

ANNUAL REPORT

APRIL 2006 - MARCH 2007

SPEAKING OUT

'At one time I felt very ashamed of my diagnosis and could not live a normal life because of this. The support of the HUG group has set me free and made me feel much more confident and accepting of myself and others.'

HUG Member

'I believe I am doing something that is needed and worthwhile. I feel useful and appreciated and ... [this] enhances my self-esteem and wellbeing.'

HUG Member

'I do not hide at home and can tell people I have a mental illness.... I have learnt a lot from HUG. I have got my life back.'

HUG Member

'Before I joined HUG I felt isolated because I could see no hope of recovery. Now I realise that I am not alone and that recovery is possible.'

HUG Member

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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 343 members and 13 branches across the Highlands. HUG has been in existence now for 11 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:

- o 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
- o Not be ashamed of what we have experienced

We hope to achieve this by:

- o 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

Over the last year HUG has continued with its work to speak out on behalf of people with a mental illness in the Highlands, to challenge discrimination and stigma, to increase awareness of mental illness/mental health and to pursue its wish to promote social justice and equality for people who have mental health problems.

It has been a busy and productive year full of activity and achievement. The office is as chaotic as ever as our workers are constantly engaged in meeting HUG members and other people who can make a difference in our lives.

It has been great to see that our reports have an effect well beyond the date that they are released and although we don't claim to be researchers it is heartening and encouraging to see our work quoted and appearing in a number of respected journals and professional publications.

As ever our work in challenging stigma and raising awareness has come along in leaps and bounds. Our DVD'S have gained a huge reputation and our 'STIGMA' play (probably in its last tour) reached at least 2000 young people with an immense impact. Our awareness training exceeded its targets and is still gaining fantastic evaluations. It really does feel like a great achievement when we see what can be achieved with such a small workforce (less than three full time workers) but with such a committed membership.

As with the rest of Highland Community Care Forum we still struggle with funding and as we move into 2007 we find that our work to challenge stigma and improve understanding is yet again under threat. If we do not find new sources of funding soon then we will lose this vital piece of work at the end of the financial year. As ever we will do all we can to continue this work but it is hard to struggle with an uncertain future.

On a positive note, our young people's work was nominated for a Community Care Award this year (well done to Emma for this achievement) and to the rest of the staff for the excellent work they do in raising awareness about mental health in Highland and beyond.

This report of our work is quite detailed and is divided into two separate documents one celebrating our speaking out work and one celebrating the work of the Communications Project 'Stopping Stigma: Increasing Awareness'. We hope this is not too much for some of you to read but it seemed like a good opportunity to show just how much we do in the HUG network.

WHO HAS BEEN INVOLVED

HUG is a network of people who have experience of mental illness. We have a total membership of 343 and between May 2006 and December 2006 we gained 50 new members, most of whom joined by coming to one of our branch meetings. Others found out about us from the suggestion of care workers or friends and finally some learned about us by visiting our website (hug.uk.net)

HUG members are involved in a great variety of ways, from supporting what we do at a distance or joining in branch meetings, to others who are in the office or at meetings on our behalf most days.

The HUG staff are Speaking Out:

Graham Morgan: Full-time (Advocacy Project Manager)

<u>Communications Project (Stopping Stigma: Increasing Awareness):</u>

Emma Thomas: 26 hours (Young People's Development Worker)
Karen Maclean-Yuille: 21 hours (Creative Expression Development Worker)
Debbie Berry: 14 hours (Mental Health Awareness Development Trainer)

However, HUG is not a just a network of users of mental health services and workers. We are also tied into the HCCF network on which we rely for our administration, finance, supervision, technical and I.T. support and general encouragement and advice.

Some of the key people in HCCF who have also assisted HUG this year are:

Sheena Munro: Executive Director
Isla Cuthbert: Administrator
Mary Rawlins: Finance Officer
Marina Patience: Clerical Officer

Brian Hill Connecting Communities Project Development Officer

The HUG Round Table is the HUG committee that we as HUG workers report to (we also report to the Board of Directors of HCCF). In these meetings we discuss our work and future plans and any topics of significance to our members. The Round Table consisted of:

Caithness West: John and David
Caithness East: Garry and Billy

Sutherland: Gordon East Ross: Andy

Inverness: Margaret and Keir

New Craigs: Ali Nairn: John Badenoch and Strathspey: Pam

Lochaber: Jackie and Ronnie Skye and Lochalsh: Marja-Liisa and Helen

WHAT WE HAVE ACHIEVED THIS YEAR

HUG 'SPEAKING OUT' PROJECT

We give voice to the views of members of HUG in the following ways:

- By holding local meetings in the places that people live and finding out what issues are important to people.
- By holding discussions at local meetings on subjects agreed by HUG members that are then turned into HUG reports.
- By attending committee meetings where we comment on developing policy and present HUG opinions.
- By holding meetings of the HUG Friday Forum where we discuss issues and meet with interested officials and researchers.
- By meeting with officials and writing letters on HUG members' behalf.

