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NAIRN CITIZENS ADVICE BUREAU – SEPTEMBER 09.

HIGHLAND USERS GROUP

Hello

Many thanks for asking me to speak with you tonight.

As has been said my name is Graham Morgan and I work with the Highland Users Group, or HUG for short.

HUG is a group of people who have all experienced mental illness. We speak out to achieve change. Much as you act with clients for change and use your evidence for a shift in social justice, so are we about justice and equality, dignity and respect.

Before I tell you all about HUG let me tell you about a few other things.

A few years ago flying home from Holiday, I was standing waiting for a flight up to Edinburgh. I was a bit early so I was walking in circles. A man came up to me and we got talking and he asked me what I did and I said that I work with people with a mental illness. He asked me why I did that and I said that it was because I had a diagnosis of schizophrenia. He turned round to me and said :

“people like you are scum, you don't deserve to live you should be wiped off of the face of the earth.”



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You don't really know what to do when faced with these attitudes. I made a hasty retreat and avoided him until it was time for my flight.

It is rare that I am faced with that degree of open prejudice but I remember when I was diagnosed that the family made a decision not tell my grandmother of it for fear that she wouldn't be able to understand. I regret now that she died without ever knowing who I really am.

It is this all pervasive atmosphere of suspicion and shame and guilt and half said untruths and sly comments that I hate.

I don't think an ice lolly called 'strawberry psycho' is that funny nor is a jar of 'insanity' chilli sauce - or that the latest psycho killer movie adds to the sum of our cultures, I don't even approve of 'Looney Tunes' as a cartoon title or of 'bonkers bruno' in the Sun newspaper.

It is sad to be a kill joy but each stupid throw away comment about "you don't have to be mad here but it helps" all begins to add up to a cultural inheritance that means has major consequences.

So we may not be surprised when we know that 85% of people with a serious mental illness are unemployed. That 40% of women prisoners are mentally ill and 64% of male prisoners have a personality disorder that 44 % of the homeless are mentally ill. That 41 % of people with mental health problems have experienced harassment or abuse and that people with schizophrenia tend to die ten years earlier than the rest of the population.

It is for these sorts of reasons we can grow to become angry and bitter and cynical and weary. We can say to ourselves "this world is wrong and unfair". Why is it that something as simple as an illness should carry with it such a burden of shame and guilt, of poverty of belief in a future and hopelessness?

Why, when one of the worst parts of mental illness is: despair and lack of motivation, is suspicion and the cloying tumble of a heart that beats with anxiety, is the drama of malevolent voices and a reality that is too harsh to bear.

Why is it when illness causes this to us that we also find ourselves in a world where all these horrible experiences are replicated by our society and culture because of its attitude towards us?

And history, which is where so many of our memories are based and where so many of our present attitudes developed is littered with the abuse of the mentally ill. It wasn't just in Germany in the forties that that cruel philosophy of Eugenics flourished leading to so many people with a mental illness perishing. Those ideals were celebrated in Britain. Thousands of people with a mental illness were sterilised in America and in other western countries in the thirties forties and fifties.

In the name of advanced humane treatment thousands of us were operated on and had brains cauterised until all the shadows of our humanity vanished. We had electric shock treatment with no muscle relaxants, we were given medications that made us into either addicts or zombies and we were kept in dim and cruel institutions for years until policy decreed that these were no longer our homes and that the community was now responsible for us.

And I am so sorry to rant at you because I know that you will all know this yourselves so well that I don't need to teach you it all over again but, look at our bright new world where hospital beds have been cut so much that people now beg to be admitted for fear that without that sanctuary they will turn round in the paleness of sadness and literally die. We talk of our new medications and yes maybe they do work but what does it feel like to be a young woman of 7 or 8 stone putting on another five or six stone maybe more, purely because it is meant to help you.

