim of the seminars is to raise the knowledge and skills of workers, so they will be better able to support and respond appropriately to young people who use self-harm to manage distress.

Planning and fundraising for the play and seminars is undertaken throughout the year but the play itself is shown in the autumn term (September-October).

The impact:

This year it reached over 1000 young people in 13 schools, and over 4000 over the last 3 years. An evaluation carried out in 2005 with 950 students showed that:

- 48% said their attitude had changed as a result of the play with many of those who said that their attitude hadn't changed stating that they already had a positive opinion about people with a ,mental illness.
- 80% thought the play was either 'very good' or 'excellent'  
Around 80% said that they had learnt between 'quite a lot' and 'Hugely' on the key themes of self harm, stigma and depression.

**"I could relate to the issue of depression and have attempted the issue of self-harm. This session made me think that I could in fact open up to more of my close family members for advice"**

*Young person*

**"I thought the play dealt with a difficult topic very well and that the young people were well engaged with and sympathetic to the subject. It provided an excellent opportunity for young people to discuss the subject and therefore allowed them to become more aware of self harm and mental health generally."**

*Principle Teacher Guidance, Kingussie High School*

## **2) Mental Health Awareness Training**

These events are carried out by a HUG worker who facilitates the session with the assistance of HUG members who act as awareness raisers.

The aim is to help people become more aware of our lives, of what helps and what doesn't. Through meeting users directly in a safe environment workers are given a unique glimpse into peoples lives and are thus empowered to discover that despite having unusual experiences and sometimes horrific pasts we remain fundamentally human and as deserving of respect warmth and equality as anyone else. They also gain an insight into our vision of our lives and those that help us. This helps inform what is often already good practice.

The impact:

Evaluations of these sessions, which range from a couple of hours to a day, have been consistently positive to the extent that HUG members have become quite used to seeing a series of questionnaires saying that their testimony was excellent.

**"I feel the day has changed the way I will look at my life forever."**

*Key Housing Worker*

**"This session with HUG members has influenced me as a person as well as a clinician."**

*Intermediate Care Team, RNI Hospital*

**"I found the very personal testimonies very brave and moving. I thought I had a good understanding of mental health problems but this improved my knowledge and understanding."**

*Student, Inverness College*

**"[Getting involved] in training was a therapy ... a way of giving something back and gaining self-worth and self-esteem. It is about feeling useful, there is a purpose to our lives ... it is empowering ..."**

*HUG Member*

Awareness sessions carried out in 2005 and early 2006 included:

- Northern College Students In Social Care and Nursing - on HUG and issues affecting users.
- Inverness College Students in Social Care and Nursing - on stigma and discrimination.
- Hillcrest Nursing Home, Nairn - on eating disorders.
- Advocacy Highland Volunteers (Caithness and Sutherland) on general mental health issues.
- Advocacy Highland Volunteers (Badenoch and Strathspey) on general mental health issues.
- Professionals who work with young people who self harm - on self harm at four seminars across the Highlands in partnership with Eden Court and the Department Of Child And Family Psychiatry.
- Key Housing Staff in Inverness twice and Fort William on general mental health.
- Housing Workers from Highland Council.
- Psychiatrists and others - on medication.
- Intermediate Care Team at the RNI Hospital - on general mental health issues.
- Staff at Pentland Housing Association - on general mental health issues.

Although our training sessions are based around the use of personal testimony followed by discussion we have moved on considerably from the days where a session was based around a succession of talks by HUG members. By providing a variety of learning opportunities we have managed to make the sessions more fun, more interactive and less intense. This is extremely important as the content of the sessions can be distressing and overpowering if handled wrongly.

However, the HUG personal testimony is not just a story but HUG members contributing to the whole debate and using their experience to inform the training.

HUG members are trained and supported if they want to participate in awareness raising - a recent awareness raisers event was attended by 8 HUG members. The purpose of the day was to spend time thinking about training in mental health awareness, why we do it and what are the messages we hope to convey, and why HUG members personally wish to be involved in future training events.

