



**Celebrating the HUG Communications Project  
1998-2002**

**Challenging the Stigma of Mental Illness**

**December 2002**

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## **HIGHLAND USERS GROUP**

The **Highland Users Group**, supported by Highland Community Care Forum, was established on 11 June 1996.

Its aims are to:

1. Represent the interests of users of mental health services living in the Highlands.
2. To identify gaps in services and to find ways of improving services for mental health service users.
3. To provide information about mental health issues to users living in the Highlands.
4. To participate in the planning and management of services for mental health service users.
5. To pass on information and news amongst mental health user groups in the Highlands and to interested parties.
6. To increase knowledge about resources, alternative treatments and rights for users of mental health services.
7. To promote co-operation between agencies concerned with mental health.
8. To promote equality of opportunity and to break down discrimination against people with a mental health problem.

At present (December 2002) HUG has 274 members and 14 branches in:

- Caithness
- Sutherland
- Easter Ross
- Wester Ross
- Nairn
- Inverness
- New Craigs Hospital
- Lochaber
- Skye and Lochalsh
- Badenoch and Strathspey

Where possible HUG works alongside local user groups in the Highlands, such as the New Craigs Patients Council and member groups in different drop-in centres.

Between them, HUG members have experience of nearly all the mental health services in the Highlands including Child and Adolescent Services and Services for Older People. However, our reports mainly reflect the views of 'adults' with experience of mental illness.

HUG is facilitated by two workers from Highland Community Care Forum, who have both experienced mental illness.

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# **Celebrating the HUG Communications Project 1998-2002 – Challenging the Stigma of Mental Illness**

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## **AIMS OF THIS REPORT**

This report details the main strands of work of the **HUG Communications Project** since 1998, although there is a greater focus on the work of the project between 2000 – 2002. It provides a forum for explaining the aims of the project, why the work is needed, the values of the work, key achievements and the key lessons learnt.

We hope this will provide a useful resource for other organisations developing anti-stigma projects led by, and involving directly, people who have personal experience of mental illness and mental health services.

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## **CONTEXT AND BACKGROUND**

HUG, the Highland Users Group, is a collective advocacy group, which represents the interests of users of mental health services across the Highlands. Our main aims are to improve the way in which we, as users of mental health services, are treated by campaigning to improve the rights, services and treatment of people with mental health problems and challenging stigma and discrimination through the work of the Communications Project.

The HUG Communications Project was established in 1998 as a result of HUG members clearly identifying the need for active work to challenge stigma and raise awareness and understanding of mental health issues with professionals, the media, young people and the wider general public.

The main strands of the Communications Project are:

- **User-led mental health awareness training** for professionals, such as GP's, psychiatrists, social workers and the police.
- Developing a **mental health educational programme for young people**. In order to bring about long-term change, raising awareness and promoting positive attitudes in young people is crucial.
- **Media work** – to gain realistic, accurate and responsible reporting on mental health issues and ensure users' voices are heard directly in the media.
- **Promotions/PR work** - to challenge negative stereotypes and bring mental health into the public forum.
- Utilise a range of **Information Communication Technologies** (including an accessible and interactive HUG Website).

HUG members are actively involved in the work of the Communications Project as **we believe it is essential that people learn about mental illness directly from those who suffer from it: as long as people with a mental illness are excluded, ignorance, fear and mistrust will remain widespread.**

Through the work of the Communications Project, HUG is part of the **See me** alliance, a key strand of the Scottish Executive's National Programme to Improve the Mental Health and Wellbeing of the Scottish Population. The **See me** alliance was formed in 2001 to generate support for a concerted, long-term, national anti-stigma campaign. Five mental health charities make up the alliance: HUG, the National Schizophrenia Fellowship (Scotland), Penumbra, the Scottish Division of the Royal College of Psychiatrists and the Scottish Association for Mental Health. All five-membership organisations share the common goal of eliminating the stigma and discrimination, which surrounds mental health problems.

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## STIGMA AND DISCRIMINATION AND ITS IMPACT ON MENTAL HEALTH SERVICE USERS

**“Not only do the public not understand people like me who are mentally ill but there is also a lot of stigma which makes people's lives - including mine - quite hard.”**

**“Often it is the people closest to us, partners or family, who attach the most stigma to our illnesses. If they cannot accept that we are ill and support us, how can we expect understanding from the wider community.”**

*HUG Members*

People affected by mental illness can experience stigma and discrimination in all aspects of their lives. Research by the National Schizophrenia Fellowship (November 2001) revealed that 41% of people with a mental health problem experienced harassment and discrimination, and of that 41%, 91% stated it had an adverse effect on their mental health. **The stigma of mental illness has been highlighted in almost every report produced by HUG.**

At its extreme the attitudes of other people can lead to physical and verbal harassment. We firmly believe that it should not be possible to discriminate against people and it should be possible for people to learn to remove any prejudices that they may have about people with a mental illness.

