

# GOOD PRACTICE IN USER INVOLVEMENT

Hello my name is Graham Morgan and I have been asked here today to talk about good practice in user involvement.

Most of you will not have heard of me or of HUG who I work with so I had better do a wee bit of explaining to set the scene and maybe give a glimpse about why user involvement is so important and can change so many things for us all.

HUG is the Highland users group which is a network of 360 people who have all experienced mental health problems. We meet in 14 different places across the Highlands to talk and talk and change the world into a better place.

The reason a group like HUG exists and the reason groups in other parts of the country and at a national level exist are numerous but as a rough shorthand I have 6 thoughts about the need for us to join together and speak out for a just world.

1. Users of mental health services have traditionally been discriminated against and marginalised – the involvement of people with mental health problems in a group like HUG is because we want to challenge this situation – we are a movement for social justice aimed at changing the lives we lead and the ways we are treated
2. As users we have an experience that no one else has – this experience is very precious and vital when we try to develop a voice and comment on our lives and the services we use
3. As users there is a power and integrity to our voice that cannot be found elsewhere
4. As users we are relatively free to speak out in ways that professionals cannot
5. By speaking out we show and demonstrate the need for respect, equality and communication that everyone deserves – the very act of getting together is a powerful statement
6. By speaking out some of us benefit ourselves and feel a sense of value and belonging and support and purpose we didn't have before.

In HUG we speak out to achieve fair and just lives for people with a mental illness in the Highlands, We want an end to discrimination and stigma, we want help when we need it, given in a manner that will make us want it. We want to stop so many of our members living in poverty, we want those who want and are able to work to have the opportunity to do so and for those for whom benefits are a better option to be able to receive them in a blameless guilt free atmosphere that acknowledges that we can all contribute in different ways and that, for some of us, this doesn't involve

payment for how we live or what we do. We want to inspire hope in our members to celebrate what we have to give to each other. We want (maybe in vain hope) the abject misery that comes along with mental ill health to be as limited as possible, after all mental illness is horrible enough as it is. It is a duty for all of us to stop all the horrid bits that come along once we are given a diagnosis and enter a system and life that is so often not one we want or choose to be in.

So how do we do this in HUG? We rely on our workers (who are all users) and our members (who are all users) to be central in changing the world into a better place and we rely on and expect the allies and supporters we have around us to accompany us on our journey. It gets a bit boring describing a process but I'll give a description of each different part of HUG and what it has achieved and hopefully we will see how something like HUG which is all about user involvement achieves real change.

First of all HUG is divided into two bits 'HUG speaking out' which acts as the advocacy arm of HUG or the voice of our members and then 'HUG stopping stigma raising awareness' that acts to increase awareness and understanding of mental health problems and tries to eradicate the stigma so many of us face.

I work with HUG speaking out and will try as clearly as I can to describe what we do. The Highlands is a huge place and our members are spread right across it, living in the city, hospitals, towns, villages and crofts. We are mainly in our thirties, forties and fifties but we have young and old members, people with disabilities, people who are gay, men and women, the employed, the unemployed, prisoners and managers and people who themselves work in the mental health system as members. We are a diverse, vibrant, crowd of people with a multitude of experiences and views and beliefs and our job is to combine these views into a voice.

To do this we travel the Highlands to find our members where they live and meet and there we hold our meetings and at these meetings we celebrate the variety of opinion that we have. There is a lot we hold in common and yet there is no one voice or one correct opinion all opinions are valid however strange or bizarre they may appear to be.

A meeting is structured in three parts. We report on our activities since the last meeting basically what the HUG team has done and achieved on behalf of its membership. In this way we are accountable to our membership and can keep them informed and enthusiastic about what we do by giving regular feedback on our accomplishments. The next bit of the meeting is centred around discussion topics where we talk and converse on a subject that has usually been selected by our HUG Round Table which is the HUG committee. This discussion topic tries to be one to which all of our members can contribute and is set around a series of key questions which are then written up and then compiled into a report which is approved by our committee and other stakeholders before being sent out to anyone who will read it before being put on our website. The last bit of the meeting is arranged around picking up on any local issues that our members have or other issues of concern that we need to know about and these are also acted on, turned in to reports or local

campaigns. In between meetings we meet officials, go to their meetings meet in focus groups such as those run by our regular Friday forum and find other ways of expressing ourselves.

