SPIRIT Advocacy
Strengthening People In Raising Issues Together
Incorporating HUG Action for Mental Health (HUG), People First Highland (PFH)
and SPEAK (Stigma Prevention through Education, Advocacy and Knowledge)

HUG Mental Health Awareness Training

MAKING IT REAL

Challenging stereotypes, improving practice, reducing stigma

A reflection on how and why we work

Graham Morgan

November 2016
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What is HUG (Action for Mental Health)?

HUG (Action for Mental Health) is a network of people who have experience of mental health problems.

HUG has several hundred members and 13 branches across the Highlands. HUG has been in existence since 1996. Between them, members of HUG have experience of nearly all the mental health services in the Highlands.

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
- Challenging stigma and raising awareness, and understanding, of mental health issues
HUG’s Aims

➢ 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 mental health problems

➢ 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

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Introduction

Ever since it was first established, HUG (which is an organisation run by services users speaking out to improve life and services for people with mental health problems) has been carrying out awareness raising, primarily with professionals but also with the public and with young people.

This training has nearly always been successful and has resulted in shifts in attitudes and practice. We have met people who have become psychiatric nurses having participated in awareness sessions in schools and we have heard from HUG members that subsequent encounters with professionals such as the police have been far better when those professionals have experienced an awareness session. We have also heard that some of our events have been among the most moving and informative that some people have been to.

We raise awareness in a number of ways:

- Through tailor made mental health awareness sessions
- Through creative expression events such as arts exhibitions and poetry readings
- Through awareness sessions in schools
- Through drama in schools
- Through media stories on radio, the press and television
- Through speeches at conferences
- Through the production of DVD’s

We have evaluated our mental health awareness raising events over many years and in recent years have used a standard evaluation form which apart, from rating the quality of our facilitation, the testimony and the session overall, also asks participants key questions on:

- The impact of the session
- How people’s views have changed as a result
- How people’s behaviour will change as a result
- Suggestions for improving the sessions

It is these mental health awareness events that we will discuss here, in the hope that it may guide other people in the process of awareness raising.

We will principally report on evaluations we have carried out with participants and on the views of HUG staff and awareness trainers on how these sessions are delivered.
We looked at all the awareness sessions that we had evaluations for in 2014 and 2015 and held interviews with HUG staff and HUG members who have provided awareness training in recent years (involving 13 trainers in total) to find, from their point of view, what it is that works in our awareness sessions.

**What is a HUG Mental Health Awareness Session?**

This is an event where people can hear, first hand, from people who have experienced mental health problems, what works for them and what doesn’t.

It is a chance to find out about the life of people with a mental health problem and to meet them in a safe and pleasant setting where dialogue and interaction are encouraged.

A typical event will be a couple of hours long but can be as short as 40 minutes or as long as a day.

It is designed around the requirements of the participants but is centred on people’s personal experiences of their lives.

Typically there will be some sort of icebreaker to start with followed by presentations from HUG members with questions and answers and discussions. There may be room to see one of the HUG produced dvd’s, both to provide an alternative form of participation but also to provide different perspectives. There is often room for small group discussion, whole session discussion, panel discussion and case studies.

It is facilitated by a HUG worker or a HUG volunteer.

Some sample programs are provided in the appendix.
What is the Impact of an Awareness Session?

An evaluation of the last two years’ awareness sessions (2014/2015) provides the following information.

In this time one of the workers provided:

12 sessions with 136 participants involving:

- Student nurses
- Psychiatrists
- Mental health officers
- Youth workers
- Health centre staff
- Councillors
- Council officials
- Support workers
- Social workers
- Third sector workers
- Prison staff

An evaluation of all of these showed:

<table>
<thead>
<tr>
<th>Sessions overall were:</th>
<th>HUG Members testimony were:</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXCELLENT 88%</td>
<td>EXCELLENT 94%</td>
</tr>
<tr>
<td>VERY GOOD 11%</td>
<td>VERY GOOD 6%</td>
</tr>
<tr>
<td>GOOD 1%</td>
<td>GOOD 0%</td>
</tr>
<tr>
<td>POOR 0%</td>
<td>POOR 0%</td>
</tr>
<tr>
<td>VERY POOR 0%</td>
<td>VERY POOR 0%</td>
</tr>
</tbody>
</table>

A selection of quotes from participants are provided in the appendix to illustrate both the impact of the sessions and how participants thought it may change their attitudes or practice.
Why do we provide these sessions?