LOCAL MEETINGS:

We held five cycles of meetings across the Highland area in our branches involving between 70 and 95 people in each round. These meetings are held in people's houses, New Craigs Hospital and drop-in centres and Training and Guidance units.

A typical meeting starts with a presentation on what we have been doing on behalf of our members since the last meeting. It is then followed by a discussion topic on a subject that has usually been selected by our committee (the HUG Round Table) and concludes with a look at any issues that are happening in people's local areas that we need to act on.

The issues raised locally are far too numerous to list here, but examples included:

- the need for a family room to meet in at New Craigs Hospital
- having to travel to Inverness from Skye for some appointments
- safe houses and dealing with debt in Lochaber
- activities to promote recovery in Wester Ross
- dealing with medicals for benefits in Mid Ross
- the role of 'supporting people' in Badenoch and Strathspey
- the future of the Gardeners Cottage in Nairn
- the need for more young people's services in Sutherland
- dealing with staff absence in Caithness

One of the problems that we find with raising these issues is that there are too many to deal with at any one time. It is difficult for HUG to follow up every one of the huge range of issues affecting our members and even more difficult for officials to respond effectively to the numerous letters we send them. However, it remains hugely important to express the great diversity of opinion of our members and to make sure that what is important to our membership is expressed by them or on their behalf. We will never be able to pursue every issue to a successful conclusion but we would be abandoning our cause if we did not at least bear witness to the hugely important views of our members.

However we are pleased that two major campaigns of the last few years seem to be reaching a positive conclusion:

The Gardeners Cottage (which is a drop-in resource in Nairn) will be demolished as part of the redevelopment of the hospital site in Nairn but new premises have been found which will be fully occupied by September of this year. Our members in Nairn are pleased with this outcome.

In East Ross the Training and Guidance unit spent some time in very cramped and claustrophobic and unhealthy accommodation. This has now changed with new rooms being made available.

THE HUG REPORTS:

The HUG reports are a distillation of the views of our members on the things that we find important. In some ways they could be seen as our policy documents, except they show the range of varying and sometimes contradictory opinions our members have and therefore do not contain a single view.

We produced seven reports last year. The following pages describe them as well as the impact previous reports had in this year.

Occupational Therapy Report (February 2006)

Number of people involved: 12

What it was about:

This report was a record of the views of a focus group of HUG members (commissioned by the College of Occupational Therapy) from across the Highlands about past and present experiences of Occupational Therapy, how they saw Occupational Therapy, what they gained from it and how they would like to see it develop.

The impact:

This report was published in full in the College of Occupational Therapy's Mental Health Strategy.

A member of the HUG team was invited to the launch of the Strategy in London and introduced to Princess Anne. HUG has been asked to be involved as the Strategy is disseminated in Scotland.

Recovery Report (April 2006)

Number of people involved: 67

What it was about:

This report looked at our members views around the concept of recovery and gathered their views on what it was that helped them to recover and live as good a life as they could despite having mental health problems.

The impact:

"...Firstly let me offer wholehearted congratulations on what is a piece of exceptional quality. What you have done and the opinions expressed by members here offer an incredibly useful and powerful tool for all our efforts to better promote recovery. This document is crammed with helpful thoughts and ideas... I firmly believe that simply discussing the concept of recovery is the prerequisite for real change and that is exactly what you have done...." (Scottish Recovery Network)

"this is probably one of the most important, thought provoking and powerful reports we have produced. In fact I felt quite emotional reading it as it captured all my experiences and many difficult challenges in my own recovery journey... the contents capture everything we have experienced and want to say..." (HUG member)

"I found it both informative and uplifting – well done to everyone for such a useful document." (Choose Life)

- The report was used at an Away Day discussion held by the New Craigs Occupational Therapy Department.
- It was publicised on the Email group of the Association of Child and Family Practitioners.
- A feature article about it was published in 'Mental Health Today' magazine.
- It was passed on to researchers in Canada.
- An article was written about it in a mental health magazine in Wales.

