



## **TALK ON USER INVOLVEMENT**

### **PEER SUPPORT FIFE**

### **CUPAR**

**29 OCTOBER 2010.**

Hello thank you for inviting us to your meeting.

May I introduce myself; I am Graham Morgan – I work for HUG and have a diagnosis of schizophrenia then here is Marja Liisa Puolakka from Skye, also from HUG who will give a short perspective after me.

HUG is a group of people who have experience of mental illness who campaign for a better society and better treatment and better attitudes to people with a mental illness. You can find out more about us at our website [www.hug.uk.net](http://www.hug.uk.net).

Today we are going to talk about user involvement – a chance to give some tips, hints and suggestions about the pitfalls and frustrations we have faced in the last fifteen years of our work in giving voice to our members in the Highlands.

Some of you will know all this back to front and, I apologise if little is new, and for others the concept of speaking out will be brand new and I apologise to you if I take for granted knowledge that you don't have.

We all know that people with a mental illness do not get a good deal, in the past we were locked up in hospitals for year after year, we were subject to horrendous treatment that people thought, at the time, was humane, our prospects were poor and the gift of hope and joy rare. Even nowadays, where we have more rights, many of us have poor prospects and so many of us lack the optimism to look to the future with that glow of the possibilities of a better life that it can make us angry and sad, hopeless and defiant.



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INVESTOR IN PEOPLE

When you look at inequalities we face as a community, we are more isolated, more excluded and have lesser prospects than most others, we are likely to be unemployed, we die earlier, we have fewer friends, we are more likely to be homeless or living in poverty or poor housing or in prison we are more likely to have addiction problems and a multitude of other indicators which if we were an ethnic minority would be a source of constant public scandal.

For the last few decades people with a mental illness have been joining together to speak out to change this and, by meeting each other, we discover the vibrancy of our companions and the breadth of talent that lies unused amongst our acquaintances and our community.

There is something so precious: having the chance to speak and to be listened to, when we have lost so much, when friends, family, work and possessions are distant echoes, to still have the power to speak out and be listened to, to have our world recognised and recorded is so important.

When that voice is acted on and change occurs then it is such a gift to offer to those who come after us and who by the fact that there is a recognition of our experience may themselves not suffer so much in the future as we do today.

When we talk of user involvement, we often talk of the health service and social work and committee meetings and consultation documents but that just scratches the surface. User involvement (or collective advocacy, in its most developed form) is a voice for a community.

We choose our agenda, decide what areas of our lives we want to give expression to and how we will create that expression.

When we talk of our lives we can talk of hospital or employment, medication or spirituality, stigma or recovery, in fact we can talk of almost anything. And, when we give expression to our views we can choose numerous methods of doing so. We can attend committees, we can write letters, we can speak with journalists and politicians and officials. We can use words but they can also be creative words, we can communicate by DVD and music and poetry and drama. The numbers of ways we can get our voice across is almost limitless. It is just that different forms of communication are appropriate and have a different impact, in different situations.

Before we join any committee or write any speech or embark on any campaign we have a whole raft of things to do. The user voice,

and I do hate the word user, we try not to use it in HUG, is a hugely varied thing.

A single individual, expressing their own personal opinion, resting on their own personal values and philosophy is important and can contribute a lot, but to my mind, it is not the best form of involvement. We are a community of people, with a host of things to say; some of us hate medication and others feel it saves our lives, some of us despise psychiatry and others rely on it, some of us don't even believe in mental illness while, to others, it makes sense of our whole experience.

If we are to express the user voice we need, as far as we can, to find out the range of views we hold as a community and, where there is consensus, to follow that line but, where there is discord, to be responsible to our fellow users and express the variety of views that they also have.

This means seeking out our colleagues, discussing issues in meetings, where the range of experience is huge, where the breadth of our values is massive and where what we think will change things for the better varies from person to person and, instead of seeing this as an impediment, seeing this as a great opportunity and indeed honour. To gather the diverse views we all have and to find some way of recording and treasuring this whole wonderful variety of opinion – even where it may differ from our own personal opinion is a wonderful act.

The act of expressing opinions is crucial to the reception of those opinions but even more important is the task of finding out the views of our community. Of course we need to harness the energy of those that actively want to speak out but equally, we need to discover the views of those that would not naturally speak out and engage in the, sometimes daunting, task of changing the world.

This might mean meeting in hospital wards or drop in centres but also it might mean thinking about the voices that are seldom heard in committees, those on locked wards, those in homeless accommodation, people with other disabilities and people from ethnic minorities, those in prison and those who can't make meetings because they are so busy working.

Once we have discovered people's opinions we need to turn them into meaningful forms of communication and once we have done that, we need to check what we have created, with the people whose voice we have been given the privilege of being able to represent.

And then there are layers to add to this, as we gather the views of our companions, if we are to grow, we need to share knowledge and strategies and new models of care with each other so that our voice doesn't remain static but is given the opportunity to grow and learn and celebrate its expression and, if we are not to tire our acquaintances, with all our questions, we must make our enquiry stimulating in itself so that when we all walk away, we feel the glow of a stimulating discussion. Once we pass on the views of our community, we need to give feedback on the effect and impact of these views so that those who do us the honour of participating in our discussions, also understand and know that there is a purpose and value to all this.