Key to what we do is making what we talk about interesting in its own right , making what we write and say and do relevant and tangible and effective and if at all possible making it fun. It is sometimes silly to say make it fun when what we are trying to change is the echoes of lives that have lost their light and some of our memories are of those who didn't survive but there is something in the solidarity of a shared cause and a common bond that can inspire and provide comradeship.

So over the last 12 years we have produced about fifty reports raised hundreds of local issues campaigned on local issues and attended zillions of boring and not so boring meetings.

Our last but one report was on physical and mental health and like each report had its own unique effect. It talked about how we sometimes have our physical illnesses overlooked, about the complex inter-connectedness between physical and mental health and about the atrociously poor health so many of us have. The effect on its release was as follows:

Our chief psychiatrist said "thank you for sending me this extremely relevant and interesting report." Our associate medical director in the health board said "as ever I read these reports avidly and with interest." A consultant psychiatrist wrote to us and said "would you mind if I forwarded it to the Royal College of Psychiatrists editorial group. We are developing something on exercise in here and the information in here is brilliant... as usual you have come up with some excellent work"

The report was used in training sports science students in Gloucester , it was placed on the Royal college of psychiatrists website, it is quoted from and referenced in the latest Scottish government publication on the same subject. It has been distributed by the International Initiative on Mental Health and it has been heavily quoted in the wellness update the E-newsletter of the Center for Mental Health Services which is run by the US federal governments substance misuse and mental health services administration as well as being used by professionals way out in New South Wales in Australia. And in this way you can see the power of user involvement. The conversations and ideas we have in places such as David's house in Gairloch in a few short months have turned into a document which has influenced policy locally regionally nationally and internationally and there we can really make a difference.

It is these myriad threads and comments and ideas that circulate amongst us and grow and grow that get talked about and spread that end up in quiet ways changing the world. We are no longer confined to our homes and villages. In HUG we have worked with Romania, Poland, Spain and Portugal to help them develop their own groups. We are in regular contact with groups in Ghana, Kenya and Nepal and by these small gestures of friendship and support we strengthen each others voice and gain strength for a struggle that will take many years.

And yet I say it makes a difference, of course it does! it makes a huge difference but have any of our members physical health improved as a direct result of this report? I have to say I doubt it and that is where the grassroots stuff comes in because it is so, so important too.

When we hear of the concerns of our members we have to respond to them because here we also make a difference. Over the years we have campaigned on behalf of drop in centres, on behalf of employment projects both with funding and premises and by supporting each other and listening to users we ensure their voice is heard. Perhaps the longest running campaign was over a drop in centre in Nairn which was threatened with closure over the development of the new hospital and because it was very run down and yet the drop in was precious to its members so we campaigned for certainty and new premises. We wrote letters, lobbied meetings, made DVDs, wrote to the press, arranged a meeting with councillors and the chairperson of the health board and, after a long struggle and the support of the health board and social work managed to get much, much better premises for the users. The next task is to keep these premises permanent.

We have a group called the Friday forum. It meets between 11.00 and 3.30 on a Friday and I struggle to say why it is so good. We look at consultation documents, we act as focus groups we meet professionals and users which does not sound inspiring but maybe above all we drink coffee and witter a lot. In the last five months the group has responded to 7 major consultation documents, provided evidence to a parliamentary enquiry into young peoples services provided questions for the health minister, campaigned on a number of issues, acted as a focus group for two consultations, met with three professionals, met with people from a user group, looked at recovery, looked at our internal work and our international work as well as commenting on leaflets, reading poetry and looking at the see me photo competition. And why do we enjoy it? I suppose it's the good company and knowing at the end of the day when it is time to tidy up and go home that we have all achieved something and that there is a place for us all to do different things, sometimes a day spent stuffing reports into envelopes is just as fun and maybe more therapeutic as when one of our members addresses a council meeting on their own and there changes minds for ever.

I'm going on a bit aren't I but let me begin to wind down my talk about HUG by talking about our work in challenging stigma. It is here that we often make our real differences and provide different opportunities for user involvement.

I'll start with our mental health awareness training. By providing testimony personally, through group discussion, through DVDs and other exercises we can change in the space of a few short hours minds and attitudes that years of text books never would. Our members can give testimony about their lives participate in discussion sit in the background act as shadows but above all participate in an environment that is safe for all. We have become so used to reading evaluation forms at the end of the day that all say what we have done is excellent that we have become blasé and may get overconfident but, little replaces that surge of pleasure when you know you have done something successful and worthwhile. We provide at least one awareness

session a month and have done them with students, psychiatrists, primary care workers, volunteers, employers, managers, housing assistants, mental health officers, a whole myriad of different people.