Psychiatrists Report (July 2004)

Impact in 2006/7:

"I think that many of your criticisms of psychiatrists are completely valid and I also appreciated your sensitivity in how you expressed them and attempted to understand what we might be up against in terms of organisational constraints." (Psychiatrist)

- An article was published in the September edition of the 'Bulletin of the Royal College of Psychiatrists' on the report and an abstract on it published in ASSIA international database of research articles.
- It was used as a reference in the latest edition of a book by Dorothy Rowe (Beyond Fear).
- It was written about in the Mind magazine 'Open Mind'.
- A presentation on it was given to around 30 psychiatrists in Fife.

Ward Rounds Report (June 1997)

Impact in 2006/7:

Two psychiatrists used this report and quoted from it extensively (especially its recommendations) for their own research project on ward rounds in New Craigs Hospital. This was completed in 2007.

Complaints Report (June 2006)

What it was about:

This report described the views of HUG members on what it was like to make a complaint, what they expected from it and how the system could be improved.

Number of people involved: 72

The impact:

"I found your report to be most interesting and felt that the way you have gone about seeking the views of people who have used services across the Highlands to be extremely effective... the opportunity of users to give such clear and succinct feedback is hugely useful to NHS Highland and I would be keen to have all of my managers to have the opportunity to read and reflect on the comments of people who have taken the time to share their experience." (Elaine Mead, Chief Operating Officer, NHS Highland)

"I think it is an excellent piece of work and it highlighted some very valid issues... the findings of the HUG report have provided valuable information and an insight into the way people feel about complaining..." (Nicola Farrell, Customer Care and Consultation Officer, Highland Council Social Work Services)

A brief presentation of the report was made to the management team at New Craigs hospital.

Grey Areas (Summer 2006)

What it was about

This was a HUG member's collection of stories, anecdotes etc. on a variety of subjects to do with mental wellbeing and user involvement.

Number of people involved:

Impact:

We had little written feedback but informally people said that they enjoyed reading these essays and thought they should be published and distributed more widely.

Incapacity Benefit Report (November 2006)

What it was about:

This was a collection of the views of our members about the proposed changes to Incapacity Benefit and how they felt about being on this benefit.

Number of people involved: 93

The impact

"keep up your excellent work." (European Network of Users and Survivors of Psychiatry)

"thanks very much for the Incapacity Benefit report – well developed and as informative as ever." (Scottish Recovery Network)

- This report did not have as much impact as we had hoped with no feedback from MP's and others responsible for the changes to the benefits.
- An earlier response by HUG as part of the consultation about the benefit was acknowledged in later materials.
- We have had encouraging feedback from other users in Scotland who have just come across this report.

Medication Report (November 1996)

Impact in 2006/7:

An article about this report was published in a magazine in New South Wales in Australia.

Psychiatric Hospital Reports (between 2002 and 2005)

Impact in 2006/7:

These reports were used by and referenced by the Acute Services Sub Group as part of the development of the policy document 'Delivering for Mental Health' by the Scottish Executive.

Harassment Report (September 2006)

What it was about:

This report was another look at New Craigs Hospital, its provision of single sex accommodation and whether patients in the hospital felt exposed to harassment in the hospital.

Number of people involved: 68

The impact it had:

- After reading the report there was a request from the Scottish Executive for a response to the report from NHS Highland. This response was made but HUG does not know what form it took.
- A brief presentation of the report was made to the Management Group at New Craigs Hospital.
- It was used as part of our response to NHS Highlands gender equality duty

Our Needs Report (February 2007)

What it was about:

This report looked at the key issues our members face in the local areas that they live in. It lists things that need to change and things that work well. It was intended to be published around the same time as the Scottish Executive Document 'Delivering for Mental Health' and was sent to politicians in advance of the elections.

Number of people involved: 70

The impact:

"Thank you for sending me the HUG document "Our Needs". It is an important document and you and those responsible for the form and content of the final report are to be congratulated. The document is conscientious, wide ranging and clear." (A user's comments)

"We all find the documents you send very useful." (Geoff Huggins, Director, Mental Health Division, Scottish Executive)

"thank you and your members for this most valuable report. It just says the things which I also feel as a service user that we need. It doesn't put it in terms like joint working, whole system change and all the other terms of jargon which I have heard over the years locally and nationally and find to be words rather than action. Thank you. (Service user.)