If discrimination and prejudice could disappear, then life would change dramatically for many people as uninformed or distorted ideas can mean that colleagues and employers, mortgage and insurance providers, health professionals and other service providers discriminate unfairly against people with mental health problems. But even closer to home, the attitudes of neighbours, family, friends and partners can also cause hurt and damage.

To compound the issue, the rejection and misunderstanding that people with mental health problems experience often *in themselves* have a serious effect on their mental health. In fact, one survey showed stigma as the *single most negative influence* on the lives of people with mental health problems.

**Discrimination causes damage: it can destroy self-esteem, cause depression and anxiety, and create social isolation and exclusion.**

### **Examples of Stigma Experienced by HUG members**

Examples of stigma experienced by HUG members included being forced to hide the fact they had been admitted to hospital, employers looking for reasons to turn someone down for a job once they knew the person had a mental health problem, kids throwing stones, being told to ‘*go away to the loony bin*’, and family members hiding/denying mental illness in the family.

**‘I felt like I had horns on me and everyone was looking at me’.**

*HUG Member*

HUG members spoke strongly about the effects of stigma on their lives:

**'Once you have been ill it is like a shadow over you for ever more'**

**'Feeling of being useless'**

**'Makes you doubt your capabilities – you can't do the things you used to be able to.'**

Many people spoke about being forced to hide, and even lie, about the fact they had a mental illness, particularly if looking for employment. Some people felt angry that they should be stigmatised for the pain they have experienced and what they have had to go through.

However, there is a feeling amongst some users that stigma is not always malicious but is often a function of ignorance and fear which in turn affects how members of the public react to the concept of mental illness in society. For instance, some members of HUG state that when people that they know have found out that they have a mental health problem there has been a very positive response. This fits into HUG's belief that we are ordinary people with extraordinary experiences and that most people with the proper information are only too willing to treat us like any other person in recognition of this fact.

This does not alter the fact that people can be very self conscious about their diagnosis or even ashamed and, therefore, can find it hard to be open about what they have been through – however it does indicate that simple information provision and awareness raising can work wonders.

By reducing stigma HUG believes that people directly affected by mental illness will lead better lives and suffer less, the public will gain a better understanding of the lives and experiences of people who suffer from mental illness and will act with greater sensitivity and empathy, and people who become ill will seek help earlier.

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## USER-LED MENTAL HEALTH AWARENESS TRAINING

**Surveys have shown that a third to a half of people with mental health problems feel they have been unfairly treated by general (non-psychiatric) health care services, including GP's, hospitals and clinics. A common experience is not being believed or taken seriously.**

*MindOut for Mental Health Website*

### Introduction

HUG has been delivering mental health awareness training for the past five years. The central ethos of this training is the involvement of trained and supported HUG members, who provide a unique personal perspective about their lives and the reality of living with mental illness.

Over the past few years we have been developing our training and facilitation skills, and exploring different tools and techniques for 'getting our message' across to a range of professional groups including GP's, social workers, youth and community workers and voluntary sector staff.

We have also organised a number of 'Training the Trainers' days for members who are interested in becoming involved in this aspect of HUG's work. These training days are an opportunity for users to explore their feelings about user-led training, consider fears and barriers (emotional and practical) they may have about getting involved and how these may be overcome. These days have been a great success and have involved around 25 HUG members.

Additional training days have taken place for members wishing to develop their skills and involvement further. In these sessions we have explored training tools and techniques, discussed issues in greater depth (such as how to keep 'safe', exploring personal boundaries) and clarified the aims and objectives of HUG training and how it might develop in the future.

### Aims Of Training

The main aims of HUG's training are:

- To improve understanding of the lives and experiences of people living with mental illness, based on the direct personal testimony of service users.
- To provide a valuable opportunity to explore issues, increase understanding and empathy.
- To improve communications (and ultimately service delivery) between people with mental health problems and professionals.
- Increase understanding of how users wish to be treated and encourage good practice in the treatment and care of mental health service users.

We provide training according to an organisation's requirements and all sessions are tailored to meet the specific learning objectives of the participants. This is achieved by detailed pre-training questionnaires and face-to-face meetings (whenever possible) with the client organisation. Training can be very general or covering very specific issues, discussion points or subjects, such as self-harm, patients' rights or being on a section. Sessions can range from a couple of hours to a full

Below is an example of some of the training we have delivered over the past year:

- **Ardlarich Medical Practice:** training session on stigma delivered to 10 GP's and practice staff.
- **Inverness Benefits Agency:** 2 sessions delivered to approximately 20 staff about users' experiences of the Benefits Agency and general awareness raising.
- **Lochaber Youth Minds:** awareness training on depression and schizophrenia to 15 Youth, Community and Support Workers.
- **Culloden Medical Practice:** users' experiences and views of medication, good and bad practice and our expectations about the role of Primary Care staff.
- **Conon Bridge Family Resource Centre:** training for 20 support and Social Workers on the subject of self-harm.
- **Mental Health Officers:** session involving 6 trainee Mental Health Officers on patients' rights and detention in hospital.
- **Management of Depression Guidelines:** HUG was involved in a series of 6 workshops across the Highlands to launch guidelines for the assessment, care and treatment of undiagnosed and diagnosed depression. The workshops were aimed at Primary Care staff, primarily GP's, and involved approximately 150-200 professionals.

