



# **VOX (VOICES OF EXPERIENCE) AGM**

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**Hello**, as has been said my name is Graham Morgan. I work with the Highland Users Group and I am a member of the VOX Interim Management Committee.

It is a huge privilege to be able to speak at this, the first AGM of VOX, which will hopefully be our national voice in the not too distant future.

VOX stands for 'voices of experience' and what could be more appropriate to a group of people who have in the past been denied a voice and led lives stuck in a separate and isolated existence than to know that at long last we have an organisation that can represent our views and experiences at a national level and hopefully internationally.

In this talk I am going to give my personal view of the importance of having a national voice and what I would hope that VOX could do for all of us and what I hope it doesn't do. I hope you find it interesting.

As I write this I am sitting in a hotel room in Romania. I have spent the week talking with people from Portugal, Poland, Spain and of course Romania. The people I have met are vibrant, dynamic and enthusiastic - well able to speak up, to influence, to change the world, and bear witness and yet the user networks in these countries are still only just beginning to develop. It seems so sad that, in countries such as these where the need for the voice of those who are dismissed is so pressing, the user voice is not yet supported in any comprehensive and truly meaningful way.

When I go to bed in this hotel I will read a book about the Asylums of England in the 1870's where there were so many people incarcerated and discarded by their communities that some didn't even have a name, and most had no diagnosis and no prospect of being released from degrading and inhuman conditions. If ever we needed a voice it was 100 years ago, or even 500 years ago, and if ever we needed a voice it is not just in this country but across the world.

In the struggle to live, either through the intolerable horror of illness or the sometimes the inhuman treatment people such as us receive across the world, life can become something that happens a day or an hour at a time. In those days where everything is bleak then the need to be heard by officials and to influence policy and to go to this committee or that meeting or this conference can seem to some of us, who are just struggling to live, as a trifling and maybe even insulting irrelevance. In my mind speaking out and challenging injustice often becomes something special when we have dealt, as far as we can, with the everyday process of survival and moved along on our journey to the point where we can look around and open our own and other peoples eyes to what is happening around us.

But then, when in the midst of the deepest sadness, we find people who will listen and respect us, work on our side, believe in us and join together in our common shared humanity then we can truly bloom and blossom and grow. When we find evidence that we will be listened to and appreciated then whole worlds can open up to us.

For me our voice can become one of the most important things that we possess. I meet so many people who want to bear witness and to provide the moving testimonies that we all possess about our individual experiences.

Our history is one that has been neglected through the centuries and our voice at times has been invisible within it. It seems to me that over the last 20 years or so, in which we have finally found acknowledgement, it would be so good to build a shared history of our treatment.

Many of those long stay patients who were so recently hidden away from the world are still very much alive, we as people, who are sometimes still subject to abuse in our communities and by our media now have the chance to speak out and to have this history recorded before the injustice of our lives escapes the public gaze.

I have just mentioned some of the abuses of the past but, despite changes for the better, the present is an age where we still have much to change.

Here are a few statistics that show just how much we need to do:

- ◆ 80% of people with a severe mental illness are unemployed.
- ◆ 20 – 40% of people with schizophrenia attempt suicide.
- ◆ Only 51 % of older people with depression have it recognised by their GP's.
- ◆ Around 40% of the homeless have a mental illness.
- ◆ Only 37% of employers say that they would be willing to take on someone with a mental illness.
- ◆ At least 76% of women remand prisoners have a mental health problem.

This shows that we still have a huge need to speak out to try to change the conditions some of us live under. But it is not just this that justifies a voice, as the title VOX says, we are the voice of lived experience - this is something that is unique to us and cannot be replicated by people with no direct experience of mental health problems. It is our voice, no one can take it away or replace it, and it has an integrity that cannot be overstated.

There is a moral dimension that is hugely important when speaking out with our own voice, the voice of the physical disability movement which may seem like a tired cliché: 'nothing about us without us' is still relevant and powerful and also applies to us. We have this voice in many parts of Scotland already but this opportunity to regain a national voice is so precious. To know that we will have a body that can represent our views and find new ways to use our voice, to not only discuss mental health services and policy but to influence the wider society we are all a part of is just so exciting.

These things that I have just said are things that we all know back to front and inside out but let us talk about VOX itself.

My personal hope for VOX is that it will rapidly become a credible and powerful voice for users across Scotland. Ideally it will have a structure that is truly democratic and as representative of the grass roots as possible.

HUG is a regional group that represents people in the Highlands but it draws its membership from even more local groups. I would hope that VOX will draw its membership from regional groups like HUG and that it in turn will be represented in Europe and then globally where we have so many shared issues with users in other countries and from different cultures.

In this way within a few rungs of involvement we could hope to have an easy mechanism in which to convey the grass roots experience straight from such small places as Dornoch or Golpsie to a national or even international level.

This is, to me, an ideal way of developing policy; by raising issues in our local communities and consulting our grass roots members and then passing them along to regional and then national groups who can in turn campaign on our behalf.

But, there can be problems with this. In HUG we have long known that there is no one unified view that we as users possess.

We are a diverse group with a huge range of experience. Some of us feel that our lives have been saved by those that are there to help us - others that those same people have ruined our lives.

To me it is very important to express this range of opinion so that everyone knows that in some way that most important treasure, our own unique voice, is heard and included within VOX.