HUG members have the opportunity to be involved as 'shadows' or observers if they are worried about their input but equally may be central to a session with the delivery of their testimony.

### **3) Working with the Media**

Keeping the profile of mental health in the media allows for an increased public understanding about our lives and experiences as well as the issues that we face.

We aim to have one article placed in the media every month. Articles can often be a response to a request for information over a news story or may be planned in advance as a feature article about a members experiences or an issue that we have raised.

Both workers and HUG members contribute to media requests, and HUG members are supported and trained to get involved with the media. A recent event was held for media volunteers and attended by 15 members.

#### The impact:

It is hard to keep track of all the media mentions we have had over the year as we don't have the capacity to analyse all the local media, but examples of media placements include:

October 2005

- Feature article in 'Mental Health Today' on the Employment Report.
- Article in an international user magazine on the Medication Report.

- Article on Medication Report in 'the pink one', a Highland newsletter aimed especially at pharmacists.

November 2005

- Front page mention in Inverness Courier on HUG views on a psychiatrist who worked in New Craig's hospital.
- Quote in Press and Journal on self-harm in the Highlands.
- Feature article on users' views of psychiatrists accepted for publication in the bulletin of the Royal College of Psychiatrists.

December 2005

- Article on bi-polar disorder and substance abuse in 'On the level' a newsletter for the Bi-Polar Fellowship.
- Profile on a HUG worker in Third Force News.
- Article on depression in Lochaber Life.

Our members have frequently told us that with adequate support they can feel very good about appearing in the media:

**"I would hope that my experience in the press has had an impact by telling people that if you have a mental health problem you don't have to sit permanently on the side."**

*New Craigs HUG*

**"It is well known that direct contact with people with mental health problems is the single most effective way of overcoming stigma and prejudice."**

*Catherine Jackson, Editor, Mental Health Today*

#### **4) Producing Training and Educational Resources**

Over the last two years we have produced a number of CD's, videos and DVD's featuring our members' stories and views. The DVD production is led by a HUG worker, whilst filming and editing is often carried out by the IT Development Worker from Highland Community Care Forum. HUG members are at the core of any DVD produced and are involved in its development.

This medium is proving increasingly important as it allows the voice of members to be heard who find it difficult to attend training sessions personally (e.g. due to geography, stigma or the changing nature of mental illness). DVD's also enable us to get our message out to a much wider group of people and are an alternative and creative way of getting the voice of our experience recorded and listened to.

We have produced a number of DVD's this year, which are most often used as awareness raising tools and are sometimes distributed widely and at other times

kept for limited distribution depending on the wishes of the HUG members who appear in them and the original scope of the project.

The Impact:

The production of DVD's not only has an impact because of the finished product but also because HUG members feel good about participating:

**"I was involved in filming for the new Employment DVD. It was a really positive experience I felt valued and worthwhile."**

*Margo*

**"I have had people come up to me in the street after the DVD and play and all the responses have been very positive once they have explained why they are speaking to me."**

*Wick HUG member*

**"I got a lot out of making the DVD's. It helped me to gain confidence especially when we got feedback."**

*HUG member*

This year we have been involved in the production of a number of DVD's:

**The Mental Health Act** - we produced a DVD on the new Mental Health (Care and Treatment) Scotland Act. The DVD focused around the principles underpinning the Act with an illustration of what we as users would like to see happen. It also featured discussions around new aspects of the Act such as advance statements and named persons. The DVD has been distributed widely across Scotland (over 400 copies have been sold) and often forms part of the mandatory training for all professionals who have responsibilities under the Act.

**Self-harm** - our main DVD (entitled 'Silent Cry') features two members talking about their experience of self-harm, and has been shown frequently with great impact at a number of seminars and training events across Highland and Scotland. We also have two audio DVD's of a young person's experience and a HUG member's experience of self-harm which have also been heard and have had a great effect.