We have also delivered training to:

- Housing Officers
- GP's and Psychiatrists
- Nurses and Health Visitors
- Police Officers
- Social Workers and Foster Carers
- Care Managers
- Youth and Community Workers
- Teachers
- Voluntary Sector Workers
- Benefits Agency Staff
- Welfare Rights Officers

### **The Need for User-Led Training**

HUG members regularly report that there is limited awareness by professionals of the issues and perspectives of users of mental health services. Users regularly report of negative attitudes and poor practice, and HUG reports clearly demonstrate this recurring theme.

HUG is receiving an increasing number of requests from professional agencies for our training, for example, Social Work Services have recently requested a 12-month rolling programme of training for their staff and we are involved in the annual training programme for trainee Mental Health Officers. The number of requests we receive exceeds our ability (at the moment) to respond as, currently, HUG is only able to deliver about one or two training sessions per month as we have a limited 'pool' of trained HUG members.

## **Evaluation and Feedback**

Formal and informal feedback from participants has shown the value of hearing the first hand experiences of individuals living with mental illness, their variety of experiences, views and outlooks and the importance of responding to the person, not the diagnosis/illness.

Post-training evaluation forms are completed by the majority of participants, the results of which are collated and compared to the pre-training questionnaires completed. The evaluation forms ask the participants to reflect and feedback on:

- How they would rate the training (excellent, very good, good, average, poor).
- How far the training met their stated learning objectives.
- Which parts made the greatest impact (and why).
- How the training will change or influence their existing professional practices.
- How the training session was delivered and facilitated.

The overwhelming majority of participants have consistently rated HUG's training as 'excellent' or 'very good'.

Below are some comments from participants about HUG's training:

**“Personal experiences are the best, most powerful tool. By taking on some very emotional accounts made me (more) emotional about changing things or at least trying to.”**

*Member of Joint Committee for Action in Community Care*

**“This training gave me a better insight into the patient perspective.”**      *GP*

**“I hope I will be able to spend more time making sure service users know their rights and I will challenge staff when they misinform users.”**      *Mental Health Officer*

**“Listening to the informed contribution that HUG members are able to make to the understanding of service providers it seems to me that there will be an important and growing role for this service in the future ..... since the onset of our training days I cannot remember such a unanimous verdict or such superlative comments.”**      *Social Worker*

Social and health care professionals have credited HUG members' personal testimonies as being extremely powerful and effective in challenging professional attitudes and encouraging good practice. This has been supported by anecdotal feedback from service users who have reported on examples of changed attitudes and more sensitive treatment by professionals.

## **Main Lessons Learnt**

We are constantly trying to develop our training, to explore new ways of working and learn from past sessions – continuous evaluation and reflection has an important role. Over the past couple of years we have learnt a number of key lessons, a couple of which are detailed below:

## **Use of Personal testimonies**

Users' direct accounts of their illnesses and lives, and the treatment and care they have received, are at the very centre of HUG's training. The use of personal testimonies has proved to be extremely powerful, which can be potentially risky for both HUG members and those participating in training sessions as people's personal accounts can often be very intense and HUG members can feel very 'exposed'. Participants can also find it difficult to absorb and respond to these accounts (this has, on occasion, made it difficult for them to engage with HUG members and explore the issues in more depth).

We have learnt a great deal over the years and have adapted our use of testimonies to make it safer for everyone, and whilst we continue to firmly believe that formal testimonies have a vital role in HUG's training, we have learnt that they should be used carefully. This has enabled participants to engage with HUG members and respond much easier. To supplement the formal testimonies, other training tools and techniques are used, such as quizzes, videos, poetry and art, which still enable us to use people's personal experiences, but in a safer, less intense format.

## **Safety for Participants**

We initially made the assumption that professionals can deal with the impact and emotional content of our testimonies, and there was no need to ensure their safety and ability to deal with what we had to say.

Clearly this is not necessarily the case, and over time we realised that some people found it extremely difficult to respond or react to what we had said. In some instances this led to complete silence in training following HUG members' testimonies. We tend to live with so much pain and distress, and learnt to speak about it very openly and honestly – not appreciating that what was normal for us, could be very distressing and perhaps shocking for other people (this was particularly so in the case of self-harm training).

Consequently, we made a number of changes to our training, including establishing ground rules to cover *all* participants, a clearer focus on the learning aims of the participants and taking time to 'set up' training, for instance, explanation about aims of training, what we can and cannot achieve/deliver, safety to ask questions.