But a structure such as the one I have mentioned may be one that itself excludes people - you can guess that as we develop, there will be a movement of those users that are articulate and confident and able to mix with the so called great and the good, graduating to the regional and national committees and, in some ways, this is good. We need the able and motivated speakers, negotiators and representatives. But we do have to be careful, we need to remember that our constituency is often composed of those that do have difficulty in speaking out, who do feel completely rejected by the system. Many of the people we would venture to speak for would never go anywhere near any sort of committee or meeting and may even regard groups such as VOX with great suspicion, perhaps, because they don't believe change will occur or because they would see us as too closely associated with the system that some of them see as responsible for causing some of the distress we experience or just because it may not seem necessary or relevant in their lives.

We need to be sure that we remain connected and based in everyday experience so that we can say with confidence that we really are grounded in the world of all of our members and so that they really do feel confidence in organisations such as VOX.

This means that quite apart from developing structures that involve the range of user groups that already exist across Scotland we encourage them, and VOX itself, to seek out the whole vibrant and diverse community we claim to try to represent. This means including those who come from other marginalised groups, but it also means including those who struggle so much to play any part in any form of organised meeting. It means contacting people we rarely hear from - maybe people who have mental health problems and who are in prison, or young people receiving treatment hundreds of miles away from their families or people in secure units or those people who only see their GP and may not feel an immediate connection with groups such as ours. It means reaching out in a whole variety of ways. It means continually returning to our membership and continually checking the views of those who are most important. It means being confident that we can find ways of representing a huge variety of experience that will often involve disagreement but without excluding peoples views or forcing one view for all of us when that consensus may not exist.

To me this is so important; we are not one united voice but are a range of people with shared experience and each different view point needs celebrated and respected.

Some people say that one of our failings is the lack of an agreed way in which we should be treated or helped to recover and part of me agrees. We need those liberating conversations where lights burn, words dance and we feel that if only this or that changed, if only these people listened then all would be good and rosy - but then another part of me disagrees. The various models that have developed over the years by their very nature, by looking at the world as a concept and forgetting the individuals who make it up, have both helped and damaged us. The building of the asylums was first celebrated and then condemned, the reduction in hospital beds was celebrated to start with but

didn't help those who wanted sanctuary in an old fashioned sense. The ideas of community care are still hugely important but there are many who wonder what difference it has really made when funds are so short. New ideas can create progress but when they become too rigid and orthodox can also damage. I think we need to guard against signing up too quickly to overarching theories about what is and isn't good for all of us.

In a group like VOX, which is taking on the voice of users across Scotland, we must above all realise the potential arrogance we gain by claiming to represent hundreds of thousands of people across the country. We must bear in mind that to speak for another person is one of the most precious and fragile gifts of trust another person can give us. We have moved beyond the dimension of expressing our own views and opinions to one where we have to become conduits for a whole breadth of varied experience - to do this is difficult and a huge responsibility.

As I have said, in order to grow and flourish we need representatives with the expertise and the skills of canvassing opinion, people with the ability to inspire, to communicate, to lobby and to press and press for change. These sorts of people are rare to find and in some ways may, once we find, them may be the people we need to limit.

It is so tempting when given a powerful role and voice to begin to get involved in issues of ego and power and feelings of superiority and it is here we need to be careful. It would be so easy for our various committees to become divorced from the membership, so easy to get caught in the destructive power of internal politics and anxieties about who says what and where. Not only can this damage our representatives but also the organisation and our membership. We need a good balance in our organisation which has core values at its centre and continually draws in new voices, new and creative ways of speaking out and reaching out to the hugely diverse mental health community in Scotland. We need to be so busy finding out opinion and new ways of representing our members that we grow together in strength and learn from a shared vision rather than, as is so easy to do, to start to resent each other and argue the minute details that detract from rather than enhance our voice.

We must make involvement a gold standard in Scotland and guard against any temptation to sign up wily nilly to fashions and new trends and policies. OK, examine them and study them but do it with a degree of scepticism and remember that most people with a mental illness across Scotland have little knowledge of policy yet a wealth of experience about mental health. It is that experience we need to draw on and be based in. Yes, there are all sorts of issues to talk about but let us set the agenda and let us decide how we will raise those issues and the ways in which we will raise them. There are myriads of ways of bearing witness and giving expression and illustrating our views. We need to go to committees and meetings, but in some ways this should be one of the least of our concerns. Our voice can be stifled in the rules of procedure of a formal meeting, our voice can be lost in the complexity of a new policy from the Executive, but our voice can be glorious in so many ways when we find new ways of expressing it. We are funded by the Scottish Executive but this does not mean that all we are is a tool for consultation on their own ideas. Important as that is we would be letting ourselves and them down if we just stuck at that - we are a movement for equality and justice and expression and it is this, this yearning for a better world for all of us, that will inspire our members.

Lastly, a note of caution. When I first got involved in this movement it was so important for me to speak out and to feel the righteous anger so many of us have. But as more and more of us speak we gain a power and, sometimes with that power, we feel that it is only our voice that should be listened to and, sometimes in gaining ownership of a voice, we see all the other groups as the potential enemy - the psychiatrists, the managers, the government can all be viewed with deep suspicion as people engaged in stopping us from achieving lasting change. Sometimes when we

speaking out I see professionals listening and disagreeing but unable to say so because we are users and it is just not something that they can do publicly.

To my mind progress occurs when we can all talk to each other freely, with respect and as equals. The professionals we meet are not necessarily always the enemy. In fact most work in this field with huge personal commitment and are often hugely influenced by direct experience.

It seems to me that as we develop our national voice and unique identity that we will make even faster progress when we find shared issues and find that by joining, where appropriate, with others such as carers or professionals we add to each others cause rather than detract from it.

I wish VOX all the best. In HUG we tell our members we are out to change the world but that this is a slow process – hopefully with VOX there for us it will become that little bit quicker.

*Thank you.*