And go round the world; visit Nepal where the lack of alternatives means that people can be shackled to the equivalent of the stocks to protect them, where in Ghana people have been found tied to stakes in the village because there is no medication and no other help. In these bright worlds of viciousness it is easy to see why the community of people with a mental illness can despair and grow angry and find it hard to give or join in or accept the company of so called 'normal' society.

In Hug, we have tried to grow beyond this. We try to be a place of hope and joy and comradeship, a place of equality. Somewhere where we can give and be needed.

Where we can find value, where once we felt we had none. Where we can share the pleasures and the shared sorrows of those that travel similar roads to us.

We are blatantly an organisation that campaigns for the rights and dignity of our membership and we do that by being based right down in the grass roots. We act as a voice and our membership is that voice. Whether our members live in Tradespark in Nairn, Achiltibuie in Wester Ross or Merkinch in Inverness we seek out their everyday views about our services, what helps, what doesn't, what would if only it existed and we try slowly; drip by painfully slow drip to achieve that change.

We know that one of the worst aspects of our lives is that of stigma and discrimination and of harsh attitudes, ignorance and lack of awareness. By placing the voice of our members at the heart of our work we achieve huge changes in the ways that people see us and react towards us.

We have one full time worker and two part time workers to do this. The fact that they themselves have all experienced mental illness is an asset but this is far outweighed by the voluntary activities and activism of our membership which ranges from those who support us at a distance to those that do almost more work than the workers and has helped us to achieve a national and indeed international reputation for effectiveness.

It's no use saying that what we do is good and important we need to demonstrate that we actually achieve things for our members, so, looking at last years work lets see what we have done:

In our 'speaking out work' we concentrate on producing reports on the different issues affecting our membership. Each report involves a discussion with groups across the Highlands and ultimately will include between 70 and 100 people.

Last year we produced eight reports so I'll just give an inkling of the reaction to them.

Our report on the relationship between physical health and mental health; which highlighted the poor mental health so many of us face and the difficulty some of us have in getting our physical health recognised had the following reaction:

" I was very impressed with the report, would you mind if I forwarded it on to the Royal college of psychiatrists editorial group. We are developing something on exercise and the information you have come up with is brilliant. As usual you have come up with some excellent work. "

Consultant psychiatrist

A precis of the report was also published in the E.newsletter of the centre for mental health services in the USA.

Our report on peer support which is about schemes where users offer their skills gained through the experience of mental illness to each other had the following reaction:

" I am a consultant psychiatrist ... and am part of the peer support steering group led by the Scottish government ... may I take the report to the next meeting and quote from it in future presentations?"

A mentally healthy work place was about just that. What makes the workplace a good and healthy place for any of us to work in and here's a quote about that

"Another great report. Thank you. I have forwarded it to our director of public health ... I thought your report would raise the profile of mental health and try to get some positive action started around the recommendations from users." Director of community care NHS Highland.

Our last specific report was about the impact of being given a diagnosis of a mental illness, what it does to us, how it makes us feel and what the difference is between a label and a diagnosis. A team from a psychiatric hospital in Gloucester said the following:

"I found your latest report excellent and helpful, especially the quotes that help bring the conclusions alive.. I shall be letting colleagues in my team know about the report and encourage them to read it."

Lastly we write reports describing the huge varieties of issues that affect us across the Highlands. These are called our local reports and I am sure that it won't surprise you to hear that welfare reform is the current topic of debate and anxiety.

"it was very powerful reading ... thinking how we can use some of the information you have collected to influence the agenda at some of the strategy groups where we have representatives"

that was from VOX our national user voice.

While I am on the lobbying, changing the world with our voice side of things, I better mention a few other ways of doing this.

We have given talks at 7 national and highland conferences in the last year, we attend the various committees that discuss issues affecting us and have standing items on their agendas to raise issues of importance to us and we have the Friday forum where, on odd Fridays, we meet together to remind the world that we would like it to change.