## **Final Words**

We hope to continue developing our training skills and the confidence of our members, as we firmly believe this to be a vital part of HUG's work. The response and feedback from statutory and voluntary sector agencies to HUG's training is extremely positive and encouraging, and demand for our training is increasing all the time.

The challenge for us in the future will be in responding to the level of demand and in establishing more thorough and measurable evaluation techniques in order to monitor the longer-term impact of user-led training.

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## MENTAL HEALTH EDUCATION PROGRAMME FOR YOUNG PEOPLE

**The average secondary school of 1000 pupils will have 50 students with depression, 10 affected by eating disorders and 5-10 attempting suicide in any one year.**

*YoungMinds*

### **Introduction**

For many years HUG members have been saying it is important to raise awareness of mental health issues with young people and we are now developing a programme of educational and awareness raising work with senior pupils in schools.

HUG members believe this work is of great importance for a number of reasons:

- i. Many young people have misinformed and unbalanced images of mental illness, and we believe it is vital to redress this imbalance with open and honest discussions on a range of mental health issues.
- ii. Many people who use mental health services say that young people can be the cause of great distress due to their damaging and negative views of people with a mental illness.
- iii. A significant number of HUG members first experienced mental health problems during their teenage years and believe that if there had been open discussions about mental illness whilst they were at school, it is possible the impact of their illnesses could have been minimised.

### **Aims of Educational Work**

The main aims of this work are to help young people to gain a greater understanding of mental health problems and issues, and the lives and perspectives of people who live with mental illness. We hope that young people will develop the ability to discuss mental health issues with greater confidence and will be more empathetic towards people experiencing mental illness.

The main messages we hope to communicate are that mental health problems can affect anyone, we can do something about them and there is support and help available.

We are currently hoping to achieve our aims by:

- Working directly with young people in schools (senior school pupils).
- Providing accurate and relevant information to young people about mental illness.
- Exploring exciting and innovative ways of engaging with young people and talking about mental health (e.g. drama, art, and video).
- Involving and supporting teaching, youth and community staff and providing them with the knowledge and confidence to explore mental health issues with the young people they work with.
- Playing a key role in the Lochaber Youth Minds Group.
- Working in partnership with health, youth and education professionals to achieve these aims and ensure we develop good practice in working with young people.

## **Young People's Attitudes to Mental Illness**

Surveys of young people's attitudes reveal a lack of sympathy for those experiencing mental health problems. In 1997 The Samaritans revealed that a worrying 37% of the young people sampled agreed that depressed people should pull themselves together, 20% agreed strongly.

Research carried out by Mind in the same year revealed a number of misconceptions. The respondents seemed to be affected by negative stereotypes. They felt that people experiencing mental distress were often violent or old or abnormal and generally likely to behave unpredictably, aggressively or violently.

These examples illustrate why it is important for young people to hear directly from mental health services users about their experiences.

## **The Need for this Work**

HUG's Educational Report (based on our work with 350 young people during Scottish Mental Health Week 2000) and the subsequent work we have undertaken in schools, has shown the value of this work and approach. A consistent majority of young people state that their attitudes towards mental illness has changed significantly from negative to increased understanding and empathy. The young people also recognise that mental health is an issue for everyone, and mental illness can happen to anyone, to 'normal' people.

HUG is receiving increasing requests from schools for this programme and is a key partner in Lochaber Youth Minds, a group focusing on young people's mental health and emotional wellbeing.

## **Key Achievements**

The focus of HUG's work with young people has been two-fold: playing a key role in Lochaber Youth Minds and delivering awareness raising sessions to senior school pupils within their Personal Social and Development classes (PSD):

### **Scottish Mental Health Week 2000**

HUG's first work with young people was during Scottish Mental Health Week 2000 when we worked in partnership with a theatre company and staged interactive drama productions in four schools across the Highlands, involving approximately 350 pupils. The drama production provided a forum for exploring depression in youngsters and the stigma surrounding mental illness.

We learnt a number of valuable lessons during this rather intense week of work in the schools:

- Young people *do* want an opportunity to hear about mental health issues.
- Many young people hold misinformed and inaccurate images of mental illness (based, it would appear, on mass media portrayals), but are extremely receptive to this type of direct work.
- The young folk found the medium of drama and contact with people who have experienced mental illness very powerful and believe this an extremely effective way of exploring the issues.

**“Stress and also suicide would be important to talk about because I feel these are issues young people are faced with.”**

*Young Person*

**“I think the issues of suicide especially among young men would be important as well as stress and pressure.”**

*Young Person*

HUG’s Educational Report provides a more detailed account of the work undertaken during Mental Health Week 2000.

### **Lochaber Youth Minds**

HUG has been key in establishing and facilitating the development of the Lochaber Youth Minds Group. This is a multi-agency group, which aims to work in partnership with any interested organisation or individuals to raise awareness of mental health issues with young people in the Lochaber area, challenge stigma and find the most appropriate means of disseminating information about mental health.