When we were first approached about 20 years ago to do this, we knew that workers wanted to hear first hand from us about what our lives are like and what does and doesn’t work for us. Often a sub text would be that the person asking us to provide the training would be keen for their staff to see and understand that people with mental health problems were ordinary everyday people that they did not need to stigmatise or fear in their work.

This was in accord with the wishes of our members: ever since we first started finding out our members priorities for action, challenging stigma was either the top priority or one of our top priorities. We have always felt that in challenging stigma that the best people to do so are those who have personal experience.

The main aim of our sessions was to help people understand us and respect us but also to learn about our lives in all their diversity and in this way take away from the sense of us as other and move to us in the sense of together.

A focus group with trainers revealed that, key to our awareness training, is the desire to remove stereotypes, to make our situations real and understandable and therefore to help people engage with us in a human and non-judgemental way. The sessions have to make a difference and have value to the participants as otherwise there is little value in them.

By speaking about our experiences of what works and doesn’t work for us, by giving a broader perspective than symptoms and labels and by focusing both on our wider lives and yet also our illness we provide an insight that promotes a social model of viewing us and helps participant understand the rights and underlying social justice issues that are part of our lives whilst at the same time helping participants find out what things are key to us when they provide care and treatment to people with a mental illness.

This means that we can address both social attitudes but also, to some extent, clinical practice.

A typical session is usually worked out with the organisation concerned and tailored to their particular needs – examples of the aims of some sessions are below:

**Signpost - Inverness**

**AIM:** to give an introduction to mental illness/health and to help convey the value of volunteering for and with people with mental problems and the support needs that they might have.
Ullapool Medical Practice

**AIM:** to give staff an insight into our experience of mental illness/distress, our anxiety when contacting professionals when in distress; how we can become upset when dealing with professionals and our experience of primary health care.

Mental Health Officers – Robert Gordon University

**AIM:** to provide an awareness, through testimony and discussion, of what it is like to be sectioned and through this to understand its effect on people. To explore whether a section is necessary and some of the circumstances around it. To look at what qualities in a professional help us in our treatment.

The power of Personal Testimony and how we use it

Personal testimony/experience is key to all our awareness events and especially to our awareness training.

In the early days of providing this we learnt quickly that long testimonies followed one after another were not the best ways of providing training, they could be overwhelming for participants and trainers alike.

Instead they are now usually five to ten minutes long, fifteen at a maximum, and interspersed with other exercises. They take the form of a story and a narrative and are designed to be the opposite of a lecture. Although we may individually give messages about how we want to be treated, we try, as far as possible, not to tell people how to think or behave, instead we believe that by hearing our stories in an honest and frank fashion that people can do their own reflecting and reach their own conclusions.

In some training sessions we deliberately reinforce the need for people to consider and reflect by arranging to have people talk on the same subject but from very different perspectives and with very different opinions. This all goes to show that we are all different and that what works for one person may not work for another person.

We try to avoid any sense of portraying ourselves as victims and subjects of tragedy or, for that matter bravery, but do talk openly about subjects and experiences that are rarely heard publicly and do demonstrate that we have reflected on our experience and can see where our experience and occasionally treatment has been damaging to ourselves and sometimes others and yet may have, in itself, sometimes been liberating.
We try to deliver our testimonies in ways that are accessible and engaging and although some people rely on written speeches, most of us speak freely, though sometimes with notes as a back up. It is important that our talks are interesting and on subjects that people will listen to.

It is also important that they are relevant and knowledgeable so when we provide training on a specific subject we make sure that the people speaking have direct experience and that this experience is still relatively recent.