**Eating Disorders** - this DVD is still in production and should be complete in the next few months.

**Dual Diagnosis: Substance Misuse and Mental Health Problems** - this DVD is now complete and will be used in appropriate training sessions. Two members and a dual diagnosis worker in Inverness were involved in the filming of this DVD. They spoke about their problems with dealing with Mental Health issues and substance abuse. Both the members in the DVD are willing for the

distribution of the DVD to be over a wide audience. There is already a demand for this DVD to be used in training and it will prove to be a valuable resource in training sessions.

**Employment and Mental Health** - this DVD was commissioned by Scottish Health at Work to be used in their training pack to employers in Scotland. Several HUG members shared their experience of accessing employment. There is a good balance of positive and negative experiences and a lot of information for employers in how to maintain good mental health for their employees. The feedback from SHAW for the rough edit was very positive and they are sure that this DVD will prove to be a valuable resource in the work that they do.

**A DVD on HUG** - filming is almost finished for this DVD. Several HUG members have shared their experience of being a HUG member. The DVD demonstrates the wide variety of ways in which members can be involved in the work of HUG. All the HUG members involved speak very highly about the work and many are involved in several ways. This DVD is intended for wide distribution and will also be used for training purposes and for presentations.

The impact:

**"Commission staff have been particularly impressed with the way the Mental Health Act DVD brought the principles to life and we have used the DVD widely in the training of our staff."**

*Douglas Seath, Mental Welfare Commission*

**"The DVD continues to be very well received and forms an integral part of our training on the new Mental Health Act."**

*Laura Gillies, Highland Council Social Work Department*

## 5) Using Information Communication Technologies

### **HUG WEBSITE, BULLETIN BOARDS AND EMAIL:**

The HUG website is now regularly updated and contains all our current reports, talks and newsletters as well as featuring information about HUG and members' stories and artwork.

The impact:

We hear anecdotally that people consider the website well designed and accessible. We often have contact with people who have found out about us through the website and often refer students who contact us to the website where they can gain information for their studies.

We have established contact with users internationally via their visits to the website.

We are investigating other ways of recording the impact the website has.

We use email routinely to communicate with our members – we have an email network to whom we pass on information that we think will be of interest. We also use it to communicate with HUG members who cannot participate in other ways – perhaps through geography, work or an inability to be in other peoples company.

#### The Impact:

This contact has helped HUG members contribute to awareness raising through articles that they have written for us which have then been used in our newsletter and in other settings

**"For a long time I depended on HUG via Emails."**

*Lochaber HUG Member*

#### **The HUG Message Board**

We are in the beginning stages of setting up a pilot message board. There are currently nine members who participate in the message boards and we are currently trying out a couple of different ones to test out ease of use and access.

### **PUBLICITY AND PROMOTIONAL MATERIAL**

#### **The HUG Newsletter**

This is produced 3-4 times a year and is edited by a HUG member on a work placement with us. It has been transformed from a tool that workers use to report on their activities to a publication with many articles by HUG members.

#### The impact:

The newsletter is distributed to about 600 people and organisations every quarter, including HUG members, MSP's, service managers, professionals and carers. It features stories of recovery and struggle, news and issues of interest.

It is a large publication but feedback from our members' show that it is a useful and helpful publication which they like to receive.

#### **HUG Publications**

'A User's Guide to Recovery' - a HUG member wrote about her personal vision of recovery in her guide to recovery, which has been distributed to 360 HUG members and used as awareness raising material in HUG awareness events.

#### The impact:

HUG members have commented on how good they felt the guide was. We also received a request for it to be placed in the Scottish Recovery Network website.

## **CONCLUSION**

The last year and a bit has been a very busy one. HUG members and workers have continued to press and lobby for change throughout the area in which we have members.