The first meeting of the Lochaber Youth Minds group was held in February 2001, and came about for a number of reasons:

- i. In the previous October - during **Mental Health Week 2000** – a very successful piece of work undertaken by HUG had taken place at Mallaig High School, which aimed to raise awareness of mental health issues through the use of drama.
- ii. The **Mental Health Framework** document for the Highlands highlighted the needs of young people and, at the same time, people working in the community recognised the need for work to be done in relation to young people and mental health.
- iii. **Lochaber Health for All – Survey of local services – September 2001** – a range of gaps in services and other issues were identified including the need for positive work to promote mental well being.
- iv. **Incidence of youth suicide in Lochaber** – The Highlands, and Lochaber in particular, have a high incidence of youth suicide.

Over the past 18 months, Lochaber Youth Minds has organised and facilitated a wide range of activities and events, including:

- Mental health awareness training for 20-25 youth and community workers.
- Training for local workers on young people, depression and suicide.
- Production of a Directory of Services for Young People in Lochaber.
- Focus groups with young people to find out their attitudes towards mental illness.
- Compilation and distribution of mental health resource packs to 25 youth and community groups.
- Organisation of a ‘Feel Good Day’ (*detailed below*).

## **'Feel Good Day'**

In September 2002, Lochaber Youth Minds and Fort William High School organised a 'Feel Good Day' for approximately 200 4<sup>th</sup> year pupils. The aim of this event was to help young people consider the links between their minds and body, dispel some of the fear around mental illness, encourage young people to talk about how they feel and to have some fun.

The day was focused around interactive drama productions, which explored depression in young people and self esteem. Workshops, entitled 'Stay Cool and Relax', 'Cool Heads' and 'Impact Art' provided the pupils with an opportunity to explore mental health issues, cope with stress and try their hands at Indian head massage, aromatherapy, Thai boxing and street dance.

Below are some comments from the young people themselves:

**'Depression isn't something to be ashamed of.'**

**'I am more aware [about mental health problems] and I do not find it so worrying.'**

**'I didn't know about hearing voices and I was really interested'.**

Overall the day was a great success and we hope to organise a similar event in 2003 in a different High School in the area.

## **Work in Schools - Personal Social Development (PSD) Classes**

Over the past year we have delivered 8 sessions in schools, involving approximately 150 senior school pupils during their PSD classes, ideally two hour-long sessions over consecutive weeks (we found it quite difficult to do any meaningful work in only one lesson).

In the first session the young people work in small groups to complete a mental health quiz, entitled 'Debunking the myths of mental illness', which asks them to consider questions such as:

1. What do the words 'mental illness' make you think of?
2. Who can be affected by mental illness?
3. What are the trigger factors that can cause mental illness?
4. Do you think people can recover from a mental illness?
5. What % of people are likely to experience some kind of mental health problem in the course of a year?
6. What % of adolescents experience severe depression?
7. What is the second greatest cause of death of young people?

The responses are interesting, with the majority of pupils recognising that mental illness can happen to 'anyone and everyone', yet in response to the first question pejorative words such as 'schizo', 'nutters', 'madness' and 'crazy' are overwhelmingly used.

This is usually followed by a video produced by Manic Depression Fellowship Wales, entitled 'Mental Illness – Does it Blow your Mind?' in which two young men talk about their experiences of living with schizophrenia and manic depression.

In the second session HUG members come into the school and the pupils are provided with an opportunity to work in small and larger groups to learn about people's individual experiences and are encouraged to ask questions in order to really gain a greater understanding. This session works extremely well with the pupils asking such questions as:

- How do you cope with mental illness?
- Were you in denial that you suffered from depression?
- What was the most extreme thing you did on a manic high or low?
- Did you seek help yourself or was it friends and family who sought help for you?
- How did your illness affect your behaviour?
- How did you overcome your illness?
- How did they treat you when you were in hospital?
- Have you ever harmed yourself because of depression?
- What sort of things do people hear when they hear voices?
- Do your family and friends disown you if you are mentally ill?
- How do people react when you tell them you have schizophrenia?
- Did you feel embarrassed about having a mental illness?

Below are some comments from the young people about these sessions:

**“I understand a lot more about it and feel privileged to have heard the stories people had to tell.”**

**“I have a much greater understanding and no longer have a prejudiced view.”**

**“HUG members seemed like everyone else so you would not have realised they were ill unless they told you.”**

We hope to expand this work in schools over the next couple of years and build up relationships with High Schools across the Highlands.

### **Final Words**

Currently we are involved in consultation with HUG members and agencies working with young people in order to produce a good practice guide to working with young people in schools - exploring different tools and techniques for getting our message across, our values, roles and responsibilities and ensuring personal boundaries and the emotional safety of everyone involved.

In order to bring about long-term change, raising awareness and promoting positive attitudes among young people is of vital importance. Whilst the main focus of HUG's work with young people is as a partner in Lochaber Youth Minds, we hope that the next year will see us building relationships with more High Schools in the Highlands and working directly with young people through their Personal Social Development classes.