The expression of voice can be just as effective in a school as in a committee meeting but it needs different approaches and skills and different knowledge that adapts to the variety of settings we can find to pass on our messages.

A school or a community group may not be the best place to talk about the care program approach and the intricacies of a section, different settings may need us to learn of different forms of engagement that are appropriate but vibrant and in a way fun, of forms of communication that engage in inspiring ways but which respect the world of the people we are with and the age and background they come from.

The same applies if we engage with professionals. The temptation is to turn up armed with the indignation of the years of our experience, to see them as the people responsible for our woes and the people who can make the world a better place if only they would listen and act. The temptation is to stamp our feet and to grow angry with the lack of action.

What I think we need to understand when we join government committees or council meetings or health board seminars is that we are a coming together of two cultures; sometimes with different aims and often, even if we share similar values and visions, different ways of achieving this.

When I am abroad especially if I am in a completely different culture I need to pause for a while and while having confidence in my own background make sure that I don't, with that confidence, feel it is my right to impose my values and beliefs on people and places of whom I am only a guest and who have accepted me as a courtesy and, as I accept the good will of new communities and they learn to adapt to my difference, hopefully, I will also learn to adapt to their perceived difference that they may have to me.

This sort of mutually respectful approach needs to apply to the committees we join with. As we get involved, we need to remember we are guests, sometimes guests by right and able to make demands, but still guests, who need to respect that, just as our hosts have a requirement to be hospitable so do we have a requirement to respect that hospitality.

User involvement may mean that some of the groups we join are, in essence administrative, they are there to administer the implementation of policy and have as little control over that policy as we do, in turn over their discussion, and that means we need to find the places where a voice enhances the mechanics and bureaucratic effectiveness of system and also those places where it is the core spring water that develops the policies and values in the first place.

When we sit in a committee we may get fed up with all the agenda items and the seeming irrelevance that they have to our lives, but, if we are able, we need to see how our reality can influence what seems irrelevant and to expect that if we have been invited to participate that room will be made for our voice to be heard and become meaningful.

It is sometimes this skilled task where we and they fail. We may get so frustrated\*\*\*\*\* we may want to shout out at them but don't you understand what it is like why can't you do this and they may in turn stare at their agendas and because politeness doesn't allow them to contradict us fail to tell us that either they are well aware of this or that our anger is rooted in the personal and not the collective or that although they agree with us and know we speak the truth that this is not the place to act on what we say.

And equally they can get caught in their job descriptions and the need for proper referral routes and the contingencies of restricted budgets and groan inwardly each time we speak and we need to find those ways of expressing and joining in that enhance the debate and bring a new respect for us and maybe find ways of making what is often bureaucracy sit up and take notice find those appropriate ways where we can raise an issue provide testimony and the expression of the everyday reality that makes people realise yes that is why they are sitting there and that is the purpose of the system that we are a part of.

It is not our responsibility to make the health service the council the government to work more efficiently or more effectively they have to take responsibility for how they serve us their population,

electorate, clients or patients and we need to seek out our own responsibilities.

If we can get what we do right, if we can give expression and join in and be heard and remembered then we are fulfilling our obligation to our community and what happens afterwards is not in some ways the issue as long as our community know that we have given voice to them and done all we can to ensure that justice occurs that the basic needs we have are recorded and that we have engaged with wider society in such a way that our reality is understood our needs recorded and our voice respected.

That leaves us at the basics. It is a part of user involvement to know how an agenda is set how we can have an item that is important to us on it how we can contribute to committee that seems to be populated by people in suits with issues that we don't initially understand but that is something we grow to learn about and something that to be frank few of us need to engage in to any great extent.

We need to think what gets us listened to? What emotion creates a helpful response, for instance does the need to shout and scream of injustice make people listen or does it make them shut their ears and equally does a voice that seems unconcerned and uninterested make people sit up and listen or does it make them think they can easily ignore us.

What is our voice? can we be sure that it covers a wide variety of opinions and experiences or is it so partisan and biased that it will be dismissed as the voice of a tiny minority.

What do we do when we hear of an example of injustice or grow a grievance on a particular issue are we so hurried to demonstrate our victimhood which may be based on half heard stories or personal antipathy that we miss out the wider oppression we are devoted to challenging.

When we grab hold of an issue do we consider the consequences of its expression, just because it is newsworthy does that mean the health board will respond better to us if we highlight it in the national media, just because we have the ear of a chairman of a committee does it mean that they should hear of our issues before the person who is either responsible of can change them for us does.

Then of course there are the times when we do not act as reasonable rational logical people, there are times where the issues

that affect our community need expressed with the power of the personal and the emotional; where turning the individual witness of the horrors of our lives in the right medium can do more than a hundred committee meetings and a dozen well measured reports.

It is working out where we can and can't do this and when we come to bringing the reality into the open even then being deliberate with the expression of our reality, a series of shouts or a bucket of tears may be threatening or moving but despite the need for spontaneity and the personal it still needs to be crafted – we need the words we use and the way we use them to move hearts at the same time as shifting policies and changing agendas, and that is a skill we need to learn together and in our own space where we reflect on what we believe in and how we give voice to that experience and belief.

Thank you