We have raised issues throughout the year. This report shows that we have been very successful in raising the concerns of our members and equally that we have been very successful in getting our voice heard. When we look at our lobbying activity it is harder to demonstrate tangible change as a result of our activity. We need to learn more creative ways of achieving change but, equally, as a group that has only the power of its voice as a means of creating improvements for its members, we need to be aware that progress will often be slow and that it rests on the willingness of the agencies such as the Council, NHS Highland and Scottish Executive to be agents of change. As a small regional group we have had a big impact but the struggle we are engaged in is a long-term one.

We are very pleased that our work in challenging stigma has had a consistently positive impact. Over the year we have helped many young people, professionals and the public to view us in new and more positive ways. In the long term we hope that this will not only result in better treatment but will diminish the stigma of mental illness to the extent that our members don't feel unnecessary guilt or shame because they have a mental illness. We find that our members see this aspect of our work as one of great importance. Our current uncertainty about achieving sustainable funding for this work is a great worry to us.

Over the year HUG members have reported an overwhelmingly positive effect of the HUG's anti-stigma work, with people reporting: increased self-confidence; enhanced self-esteem; feeling more valued; being more proud of who they are; experiencing improved social networks; sense of empowerment; reduction in stigmatising actions and attitudes, and recovery from illness. This has enabled people to enjoy better lives within their communities due to greater awareness, understanding and acceptance and tolerance from the general public.

Knowing from our membership that they appreciate what we are all trying to achieve, and in many cases benefit from it personally, is a great reminder of the importance of groups like HUG and the cause that we are all a part of.

## **APPENDIX I**

### **TIME SPENT IN A TYPICAL WEEK BY HUG WORKERS**

#### Advocacy Project Manager

Week beginning March 20<sup>th</sup> 2006

- Monday: Travel to Glasgow for Interim Management Group of VOX (an emerging national user group.) Stay overnight and read background material for HUG and work on HUG report.
- Tuesday: Participate in panel for the opening session of the Mental Health Today conference. Meet other users and groups at the conference.
- Wednesday: Attend Employment Working Group. Give talk to trainees at the Training and Guidance Unit (TAG). Participate in appraisal and supervision session with line manager.
- Thursday: Meet People First worker for supervision. Met manager at New Craigs hospital to raise issues of concern to our members. Meeting in Dingwall to discuss developing the drop-in.
- Friday: Hold Friday Forum drop-in session. Meet with the Patients' Council.

#### Development Worker (Media & ICT)

Week beginning March 20<sup>th</sup> 2006

- Monday: Gather training materials together for Training Day.
- Tuesday: Media Training Day. A day for training HUG members to increase confidence when working with newspapers, radio, TV and filming training DVDs. Part of the day was devoted to relaxation techniques.
- Wednesday: Editing material for Scottish Health at Work DVD. Meeting of the Employment Working Group. Start collating the HUG questionnaire. Find materials on the internet for specific Mental Health problems for one of the HUG members.

#### Development Worker (Young People and Training)

Week beginning April 3<sup>rd</sup> 2006

- Monday: Final planning and preparation for training for Key Housing staff on bi-polar disorder; met representative from charitable funding trust to discuss a funding application.
- Tuesday: Attended HUG Round Table meeting.
- Wednesday: Day delivering training in Thurso to 20 staff members from Key Housing, involving 2 HUG members with diagnosis of bi-polar disorder.

Thursday: Worked on budget for Comic Relief, monitoring for Connecting Communities Project and planning for work with young people.

# THE INVOLVEMENT OF HUG MEMBERS IN HUG ACTIVITIES

### Background

The HCCF Connecting Communities (ICT) Project received Big Lottery funding in 2004 to work with the HCCF Projects, including HUG, to use ICT to support people to speak up. As part of this work we looked at how HUG members feel about their involvement with HUG activities. In December 2005 we sent all HUG members a questionnaire asking about:

- The different ways in which they have been involved with HUG?
- How they found this involvement?
- How they would have liked to be involved?
- What has prevented this from happening?