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## **MEDIA WORK**

The Mind report '**Counting the Cost**', identified that more than 60% of people with a mental illness blame media articles for the discrimination they face.

A report by the **Health Education Authority** in 1999 stated that 40% of tabloid articles about mental health used pejorative words such as "nutter" and "loony" and that almost 50% of press coverage of mental health was about crime, violence or self-harm.

### **Introduction**

For most of the public the mass media remains the most common source of information about mental health issues and plays a crucial role in forming our attitudes towards mental illness. Many users of mental health services have identified unfair, unbalanced and negative UK media coverage as one of the key factors in the discrimination they experience. HUG members consistently cite the media as a contributing factor in fuelling public fears through their sensationalist approach to reporting on mental health stories and concentration on the tragedies and violence which does, occasionally, occur.

In a recent consultation with approximately 100 HUG members on the subject of stigma, many users commented on the damaging role the media can play in fuelling the public's fear and suspicion of mental illness. HUG members commented that the media:

**“Portrays people as attention seeking and makes you seem as if you are from an entirely different world.”**

**“Uses tragic cases to generalise about all people with a mental illness.”**

Two strong messages came from HUG members as people felt that there should be more TV coverage of people's real experiences, for example, in documentaries and needs to be more balanced and not concentrate on the tragic stories.

Nevertheless, HUG's experience of the Highland and Scottish media has been very positive and we have received great support from individual journalists who have written with tact and sensitivity about our work. Our on-going work in this area aims to build upon this solid foundation and encourage responsible reporting through raised awareness of mental health issues amongst media professionals.

### **Main Aims of Work**

HUG's work with the media aims to encourage balanced, accurate and responsible reporting about mental illness and ensure regular press coverage on mental health issues. We hope to achieve these aims by building up longer-term relationships with local, Highland and national journalists to raise awareness of the issues and lives of people living with mental illness, and to encourage appropriate use of language when reporting on mental health issues.

We believe that the media has an important role to play in creating a climate in which such issues can be talked about and is an extremely powerful medium through which it is possible to reach a wide public audience and ensure the voice of users are heard and represented.

An important aspect of this work is to ensure that the direct voices of users of mental health services are heard loud and clear in any media coverage of these issues. In a survey by Mental Health Media in 2001, only 6.5% of press articles contained the views and voices of mental health service users. (*Mental Health Media, Mental Health and the Press, survey 2001*)

We believe it is less easy for journalists (and the wider public) to dismiss someone who can talk articulately about their experiences and engage in debates on wider issues. We have a group of HUG members who are willing to be interviewed about their personal experiences, and who have spoken openly to the media in radio interviews, on TV and in newspaper feature articles on e.g. depression and schizophrenia.

### **Working with the Media**

Whilst we should be under no illusions about what motivates many media stories, HUG's experience in the Highlands (and indeed beyond) has demonstrated that it is not so black and white. We have had regular contact with a handful of media professionals who understand the need for sensitivity and careful reporting and who have consistently proven their warmth and 'humanity' in their relationships with HUG members.

We have learnt a great deal over the past few years, and some important things to consider before engaging in media work (particularly that involving users of mental health services). In our experience, building up trusting relationships with individual journalists is of great importance.

However, relationship building is very much a two-way process and there are important emotional and practical issues to be clear about before encouraging contact between service users and journalists. During a media training day in December 2001, HUG members (and some Highland journalists) drew up the following 'guidelines' and issues to consider before users engage in media work:

#### ***Being clear why we wish to use the media:***

- To break down prejudices and combat stigma and raise awareness.
- To promote a positive image of people who live with mental illness by showing the human side.
- To challenge inaccurate media coverage.
- To encourage good practice by media professionals on reporting of mental health issues.
- To reach out to new audiences.
- To inform people about issues (accurately).

#### ***Keeping safe and supported:***

- Be clear about what you are prepared to share about your story.
- 'Negotiate' with the reporter about what you want to say/how much of your personal story.
- Never answer questions you are uncomfortable with.
- Debriefing is important.
- It is always OK to say 'no' to questions.

### ***What do we need to consider/know before speaking to the media?***

- Who are you representing? It is a HUG line or an individual user voice?
- Do you know and trust the reporter or newspaper?
- What is the journalist looking for? What is their angle?
- What difficult questions may you be asked? How will you deal with them?
- What could be the effects/consequences of 'going public' about your illness?
- How much preparation time do you have?
- What type of interview is it? Is it at home or in the studio?
- Do you want to be identified or anonymous?
- What is the circulation for the newspaper? Which friends and family members are likely to see it?

HUG ensures that before any of our members are in direct contact with the media there has been time to discuss in some depth the above issues. No member would be unsupported in their contact with the media, and a HUG worker would usually be present at any interviews.

And remember, it is important to acknowledge when a good piece of journalism has been produced and never underestimate how valued a thank you card can be – everyone wants to know they have done a good job!