Our young peoples' work is wide and varied and perhaps the most demanding for our members, we go into schools PSE classes to meet the young people, we help young people educate each other through peer education projects, we make DVDs with young people acting the story of a young person going through psychosis and lastly some years ago we took our play 'stigma' in partnership with Eden Court Theatre Company and the Primary Mental Health Workers around the Highlands. In four years at least five thousand people saw the play and an evaluation showed that 97% of young people said their attitude had changed as a result of the play and workshops. HUG members accompanied the play, educated the actors and provided all the raw material for the script.

Not everyone wants to stand up and speak in public so we make dvds where HUG members can appear on film in a safer atmosphere and if they don't want to be filmed can plan and help create projects. We have made many DVDs, especially DVDs on the mental health act, mental health first aid, employment and borderline personality disorder. These have been seen by thousands and thousands of people across the country. At present are making DVDs on self harm, social exclusion and recovery. All big projects with a lot of work involved in them .

Then there are the other bits, HUG members who try to maintain our website, HUG members who write for our newsletter, those that distribute our postcards and those that speak out in other ways maybe through creative writing or through photography or painting. Lastly there are a few of us who give speeches one of the most successful being one being one on the mental health act which featured on BBC radio 4 all in the mind program and was quoted in questions asked in the House of Lords.

There are so many myriad forms of user involvement and this is where I'll begin to wind up.

User involvement is a deeply boring word, I never got involved in this world to become an involved user. I got involved because of a passion and a commitment to my community of fellow users because of the need for justice and equality and a voice, and the need to be listened to and heard, for our experience not to be ignored, dismissed or forgotten. So when I think of HUG I don't think of user involvement I think of people, my friends and comrades who join with me in mutual respect and friendship for a mutually agreed cause.

I hope you will have seen that user involvement is not about going to meetings with professionals. We need to attend our networks and operations groups and management groups, we need to have our say and know how an agenda works and what the words all mean and how to participate but that is only one small tiny aspect of what makes a difference in an unfair world. There is so much more that is more

effective, more fun and which really works. In many ways a well written poem can say much more than a year of lobbying and committee meetings.

It is easy in the struggle to be heard to become disheartened and disappointed at the lack of progress to see the paltry sums we have to work with as yet more evidence that 'they' the formless negative 'they' who do not understand why we do what we do are actively through their own lack of interest conspiring to diminish our cause. It is easy to grow bitter and cynical because the obvious never seems to happen. It is easy to see darkness in our services because again and again we don't get what we want.

I would say the root to good user involvement is to put the ideas of recovery into our work. Instead of concentrating on the awful let's look at what we have to give, let's celebrate the wide variety of talents we have, let's look to the positive and remember that this is a long journey we are all travelling that there will be ups and downs and that all the time we need to remember what we can do, what we can achieve. We need to remind ourselves how much we personally have to give if that is what we want to do and how much we can get from those around us. We need to concentrate on the respect and comfort of our friends and community and a shared sense of where we are going and what that journey involves. We need to realise that this journey takes over some of our lives and for others we briefly dip a toe into the cause and that this is fine and lastly we need to remember hope and responsibility hope, because it is easy to lose hope and despair especially when faced with the lives so many of us live and responsibility because this is our journey and our cause and our voice and we are in control of that. If we are to be a voice we need to be an accurate voice that reflects our community not just a disgruntled minority, if we are to change the world we need help in doing this and to do that we cannot alienate our partners in this journey, if we are to lobby and press for change we may have a well of righteous anger but how do we speak out? how do we lobby using the media? Does it help people understand us and take them into our world or does it turn them off and make everyone angry and defensive.

There is a world to say about the ways in which we support each other in all of this and how we achieve what we do but I will finish with a last few points. Make the process good in itself, a talking shop is disheartening but a wonderful conversation is a joy, make it possible to achieve at least small things, each bit of praise and progress should be treasured and stored and passed amongst us. Learn the joy that can be had in our very companionship, make links with the people who are already doing this all over the world. Remember we are trying to make the world a better place rather than to apportion blame and, be realistic, we will never stop suffering or injustice but we can do a lot to do so and know in our hearts that if only they knew how so can loads of the people around us. This is a common cause and a struggle for everyone but ours is a unique and precious voice within it all.

*Thank you*