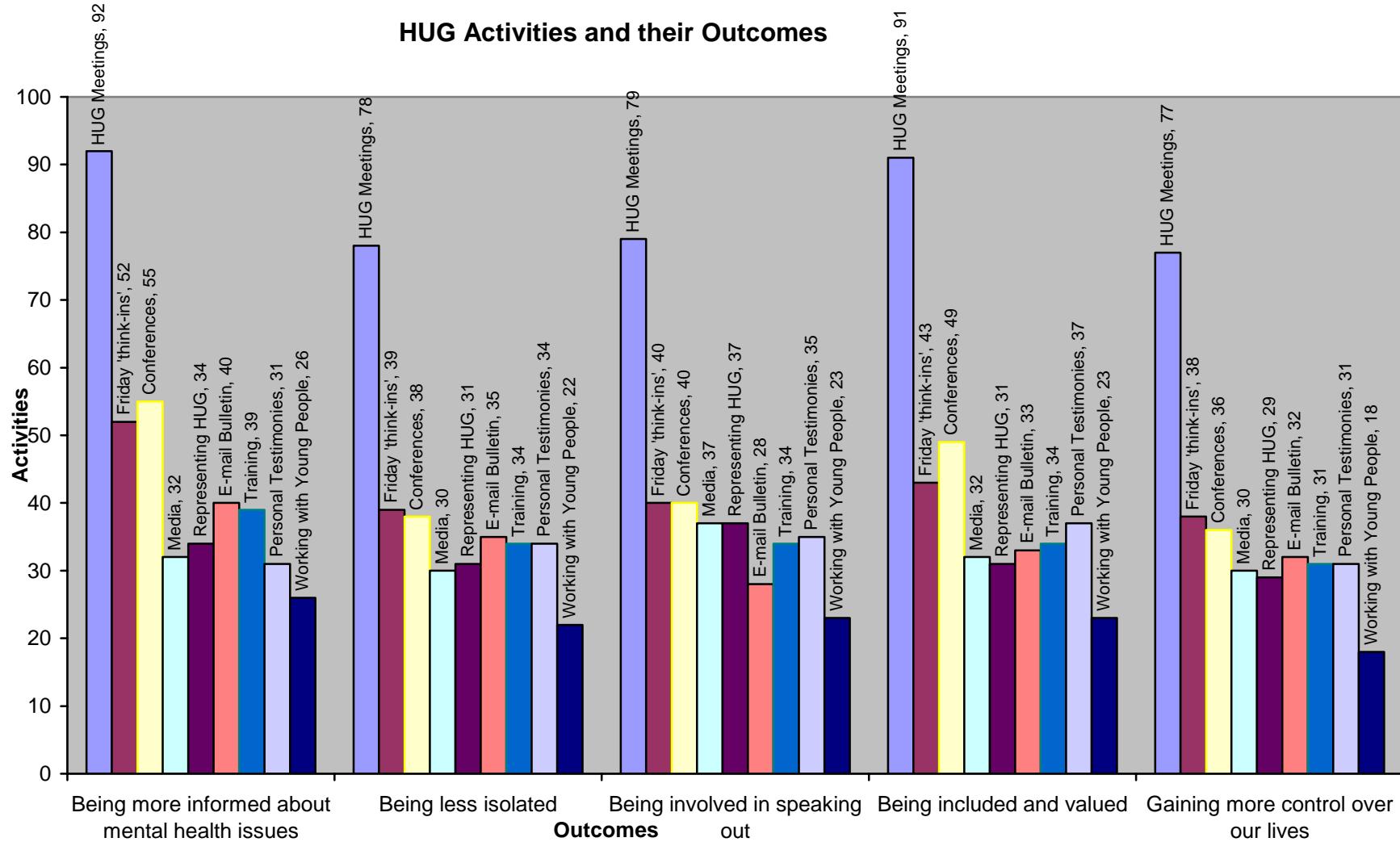
### Scoring of HUG activities and the outcomes they result in for HUG members