" just to let you know that the report is really good and clear.... Congratulations on the wonderful work, it's an uphill struggle sometimes but we are all making a difference" (Theatre Nemo)

We also received requests for the report and good feedback from other user groups across Scotland.

Smoking in Public Places Report (February 2007)

What it was about:

This report looked at our members views on how the first 6 months of the smoking ban had affected them and how they viewed the possibility of making psychiatric hospitals smoke free.

The number of people involved: 85

The impact

"Thank you very much for the excellent reports you have sent me regarding Hug's needs, the smoking ban and more recently Inclusion... I very much appreciate your sending me the reports...." (Dr Chris MacGregor, Clinical Lead Mental Health Services, NHS Highland)

- Some NHS employees were very keen to see the report widely distributed and especially to the Scottish Executive.
- The report was extensively quoted from in a research/consultation document on Mental Health and tobacco commissioned by the Scottish Executive.

Inclusion Report (March 2007)

What it was about:

This report looked at the balance between being a part of mainstream society and being members of what might be called a 'mental health community' and, in particular, our feelings about using services that are purely for people with mental health problems.

Number of people involved: 92

The impact:

"I found it a fascinating read and it has certainly given me plenty to think about." (Dr Ken Proctor, Associate Medical Director Primary Care, NHS Highland)

"I was particularly interested in your Inclusion document and cannot agree more with your statement on page 17 - I too have a problem with the mainstream." (HUG member)

As can be seen our reports are a key mechanism for finding out and passing on the views of our members. The impact of our reports is hard to gauge and we frequently

only find out about how they have influenced people in casual conversations and informal meetings. This is a pity as we do know that they are influential documents both within and outwith Highland.

The effect is often not immediate. Reports that stretch back as far as 1997 are still being read and still having an effect.

COMMITTEE MEETINGS

As a way of giving voice to our members, keeping abreast of developments and influencing policy and the provision of services the HUG team tries to attend as many committee meetings as we can manage:

At a Highland level we attended:

- The Mental Health Network Group
- The Mental Health Operations Group
- The New Craigs Management Group
- The Care programme Approach Management Group
- The Choose Life Group
- The Mental Health and Employment Group

In some of these meetings HUG has a standing agenda item in which it can raise any relevant issues.

At a local level there are a number of local implementation groups for mental health. These are in varying states of wellbeing but where we can and where they exist our members try to attend. There are also a number of Local Community Care Forums which some of our members participate in.

We also invite officials to occasional meetings of our steering group (the HUG Round Table). These have included the Manager of New Craigs Hospital, the Clinical Lead for Mental Health, the Head of Operations for Social Work Services and the Associate Medical Director for Primary Care NHS Highland.

We also occasionally meet informally with some of these officials to pass on issues and views.

We have also attended a variety of meetings at a Scottish level with one of our members meeting the Minister for Health and Community Care and others attending conferences and other events.

THE FRIDAY FORUM

This is a group that meets on as many Fridays in the HUG office as it can manage. It tries to be an informal, friendly group but is also a forum to allow work to be done that cannot be done in our wider network for reasons of time, complexity and organisation.

We generally involved between 3 people and 12 at any one meeting. With 3 people we can do a lot but may run out of things to say and with 12 we are just overcrowded even though we may be having fun.

A huge amount has been achieved in the Friday Forum meetings this year. It includes:

March/April

- Commented on the Smoking Policy
- Commented on the European Green Paper towards a Mental Health Strategy for the European Union
- Contributed to the Council's evidence on homelessness for the Scottish Executive
- Commented on the way the Mental Welfare Commission advertises the principles of the Mental Health Act

May/June

- Commented on Consent to Treatment consultation paper
- Commented on Eligibility to the services of the Community Mental Health Team consultation paper
- Commented on Older People consultation paper
- Commented on Crisis Standards consultation paper
- Gathered views on Braeside Day Hospital
- Commented on a DVD on Spirituality
- Held focus groups for the Grundtvig 2 European Project