### **Key Achievements**

#### **Regional and National Media Coverage**

HUG has developed good relations with the media, and as a result of this, access to a wide audience who may have little knowledge of mental illness.

Over the past few years we have secured major feature articles in regional and national newspapers, spoken on national radio on a range of issues (including anti-psychotic medication, young people and mental illness and diagnosis of depression by GP's), provided articles for professional and parliamentary publications, secured coverage on national news programmes and made regular contributions to regional and national magazines.

Specific examples of media work:

- **Scotland on Sunday** - Five-page article based around the experiences of HUG members in a psychiatric hospital.
- **Press and Journal** - Feature article on a member's experience of depression and the impact this illness has had on her personal life.
- **Inverness Courier** - Feature article on a member's experience of living with schizophrenia and her commitment to fighting stigma and discrimination.
- **BBC Radio Scotland** - Half hour broadcast on 3 people's experience of depression and admission to psychiatric hospitals, and interviews with HUG members on their experiences of delivering mental health awareness training to professionals.
- **Nevis Radio** - Ten-minute monthly discussion features for 6 months, covering schizophrenia, manic depression, stigma, alienation and loneliness and media coverage of mental health issues.

Members of HUG have regularly appeared on television in connection with news stories, such as the closure of the local hospital or as a reaction to issues such as the high suicide rate in the Highlands.

### **Media Volunteers**

In September 2001 HUG recruited its first Media and Communications Volunteers whose role was to increase HUG's profile in the local and Highland media, organise a media training day and produce a good practice guide to reporting on mental health issues for journalists. This was the first time HUG had recruited traditional volunteers for specific pieces of work and we were very lucky to find two very enthusiastic and skilled people to help us take this work forward.

### **Media Training Skills Course**

In December 2001 we organised a media awareness training day for 25 HUG members to help them develop an understanding of how the media works and to gain some practical media skills. Sessions were led by Highland media professionals from press and radio. The programme for the day is detailed below:

<b>Session 1:</b>	<b>Speaking to the media to get our message across</b> – HUG members' experiences, how to keep safe, why use the media
<b>Session 2:</b>	<b>Local newspapers: What's the busy news desk looking for?</b>
<b>Session 3:</b>	<b>The ABC of press releases</b>  <b>Workshops</b> 1) What's wrong with this press release? 2) Write an effective press release
<b>Session 4:</b>	<b>Local radio: What to do if someone sticks a microphone in front of you and starts asking questions</b>
<b>Session 5:</b>	<b>What if things don't go to plan?</b> 'Trouble shooting' and responding to negative media coverage

The day was a great success and feedback was extremely positive from both sides:

**"HUG members talking was, for me, the most valuable part of the day."** *Media Professional*

**"Gave a human dimension to what can be a very sensationalist organisation (i.e. the media) and put a new light on its workings."** *HUG Member*

One of the most successful aspects of the day was having an opportunity to hear from the perspective of individual journalists about the pressure they are under, how they work and what they are looking for in a media story. In turn, we were able to seek their advice on how to get our message across in the media more effectively and give them an idea about the type of human-

The training also provided a great opportunity for meeting informally and helping to break down some of the barriers, suspicions and misconceptions that can exist between mental health service users and the media. We hope to run a similar course in the next year to try to encourage and inspire more HUG members to assist us in this very important part of our work.

### **‘Sticks and Stones - A Good Practice Guide to Reporting on Mental Health Issues’**

From December 2001 to March 2002 our media volunteers developed a Good Practice Guide for media professionals. The aim of the guide is to encourage media professionals to cover mental health issues fairly and sensitively, and provide them with access to accurate, unbiased information.

In a survey by Mental Health Media in 2001, 64% of journalists said that media coverage of mental health could be improved and 62% said that the main barrier to contacting people with mental health problems is that they are not sure who to contact.

*(Mental Health Media, Mental Health and the Press, survey 2001)*

The guide was sent to a number of media professionals, in newspaper and radio, for their comments, which were very positive (although we did some editing as a result of the feedback). The general response was that this was a very valuable and interesting resource. Five hundred copies of the guide have been produced and will be distributed to as wide a range of media professionals as possible, both across the Highlands and nationally.

### **Final Words**

Over the past year we have not sustained the same level of press coverage as previously. This is simply due to competing work pressures and the fact that it takes time to build and sustain relationships. We have found that over the past 12 months there have been some key personnel changes in the Highland media and time must be dedicated to making new connections. This will be a priority for the coming year.

Our media volunteers have now found paid employment and we must now think about recruiting once again for these vacancies as experience has shown how valuable these placements can be, both for HUG and for the individuals concerned in helping them into work.

Finally, HUG's media work now sits within the objectives of the See me alliance, the Executive funded Scottish-wide anti-stigma campaign, led by a coalition of mental health voluntary organisations (of which HUG is a member). A central focus for this national campaign will be to develop a programme of action aimed at encouraging fairer, more accurate reporting of mental health issues. This will include working with media professionals at all levels and with students of journalism and media studies to increase their understanding of mental health problems with a view to encouraging good practice in the local and national press.