Members rated statements (the intended outcomes of the Connecting Communities (ICT) Project) from 1 ➔ 5 in terms of how effectively each activity resulted in them:

- being more informed about mental health issues
- being less isolated
- being involved in speaking out
- being included and valued
- gaining more control over our lives

'Being more informed about mental health issues' almost consistently scored the highest out of the five outcomes, with 'being included and valued' following closely. The lowest scoring outcome for almost all activities was 'gaining more control over our lives'. The chart below demonstrates that though 'being more informed about mental health issues' came out with the highest overall score, there was only a 4% difference between total scores for each activity.

The differences in outcomes that HUG members feel individual activities help them achieve



The chart above shows the total scores that HUG members gave for the outcomes they felt each activity met. The variation in scores is mainly representative of the number of people participating in each activity – those who did not participate in an activity often did not give a score for it. ‘Being more informed about mental health issues’ almost consistently scored the highest out of the five outcomes, with ‘being included and valued’ following closely. The lowest scoring outcome for almost all activities was ‘gaining more control over our lives’.

Most HUG members agreed that the activities mentioned met all outcomes. There were some activities where HUG members did not agree that an activity resulted in a particular outcome:

- did not agree that 'Attending conferences' = gaining more control over our lives
- did not agree that 'Attending conferences' = being involved in speaking out
- did not agree that 'Talking to the media' = being less isolated
- did not agree that 'Talking to the media' = gaining more control over our lives
- did not agree that 'receiving the Email Bulletin' = being involved in speaking out

For some of these activities, the outcome mentioned may not be appropriate.

### **Attending Local HUG Meetings**

This was the most common form of involvement with HUG among those who responded.

#### **Things that work well for HUG members attending HUG meetings:**

1. Venue - "*Relaxed atmosphere.*"
2. Content – fun, relaxed, focused - "*Always very interesting and informative.*"
3. Others attending – share experiences, impassioned, honest, open - "*Supportive and inspiring*", "*focused and fun*".
4. Personal development – increased self esteem – "*Rewarding, increased my self esteem*".

#### **Things about involvement in HUG meetings for HUG to respond to / think about**

1. Meetings should be in an appropriate environment; enough space, access for physically disabled.
2. Meetings should be for the appropriate amount of time – not too long.
3. Long distances involved make it difficult for members to attend meetings.
4. Risk of individuals dominating meetings which stops others participating.
5. Demonstrate changes to grass roots situation which have resulted from HUG meetings.

### **Attending Conferences**

#### **Things that work well for HUG members attending Conferences:**

1. Personally rewarding – empowering, meeting new people, enjoyable, able to take up own issues - "*Enjoyable*", "*Brilliant*", "*Very empowering to represent HUG*", "*Expand contact network*".

2. Interesting content - "*Interesting, I was able to make contact with employer re. sick leave*".
3. Good to know that the voice of HUG is getting spread further - "*puts HUG 'out there'*".

**Things about involvement in Conferences for HUG to respond to/think about:**

Things that put people off going to conferences include:

1. Perception that conferences are; 'all talk and no action'. Need to demonstrate follow up.
2. Support needs: Stigma, language can be overwhelming - i.e. too much jargon, stressful travel, fear of crowded places, inaccessible for those with physical disabilities.
3. Lack of notice that the conference is on. Lack of time available.
4. Enjoyed conferences and would like to go to more but don't know how.

**Attending Friday Forums**

**Things that work well for HUG members attending Friday Forums:**

1. Socialising and fun - "*fun, friendly, centring*".
2. Feel involved and valued – "*Enjoyed getting lunch, coffee, warm hello from all staff and feelings of being valued*".
3. Receive up-to-date information - "*Gives opportunity to focus on different issues*".