July/August

- Participated in Research Project into Ward Rounds
- Participated in Research Project into Compulsory Treatment Orders
- Participated in Research Project into Complex Needs
- Looked at a DVD on Recovered Lives
- Visited by the Mental Welfare Commission
- Commented on New Craigs Information Pack
- Responded to a questionnaire from an international user magazine
- Gave comments on Incapacity Benefit
- Met with a trainee Mental Health Officer
- Met with a Pharmacist
- Commented on Reasonable Adjustment at Work
- Commented on Recovery leaflet
- Provided questions to be asked at Royal College of Psychiatrists meeting
- Discussed Formulary Group questions
- Responded to journalists questions on Genetics and Mental Health
- Discussed Music Therapy and made suggestions about the service

September/October

- Commented on Disability Rights Commission Inequalities paper
- Met with an official to discuss Public Patient Involvement
- Consulted on criteria for Secure Care
- Met with Befrienders Outreach
- Discussed the diagnosis of 'schizophrenia' for 'see me'
- Met with the Mental Welfare Commission
- Met with a representative of the Scottish Recovery Network and NHS Education for Scotland to discuss recovery

November/December

- Responded to a consultation on a questionnaire by the World Health Organisation
- Commented on website and leaflets of the Mental Health Tribunal Service
- Met user involvement worker from SAMH

- Commented on consultation about Prioritising Services
- Commented on 'Fair Access to Community Care Services' document
- Met with Social Work Inspection Agency to discuss Social Work Services.

January/February

- Met with worker from VOX (Voices of Experience National Service User Group)
- Looked at script for Youth Theatre play
- Commented on 'see me' website
- Consulted on Culture Modern Life and Wellbeing
- Filmed for Eorpa programme on Suicide

OTHER SPEAKING OUT ACTIVITIES

HUG has developed a good reputation over the years and as part of this is often visited by or visits other user groups to exchange ideas and learn from each other.

The groups we met with this year were:

- A 'Survivors' Group in Highland
- Healthy Minds in Badenoch and Strathspey
- An Autism Group (now 'ARGH') in Highland
- A User Group in East Renfrewshire
- Ayrshire User and Carer Reference Panel
- Aberdeenshire User and Carer Reference Panel
- Western Isles Catch 23
- Homeless Peoples Group in Arbroath

We also participated in the development and launch of VOX (the developing user voice for Scotland). At its launch three HUG members joined the Management Group.

We also participated at an international level by acting as hosts in the international initiative for Mental Health Leadership to users from America and Canada as well as helping facilitate two workshops on Peer Based Recovery and speaking at the final session in Edinburgh as part of this event.

As part of our continuing work with Grundtvig 2 members of the HUG team visited Romania, the Czech Republic and Spain.

We also gave speeches at national and local events which are described in the HUG Communications Project report and held other meetings to get the user voice heard for instance by meeting with the Mental Health Act Implementation Team, looking at Advance Statements and participating in workshops on the Disability Equality Duty.

OUR THOUGHTS ON OUR SPEAKING OUT WORK

Perhaps the most telling lesson we have received this year was when one of our members handed over a collection of a few months work of her artwork. Within her artwork was an altered version of our last annual report and attached to it a poem about the vital importance of having a voice. This was a heartening expression about the importance of HUG. However, the artwork was also a demonstration that there are many ways of being heard and this is not always through words or committee meetings.

We need to keep our reports, meetings and conversations going as we know that they are very effective but it would be good to look at other ways of speaking out in the future.

We have a fantasy about having a base where we can gather and express our views in a myriad of ways - art, poetry, music, drama, photography. We do a lot of this already in the Communications Project but imagine a house where we gather and grow and learn new ways of bearing witness – sounds a hundred times better than sitting in a seminar not understanding what is being said about Integrated Care Pathways. So watch this space and maybe one day our dreams will flourish and take shape.

ACKNOWLEDGEMENTS

We hope that you have found this report interesting. If you wish to comment on it then that would be very welcome as we love to get as wide as possible a perspective on the work we do.

The people we need to acknowledge most of all are our members and other people with experience of mental ill health in the Highlands. Without their voice we couldn't do anything. A big thank you must go to the young people of the Highlands who have not only been keen and active audiences with the Eden Court 'STIGMA' play but have actively volunteered to get our message across. We also have to thank Charlie for his expertise in filming and editing and Brian in his parallel work with other DVD's. Then there are so many professionals who support us by listening to and enhancing our voice. Without the partnership of people in health, social care and education our message would be so much less effective.

So a big thank you to all those that support us and work alongside us. Long may it continue.