In the past many of our trainers have undergone training sessions in public speaking from Eden Court and the actors who work there. We are keen to reinstate this training as it has been very helpful for people new to speaking out.

While we are aware of the impact our stories may have on ourselves we also need to be aware that the participants will often be hugely affected and this may be even more so, if as is frequently the case, they also have experience of mental ill health but have not heard it talked about so personally in public before.

We also try as much as possible, to include the wider aspects of our lives in our training, just by encountering us outside of a therapeutic context with a completely different power dynamic, huge strides can be made in removing stereotypes. By showing the range of our lives outside of illness we make a difference and by as far, as we can, talking about what helps us and what contributes to a sense of wellbeing, we provide messages of hope and positivity which, while realistic, contribute to the recovery agenda even if some of our members resist the use of that terminology.

The telling of stories is, in itself, a kind of reaching out and a kind of connection and with that connection many of the negative and artificial barriers we erect can be demolished.

We are very clear in our testimonies that while our stories are rooted in fact that we are not setting out to demonise services or to make our participants feel targeted or bad about themselves. We make the assumption that most people want to do as a good a job as possible and to be as pleasant and courteous as they can be and also, that if we just put people on the defensive, then those people who are already sceptical about people with a mental illness will become even more so.

It is therefore important to make sure that our sessions are positive and warmly delivered, that, where we can, we use laughter and set our participants at ease. We want people to go away feeling enriched and encouraged instead of feeling bad about themselves or failures at what they do.
The effect of our training on our trainers

Overwhelmingly our trainers feel a sense of achievement and value in providing the training. This is based on the fact that they see from the evaluations that they have had an effect and made a difference.

However it also has other effects, trainers may feel some sense of catharsis from telling their story and they may feel that, for the first time in a long time, that they are contributing and being listened to and not only listened to but moving and affecting other people with their story.

• I genuinely like it. I have some skills in it – but I suffer a lot doing it – there were a huge number of people with the Care Inspectorate that I wasn’t prepared for and the Scottish Parliament - that freaked me out - if the value was taken away I wouldn’t do it – it needs to make a difference; without that there is no point.

• It turned to them to talk about their own lives and how they deal with work – one guy came up he was so choked up he just shook our hands; that makes it worth while.

• For me it is the one percent of the time when I know I am visible because ninety nine percent of the time I am invisible. I isolate myself for fear of being around people – I have done something worthwhile and I have been seen and heard.

• It makes me less of a victim than when I was silenced as a child – it stops me being a victim it stops me being invisible.

• I wanted to be heard and here, they are listening to me and not judging me; it adds up to me not judging me.

• Being valued for my warts.

However for many people there is a downside to training, despite the exhilaration there is the danger of opening past trauma again by revisiting it and if people are unprepared and not briefed, of being damaged by the stories other people tell. It is for this reason that we sometimes do not use trainers for whom the experience is too raw and will try to avoid trainers who are unreasonably graphic in their narrative.

Usually the trainers themselves are well aware of where to pitch their stories by judging the mood and atmosphere amongst the participants and by being aware of the impact their stories are having and then adjusting them.
How a session should be prepared - some hints and tips

Prior to the session:

➢ Find out from the participants what they want from us and what their aims are and structure a program based on this.

➢ Make sure that there is a lead for the event and that they know what they are going to do.

➢ Find out where the venue is, is it comfortable? Is it noisy? Does it have break out rooms and quiet rooms?

➢ Check that expenses will be paid.

➢ Recruit HUG members to be a part of it in plenty of time ( a minimum of a month’s notice is good).

➢ Recruit HUG members who have a knowledge of the subject and an ability to contribute.

➢ Recruit shadow members who wish to learn from others.

➢ Make sure that there are enough people so that anyone can withdraw from participating at any stage but not so many that the program and event becomes unwieldy.

➢ Involve those HUG members who you can, in developing the program for the day.

➢ Try to make it varied and interesting.

➢ Brief all people participating on what they will be doing, let them know the subject and the timings, explore any risks and worries and arrange participation based on peoples individual needs – i.e. some people want to speak off the cuff, some people want an interview style contribution, some people want to discuss the content in detail, prior to the session.