**Things about involvement in Friday Forums for HUG to respond to/think about:**

1. Some members are unaware that Friday Forums take place, and where the office is.
2. Difficult to attend due to lack of transport, being in a power chair, and problems with crowds.
3. Other commitments, work and personal, stop members attending - same day as a drop-in day.
4. Could members take an active part at a distance?
5. Could there be minutes/ reports?

**Representing HUG at National / Highland / Local Level**

**Things that work well for HUG members representing HUG at National/ Highland/Local level**

1. Included and valued when representing HUG locally.
2. Personal honour - "*I feel very honoured to have had a national representation for HUG*".

**Things about 'involvement in representing HUG' for HUG to respond to / think about:**

1. Concern that this is putting emphasis on just talking, and not actually acting to change things.
2. Representing HUG can be tiring and stressful.
3. Involves too much travelling.
4. Members are put off by the need to be involved with locally dominant people.
5. Representing HUG can result in feelings of resentment from professionals.
6. Physical disabilities stop this.
7. If I was involved in this type of activity it would upset my family.
8. Conflict of interest as I also work in the field of mental health.
9. Members who are unaware of what this involves, or if they have done it already.
10. Members who would like this involvement but feel they would first need to become much more involved with HUG.

**Email Bulletin**

**Things that work well for HUG members who receive the email bulletin:**

1. Receive information.

**Things about 'Email Bulletin' for HUG to respond to / think about:**

1. Majority of members responding had not received the email bulletin.
2. Some members would like to receive it but did not know how to do this.
3. Some had received very limited number of bulletins and didn't know why.
4. Many members did not have access to a computer, or felt unable to use a computer.
5. Some members do not like email as a form of communication.
6. Suggestion that HUG should provide a one-stop information access point for people to use as needed.
7. Content of email bulletin is only of passing interest.

**Talking to the Media: Radio / Newspapers / TV**

**Things that work well for HUG members involved in talking to the media:**

1. Support from the HUG team - "*Quite scary, but great having support from the team to help*".
2. Involved in something that is very worthwhile - "*It was really difficult, but very worthwhile*".

**Things about 'talking to the media' for HUG to respond to / think about:**

1. Talking to the media can be daunting and scary.
2. Need for support and training for any members who are involved with talking to the media.
3. Issues around being able to identify people on the radio even if they do not use their name.
4. Distrust of the media stops members taking part.
5. Many members said they had never been approached to do this, but would be happy to if they were.
6. 'Conflict of interest' for a member who works in field of mental health.
7. Concerns that this would result in upsetting member's family.

**Training: Participate in training**

**Things that work well for HUG members who participate in training:**

1. Enjoyable, satisfying, rewarding - "*Very enjoyable and satisfying*".
2. Gives a sense of purpose - "*Makes me feel valued and more confident*". "*Gives a sense of purpose to my life*".
3. New skills and confidence - "*Training excellent*".
4. Good HUG support - "*Felt well supported by HUG workers*".

**Things about 'participating in training' for HUG to respond to/think about:**

1. Member was uncertain of the purpose in this training.
2. Need for training and support to be able to do this - specifically training on dealing with stigma and emotions and specific training skills.
3. Need for information on who else would be involved.
4. Too much travel involved.
5. Conflict of interest as work in field of mental health.
6. Would like to do this but have not been asked.

**Training: Personal testimonies – e.g. video, tape, face-to-face**

**Things that work well for HUG members who have given their 'personal testimonies':**

1. Fun and helpful.

**Things about 'personal testimonies' for HUG to respond to / think about:**

1. Feedback on your own personal testimony can be difficult to accept.

2. Would like to be involved in this – particularly with employment testimony.
3. Too much travel involved.
4. Need more skills – uncertain about what would be required. Need more self-confidence to do this. Need training in dealing with overwhelming emotions, deadlines and pressure.
5. Inappropriate method for one member who has no wish to share weaknesses or strengths with strangers.
6. 'Conflict of interest' for a member who works in field of mental health.
7. Concerns that this would result in upsetting member's family.