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## **PROMOTIONAL AND PR WORK**

### **Introduction**

HUG undertakes various promotional and publicity projects in order to promote discussion and inform the public about mental health issues. To date we produce regular newsletters and a poetry and prose magazine entitled 'Moonstruck'.

### **Aims of Promotional Work**

The main aims of this work are to challenge negative and stereotypical images surrounding mental illness and bring mental health into the public forum. We are constantly striving to find new and interesting ways of encouraging people to explore mental health issues, and to explore and promote different ways of expressing people's experiences of living with mental health problems.

### **Key Achievements**

One of our main successes has been the design and production of a series of stigma-challenging postcards on the theme of mental illness, a collection of poems written by a HUG member and the design and production of the HUG website.

### **HUG Postcards: Images Promoting Mental Health**

In 1998 HUG members, in partnership with local artists, a community arts project, Health Promotion Department and Highland and Islands Enterprise, developed an initiative to design and produce a series of postcards on a mental health theme.

HUG members were responsible for giving direction regarding the messages and ideas they wished to convey and a HUG member on a work placement co-ordinated, commissioned and distributed the postcards.

Eight different designs were created, some clearly on a mental health theme and some highlighting the creative talents of people with a mental illness. The postcards were intended to challenge stereotypes held about people with mental health problems by providing basic information about mental illness and positive messages that provoke discussions in the wider community.

Over 60,000 cards have now been distributed locally and nationally through a series of public and health outlets, mental health conferences, training days and schools and youth groups. The designs have also been converted into posters, which have been widely displayed.

Whilst there is no expectation that these postcards will dramatically change attitudes, they provide a starting point for discussion and debate, through the media, schools, mental health community and further afield.

## **'Maze of Darkness' – Poetry Collection**

In October 2002 HUG published a collection of poems written by Marcia, a HUG member, who explains in her own words why poetry is important to her:

**“My name is Marcia and I have been a service user with a diagnosis of schizophrenia and depression for the past 10 years. During this time I have been writing poetry. Through my poetry I would like to share some of my experiences of life as a mental health service user, my feelings and all about my family, friends and life in general over the last 10 years.**

**When I first started writing poetry, the first poem I wrote was “My Maze of Darkness” during a period in my life when I felt very depressed and despairing as to what I should do next, due to feelings of helplessness and hopelessness. After I wrote this first poem it felt so therapeutic. I felt great pleasure and a burden just lifted from me because for the first time in months I could finally express what was going on inside my head. For the first time it just made sense to me what I was going through.**

**Then I wrote many others, which also gave me an immense emotional release through just getting my feelings out of my head and onto paper.”**

If anyone would like a copy of Marcia's poems, they are available through the HUG office.

## **Moonstruck, 'Tools for Training'**

In 2002 a HUG member, on a supported work placement, planned and produced a special edition of our poetry and prose magazine, 'Moonstruck', to be used as a tool in HUG's mental health awareness training. The collection of poetry and prose was written by HUG members and was about their personal experiences, feelings and reflections of living with mental illness.

It is the eighth in the series of Moonstruck publications. Circulation of most of these publications is confined to HUG members, although in the future we will distribute them to the wider mental health community.

## **HUG Website**

Over the past year we have worked with a HUG member and staff at Highland Community Care Forum to develop a HUG website, with artwork, talks, reports and creative writing.

We have currently completed the first stage of this development and hope to eventually create a 'virtual HUG branch' on the web to help HUG to reach a wider audience and facilitate the exchange of ideas and views amongst service users.

The HUG website can be found at [www.hug.uk.net](http://www.hug.uk.net)

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## CONCLUSION

The Communications Project has achieved some significant achievements over the past few years and is regarded by many in Scotland as leading the way locally in challenging the stigma of mental illness and raising awareness and understanding of mental health issues.

The main strength of the project is the fact that the work is grounded in the realities of people's direct experiences and involves HUG members in actively challenging the stigma and discrimination they experience in their homes, local communities, through the media, from the professionals responsible for their treatment and care and from young people.

HUG, as a member of the See Me alliance, is able to ensure that work at a national level is informed by the views and experiences of people in their local communities. We regularly receive requests from across Scotland to share our experiences of anti-stigma work with agencies and organisations.

We have recently secured three-years' funding from the Scottish Executive in order to greatly increase our capacity and to ensure that HUG has the capacity to assist in taking forward local work that goes further and faster in addressing stigma and discrimination. We believe our work, approach and ethic has national significance and this funding will enable us to evaluate the impact of our work more effectively and to disseminate the results across Scotland.

*If anyone would like further information about HUG or any aspects of the work of the Communications Project, please contact us at:*

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**A special thanks to all HUG members who have been so vital to the success of the Communications Project – without your openness and honesty none of this work would have been possible.**