➢ Check that people can get to the venue, ie are people comfortable travelling in a car? together? Have stops been made for refreshments and fresh air on the journey? Will those people who need support be picked up at the right time and called in advance?
➢ Send out the program in advance.

➢ Make sure evaluation sheets are prepared, that all the equipment is available and any hand outs are ready to take along.

**During the session:**

➢ Greet the participants and make them feel at ease.

➢ Have a facilitator who will organise, create safety, guide the program and support the trainers.

➢ Make sure the organisers are ready to support the participants if necessary.

➢ Create enjoyable ice breakers.

➢ Ensure the room is in a fit state – chairs lined up, as if for a lecture, tend not to work well.

➢ Make sure everyone is aware of the groundrules and ensure that everyone knows they can leave if they need to.

➢ Provide water etc for trainers.

➢ Help trainers to stick to time, be ready for those who get stuck and those who maybe need a break.

➢ Be fluid – programs often do not go to plan and need adapted – but be aware that major changes to the program can be very stressful for people giving testimony, especially changes in timings or order.

**After the session:**

➢ Gather the evaluations and check for any alarming comments – then pass them around trainers.

➢ Be available for any participants who want to talk or want help.

➢ Tidy up if expected.

➢ Go for coffee or food if trainers wish.
➢ Do an immediate informal debrief.

➢ Make sure that everyone has the facilitators phone number in case they need to call for support afterwards.

➢ Check if anyone wants called that evening or the next day.

➢ Be aware that some people may have a reaction to the training some days later.

➢ Write up the evaluation and pass to the organisers and participants.

➢ Act on any issues that have come out of the debrief or evaluation.

➢ Make sure everyone is able to get home and provide transport if necessary.

➢ Check everyone has had their expenses paid or that they are happy to wait for a cheque.

Some things not to do or to consider in a program:

➢ Do not use power point unless it is very good indeed, ie multimedia.

➢ Do not provide educational talks based on people’s illness and symptoms, this should be done by people with direct experience and be about more than this; ie, do not inadvertently present people as different, alien, malfunctioning or threatening.

➢ If providing specialised information ensure that the person doing so has the expertise to do so.

➢ Consider how much your organisation itself needs to be concentrated on, is it always integral to the program?

➢ Be wary of technology – it often malfunctions.

➢ Consider the use of IT and multimedia presentations in sessions – if we could find people competent and skilled in using this, it could enhance our sessions if we were confident in it.

➢ Consider the use of DVDs in sessions, high quality, short DVDs preferably featuring service users or produced by service users. Do not allow them to replace the direct person to person part of the program.

➢ Reinstate the training of awareness trainers; anything from public speaking, to how much to say to attitudes and conduct.
➢ Be professional but recognise that spontaneous and unpolished testimony can also be very, very, effective.

➢ Incorporate humour.

➢ Avoid the ‘poor me’ syndrome.

➢ Incorporate support for each other throughout.

➢ Make sure that members are involved as much as possible in planning and delivery, make sure there is ample time to plan.

➢ Provide opportunities for mentoring and shadowing.

➢ Develop a template for a standard awareness session to meet the needs of the many organisations who want a similar program to other ones, include room to include the aims of the session and how to meet these.

➢ Organise the selection and training of trainers – consider why we ask certain people, why we don’t ask others, what support and briefing and training people need.

**Awareness Training with Young People**

We have been proving awareness training with young people for many years and increased this dramatically with the creation of SPEAK (the young peoples’ mental health voice in Highland) which provided its own training. Discussion with people who have provided this gives some of the following hints that may be particular to young people and maybe to training in general:

➢ Personal experience is vital.

➢ We need a good ice breaker.

➢ We need to keep people interested throughout.

➢ We need to have short bursts of things to maintain interest.

➢ We need balance with personal testimony – it is important not to upset or shock people too much.

➢ Make it relevant – ie, in schools talking about eating disorder and self harm are often more relevant than sectioning.
➢ Do not just read from a paper; it needs to be personal and emotional and relevant to draw people in and engage them.