### **Training: Working with young people**

#### **Things that work well for HUG members who are involved in working with young people:**

1. Enjoyable - "*Enjoyed work with the young*". "*Privileged to work with young people*".

#### **Things about 'working with young people' for HUG to respond to / think about:**

1. 'Conflict of interest' for a member who works in field of mental health.
2. Physical disabilities stop this.
3. Too far to travel.
4. Intimidating and made me nervous. Can be particularly difficult in a school in the town where the member lives.
5. Anti stigma presentation in my area has been cancelled on a number of occasions.
6. Need more training.
7. Why concentrate only on young people? This should be included as a core section of any disability awareness and disability equality training. It is much less onerous to do this in the controlled environment of a school than, say, a public bar.

### **Other activities where HUG members are involved**

1. Grunting 2 Project - "*Very rewarding, but very hard work. Quite stressful at times*".
2. HUG Website.
3. Telephone HUG office for advice - "*Very supportive and helpful and consistent*".
4. Round Table- "*Good to hear what other areas are doing and extremely interesting speakers*".
5. LIG meetings.
6. Post Natal.
7. Management meetings.

8. HUG Postcard Project - "Very successful. Postcards still in circulation and reprinted".
9. Stigma Play - "Fantastic".
10. Newsletter - "Excellent".
11. Reports- "Keeps one informed".

#### **Ideas for future involvement**

1. Creation of a self-help directory.
2. Creation of a directory of mental health provision for the Highlands that is regularly updated.
3. Computer, arts, crafts, meetings.

#### **HUG members have the last word - 2 contrasting comments:**

**"This questionnaire is centered around activities involving the media and with 'image projection' rather than bringing support to people who have fallen through the net and are unable to seek it. Rather than encouraging people to raise their expectations without means of fulfilling them, I would like to see HUG concentrate less on the propaganda and more on improving the quality of life for those with any form of mental disability."**

**"I am happy with the involvement I have and support I get and the knowledge HUG will help if I have a problem".**

## APPENDIX 3

### GETTING INVOLVED IN HUG

HUG is often cited as an example of how user involvement can work well. Our members are the key to everything that we do but are involved in numerous different ways which is possibly the key to our success.

Not everyone wants to speak out publicly about their concerns but many people wish to feel a part of what we are doing. We try to make sure that all new members are welcomed and made to realise that the level of involvement is up to them. For some people this is fulfilled by being a member of our network and receiving regular updates on what we are doing.

Other people come to our local meetings where they participate in our discussions and raise issues that are important to them locally. We are at pains to make it possible for everyone to play a part in these meetings and to make sure that everyone's voice is heard even if we have contradictory opinions.

Some of our members wish to do more than this and we try to make the opportunities to allow this to happen. Their area of interest may vary but can include: attending meetings, acting as awareness raisers or media volunteers, giving talks, going to conferences, writing reports for the newsletter, speaking with young people, reading and commenting on consultation documents, communicating by email, attending Friday Forum meetings, writing HUG reports and pamphlets, working in the office, being on work placement with us, or attending HUG committee meetings.

For people who are more active we try to provide as much support as they need as well as training where appropriate. In this way we hope to provide a whole range of opportunities which will suit those who have made a huge commitment as well as to those who like to feel a part of our organisation but want to do little more than offer support.

We try to involve HUG members in every area of our work but on occasion have to settle for the presence of HUG workers on their own. This is sometimes because we don't have anyone willing to be involved in a particular activity and at other times because the HUG worker has been specifically requested by the organisation concerned. Usually this is fine as the HUG workers have had experience of mental health problems themselves and often have a very broad understanding of the issues our members face and can therefore feel comfortable about representing HUG. At other times HUG members are happy to

represent us alone too, especially at local events. We try to have two HUG representatives at meetings both to support each other as well as to provide as broad a base as possible.

## **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:

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