These meetings are chaotic gatherings of active hug members where we drink coffee, natter and chatter and in between eating sandwiches meet other user groups and professionals who have come to find our opinions. Over the last year we responded to 34 separate consultations on policy ranging from patients rights to the smoking ban to occupational therapy services.

Now on to the more interesting stuff, attending a meeting writing a dry report, writing a letter or a speech is all very well but a voice is so much more than this. I am sometimes convinced that a poem can be a hundred times more powerful than responding to an agenda item in a committee meeting.

Our newsletter is littered with poetry and testimony, stories of what does and doesn't work, it features stories from around the world and stories from local communities, it demonstrates what we do in between the jokes and recipes, showcases the lives we lead and the issues we face.

We provide user led mental health awareness training, last year we provided it to over 220 people including actors, nurses , g.p's and mental health officers.

It is a chance for people to sit down in safety and by using a variety of methods ranging from the power of our personal stories, to dvd's we have made and group discussions - to allow people to learn of our

lives. It is a chance for those people who have the tentative fear of "how do I talk to these strange and frightening people" to relax and see us as ordinary folk who may sometimes be bizarre but despite this retain the essential core of our shared humanity. It is a chance for those professionals who have always wanted to, but never been able to, to learn about anything they want to, from our point of view, first hand and to learn from this. We evaluate these sessions and it is great to show our members the results within a few moments of the finish of the session. In the last five sessions this year we have delivered which have reached 54 people, a hundred percent said that it was either excellent or very good.

Young people are our ambassadors of the future, the people who will suffer illness and the people who will help us with it. Last year we provided training to over 500 young people across the Highlands. We also produced a dvd on psychosis that featured young people acting the descent into the agony of unreality, describing the experience of young people who have experienced psychosis and lastly the uplifting knowledge that you can recover and gain a good life shown through the medium of film and music. We toured a play called stigma through the highlands for four years and the evaluation showed that 97% of young people would now be more tolerant of people with a mental illness.

Last year we were covered by 14 media outlets; To get a message across we need to use the media , a short story about our lives can reach hundreds of thousands of people and change attitudes for ever in a way that a session on awareness which only reaches twenty or so people cannot do. At the moment we have spent the last year filming the recovery journey of one of our younger members. It'll be screened on prime time television in October and should reach millions of people.

We make d.v.d's: some of our dvd's have reached thousands of people. They are a way of talking about emotive topics without having to speak in public. We have talked about detention, self harm, social exclusion, the mental health act, being in work, homelessness, recovery and all sorts. It is a way of using creative expression and the hugely important testimony of those who couldn't sit in front of a crowd of people to shift, alter and change attitudes without having to be stuck in the glare of an audiences questions.

We have a website [hug .uk.net](http://hug.uk.net) that has all our reports and talks on it. We hope to put art work, photography and creative writing on it soon.

But increasingly we are using creative expression to get our views across. A picture paints a thousand words, a poem gives glimpses into life, a photo reveals what we cannot see, a prose article makes our world real and tangible and undeniable. We have planned exhibitions of art, books of creative writing, we have funding to develop a play for young people, an animation, a photography project, an arts festival, the future is hugely uncertain for all of us but we have the will the desire to speak out to let our lives be remembered and the injustices we go through to be recorded, we are a living breathing statement that injustice is wrong, we are a living memory of lives that were lost in the interests of policy. We will not go away, we will always assert the essential reminder that the lives of those who are ignored, forgotten and excluded, that those that seek hope even when it is distant still have a right to be remembered and listened to, whatever the political climate, whatever the latest trend. We are a community that has only just recognised itself, we need to let you know that we exist and won't go away.

Before I stop I will remind you that as the 'see me' campaign never fails to remind us 1 in four of us will have a mental health problem in our lifetime. That means that lots of you here who are entitled to be are not members of our movement. If you're interested I'll be around for a time after this meeting.

Good luck with your work we have a shared journey to follow but different ways of getting there, if we can help you let us know and if you can help us please speak to us.

Thank you