➢ It doesn’t work if testimony is too long - no more than 5–10 minutes.

➢ Get people moving and involved - ie, the ‘I in 4 test’ or ‘labels on heads’ or ‘draw round a figure exercise’ or ‘tableaus.’

➢ We need a good facilitator.

➢ Adults are more ‘compliant’; young people will get fed up if it doesn’t engage them and may become bored and disruptive.

➢ DVDs need to be relevant and good quality and not dated; ideally about and with young people – the DVDs produced by a SPEAK member, we usually use, does all this.

➢ Don’t act like you know it all.

➢ Don’t try to be their ‘friend’ - ie, don’t try to use young people’s language and be cool if you are not young or cool; using their slang will likely make them cringe.

➢ Be professional – make sure that there is room for laughter and informality but also an element of safety and control and confidentiality.

➢ Get the work done; even though people go on tangents.

➢ Finish on a high note do not finish on a sad testimony.

➢ Make sure there is access to help for the young people if needed.

➢ Be available afterwards for advice and conversation and signposting but do not turn into a service provider.
Conclusion

This short paper gives an idea of how we have made a profound difference to the understanding of mental illness/mental health problems in the eyes of the public and professionals in Highland over the last 19 years.

Our program has grown with experience and by understanding our own needs and wishes and aims over the years but also by talking to and learning from the people we train.

It is delivered in many of the ways that we have known for years work to challenge stigma, for instance by providing connection and direct contact with people with a mental illness. But it differs from other conventional training programs: we are rarely prescriptive and do not overtly tell people how to think or act, rather we expect that people will inevitably adapt their views and behaviour through meeting us and getting to know us without us being so crass that we have to tell people exactly how they should think or behave.

We deliberately encourage different perspective and viewpoints and to some extent do manufacture our training, we believe that it is important for us to provide something of high quality and this means providing an engaging and warm environment where people may feel slightly challenged but not threatened and where they can hear stories and experiences which will both fascinate and move but not traumatising.

We increasingly refer to life apart from mental illness, to our wider life, to our aspirations and daily activities and by doing this can remove the identification purely on the grounds of illness and show the things we often have in common.

We try where we can, to show what works for us, so while we are not so idealistic to say that with the right attitudes and treatment our problems will magically vanish, we do show that we can have vibrant, interesting and sometimes content lives.

We assume that everyone is trying to make life better for people and that they would like to be engaged in this too; by doing this, we do not in our own turn, oppress people with our own experience or bitterness.

We do however refer to our illness/ mental health problems and sometimes in some detail, if we do not do this, people will not understand why it is important to understand us and will not have opportunities to consider their own care and treatment of us.
APPENDIX 1

Samples of feedback from evaluation forms of awareness training sessions carried out in 2014/2015

Which part(s) of the session made the greatest impact on you, and why?

- Testimonies. Really interesting to find out about people's story and to hear how they overcome their problems and how they got where they are.

- This session as a whole had a huge impact. Listening to the life experiences that people have had. The facts and the issues that affect all ages in the community.

- Hearing peoples stories and feelings rather than receiving it from a book.

- The end discussion about stigma, hearing how and what you want from nurses – helps us to understand.

- Personal accounts and experiences. It is too easy to be sucked into a world of paper and files and lose sight of people and the very real impact of decisions and their ripple effect.

- Your personal stories, your recollections of what was positive or negative for you had a deep effect upon me. I hope it will impact my always keeping the person I am working with in mind and not just seeing his or her illness.

Identify 2 ways in which your work with (or views of) people with a mental illness will have changed as a result of attending this session:

- I feel that today’s session has increased my understanding and thoughts of how to support the young people

- Not to be so quick to judge the mental illness before the person.

- Reinforcing the realization that mental illness shouldn’t be scary.

- Listen, accept without judgment

- Such a session provided me with insightful information. It is all too easy to ‘label’ somebody who experiences mental health illness, placing them into a category of symptoms which they would/should experience. Therefore the power of effective listening, not superficial listening is essential.

- Each person presents (potentially) differently as they are unique indeed.
• I have learnt to treat everybody in a holistic manner—everybody is different with different needs. The importance of listening to your client was highlighted and when qualified and working within the mental health system I fully intend to listen and work with clients and incorporate their views and ideas into their care as much as is possible.

• I will remember that whenever I have to take control away, that I need to seek supports to put in place, if at all possible, to balance that.

• I will remember that illness is only part of a person. He or she is much more!

• Must take more time—try, try, and try again to gain persons stories—past present wishes, hopes, what's important to individual (what makes you you).

• Reminder of the need for joint/joined up working with others to ensure best interests of individual are paramount/at centre of what I do.

**How has this session influenced your role as a worker. Please explain in as much detail as possible:**

• It has made me more open to views. I think it is important to have a healthy workplace and listening and approachable.

• Never to judge or assume anything about service users. To be open and always there when needed.

• I think at times when I find myself becoming complacent or struggling I will remember these sessions and the reasons for wanting to be involved in MHO work.

• This will impact on my seeking better inter professional communication to support persons needing mental health assistance/detention. The session has reinforced to me how crucial it is to always see people in the larger context of their whole life (job, family, friends) and not just their health/mental health. I will take this from the bravery of persons turning to professionals for help.

• This will influence my social work and MHO work by keeping the **person** rather than their illness/disability /disorder etc at the centre of any further interventions. I will remember that there is great bravery in any recovery journey and that I am only the mechanic!

• Reminded me that genuinely warm and congruent practice is of prime importance.

• The session has influenced me to ensure that I work from a person centred perspective although still ensure ‘tasks’ are completed.
APPENDIX 2

Sample Programs

Student Nurse Training - Raigmore

Aim
To give an insight into HUG action for mental health and the need to have a voice, to discuss our lives with especial emphasis on trauma, anxiety, and depression. To talk about how we cope with life with a mental illness.

1.00 pm
Introductions
Program
Groundrules

1.05 pm
Talk on HUG by Graham and HUG members

1.15 pm
What HUG means to us. Why it is important to have a voice.

1.25 pm - questions and discussion

1.35 pm
Showing the anxiety DVD

1.45 pm – questions and discussion

1.55 pm - HUG member
Testimony - living with a mental illness
How she is affected by - trauma, anxiety and depression
What mental illness has done to her life
How it has affected her family and friends
How we manage day to day.

2.05 pm – questions and discussion

2.10 pm - HUG member
Testimony - living with a mental illness
How we are affected by - trauma, anxiety and depression
How it has affected her family and friends
How she manages in crisis and with the police
2.20 pm - questions and discussion

2.30 pm - HUG member
How I would like to be treated – what works and what my experiences have been?

2.40 pm - questions and discussion

2.50 pm - Graham
How we want to be treated for mental illness and anxiety and depression

3.00 pm - questions and discussion

3.10 pm
General discussion
Answering questions - possible topics:
- Medication
- Employment
- Hospital
- Recovery
- What we want from a nurse
- How we support each other
- What community services are like.

3.25 pm
Evaluation
Thanks and goodbye
One hour Awareness Sessions

Prison Staff - Porterfield Prison

Aim
To raise awareness among prison staff of HUG and the Porterfield project and to discuss and help people learn about our experience of mental illness and how we would like to be treated.

5 minutes

Introductions and groundrules

15 minutes

What HUG is: Why we do what we do – Graham and HUG members
Any questions

5 minutes

Questions – what mental health issues do you come across in Prison?

10 minutes

Experiences of mental health problems

HUG member - borderline personality disorder and her contact with the police
An interview

10 minutes

HUG member - experience of obsessive compulsive disorder – the value of having a voice – what good treatment does for her.

10 minutes (including questions)

HUG in Porterfield

HUG member

• What HUG in Porterfield is
• What we want to achieve
• What help we would like from you

Finish
Questions and discussion on the issues raised in the sessions

Feedback, evaluation and goodbye

With thanks to the members of HUG and HUG staff who created this report and who have provided awareness training with us over the last twenty years