## **H&I Ecosystem Meeting**

## Stigma and discrimination in rural areas Graham Morgan Engagement and participation officer Mental Welfare Commission for Scotland 13 may

## **UHI Inverness**

## Hello

Many thanks for inviting me here today. I have been asked to talk about the stigma and discrimination of mental ill health in rural areas and some of the ways in which this can be addressed or has been addressed.

First of all I am not sure what we mean by discrimination in a rural area and whether the absence of services in some places is a sign of discrimination or just the reality of what happens when we live in such places, but maybe I will get there later in this talk.

However let me introduce myself; my name is Graham Morgan, I have a diagnosis of Schizophrenia, I lived for 20 years in the Highlands in sort of rural areas such as Kingussie and Carrbridge but worked in Inverness. I was the manager of HUG action for mental health and spent many, many, days meeting people with mental health problems throughout the Highlands; talking about the issues they had and the lives they experienced. I am now a volunteer for HUG and work for the Mental Welfare Commission for Scotland as one of their engagement and participation officers.

In this job I roam around Scotland meeting service user and carer groups in cities and towns but also in rural areas – my current round of meetings has included meetings in Inverness, Helensburgh, Bute and Mull, Dundee, Glasgow, Edinburgh Elgin and Bathgate. Although the Commission is based in Edinburgh, I actually live in Cardross near Helensburgh which doesn't really feel very rural but it is a village surrounded by fields and woods and edged by the sea so maybe a little rural!

I am going to report on the conversations I have had recently and talk about my own experience. I am concentrating on the experience of stigma that is specifically connected to rurality but to be honest I think in some ways stigma is stigma wherever you happen to live.

I am in the lucky situation that I don't really feel that I experience stigma in any meaningful way. Once many, many, years ago a stranger said that people like me did not deserve to live. Not so long ago a person I was very close to had a habit of calling me psycho and schizo when she was angry with me, when I was married we decided to keep my diagnosis relatively quiet as there was a worry that if pupils at my sons school found out about me then he might be bullied and targeted by them.

Nowadays when I am doing publicity for my book START which is about life and love with Schizophrenia we have decided not to contact the local press about it as we do not know how people in the village might react if they saw the more dramatic aspects of my life in the media. But then again I am giving a reading in a month or so at the local library in the nearest town to me so we can't be too worried!

When I speak about my life and I have done so on the tele and on film, in the press and the radio, I have nearly always had a positive reaction from people; they tend to be interested and curious about it; open to finding out what it is like.

I tend to feel that most people are open and accepting if you are open and accepting of them; that approaching them in the expectation of a good response will provoke that reaction. Maybe people speak in dark tones behind my back but I do not think they do. But despite this that does not mean that stigma doesn't exist.

I still worry how people will react when they first hear of my diagnosis. I still wince slightly when strangers make throw away comments about mental illness which, while meant to be humorous, clearly show people like me as other and undesirable, not the sort of person you would consider an equal or a potential friend. I tend to think this is guided by ignorance of mental illness as I feel that when people communicate then prejudice and fear decrease, that the prejudice is really the result of bad information.

But I also, perhaps unfashionably, think that stigma is not based on complete misinformation, we are of course vibrant and lovely people but not all of us, people with a mental illness span the breadth of belief and politics and of niceness and warmth and friendliness but underneath this is the reality that mental illness is not pleasant and if it is hard for us, it can be impossible for our friends and lovers, our family and acquaintances. Suicide and self harm may not be illness but they are often a result of illness and I know how helpless I have sometimes felt when faced with friends and family who detest themselves, who cannot stay in the world anymore. The agony of trying to be there for someone who has lost hope and who tears at themselves in desperation is sometimes impossible to bear when we see it in the faces of those we love deeply and maybe explains why some people do avoid us, do not speak to us.

And abuse and trauma, it does not necessarily lead to wan, tragic, figures who we can hug and comfort and save. Often it leads to people tormented by self-doubt and self-hatred, consumed by the anger of childhoods ruined by unwanted caresses or the blows of words or fists that create a terrible and unique horror and which can make people truly difficult to get on with, people who while desperate for love also do everything they can to demonstrate how unlovable they are and while it is not right, I can understand the terrible isolation and loneliness we can experience as a result.

This is not a simple easy subject, there is of course overt prejudice and there is blatant discrimination but please do not think people with a mental illness are really absolutely OK but because we are labelled; people are horrible to us and without that our lives would be fine. Despair, delusions, that white anxiety in your throat and stomach, those nights where we greet every hour of darkness wide awake; unable to

stop thinking, those times when we feel that we are always in the right and have all the answers. Those times when we feel that we are too vile to be touched, of course that is difficult for us and for those that love us, sometimes the discrimination we experience as a result is understandable if wrong.

And this is where I come to rural areas, in the past I have heard people say that in a rural area stigma is a lesser reality as, if we have grown up with each other and are well known by our community, then they are more likely to look out for us; to gather us to them when we suffer, to look on us as people deserving of the dignity of being respected for ourselves despite the difficulty illness causes us. But I have also heard people say that that very closeness can be cloying, can mean that everyone knows everything about you, whether you like it or not, that they know when the CPN comes to your door, when the ambulance takes you to hospital and that this can be remarkably exposing and in some ways humiliating. When once I went into hospital and the plumber knew I had been admitted before my family did, it says something and for some people this is not nice.

Equally in close knit communities it is not too hard to build an image of people, where a rumour or a worry about someone, maybe someone who has newly come to live there can build into unreal and terrifying assumptions about them. I have, in the past, heard of people made to leave communities on the basis of wild theories and ideas about people who appear different, people who come to be seen as a danger or a threat.

I have to admit that I know very little about what the culture in a rural area is, I do hear rumour that especially in the farming community people have the need to show a coping, independent, reliable, unemotional, self sufficient front. And maybe in some ways that is a blessing sometimes, to be able to stand in the certainty that you are strong and can cope is great, but when you stop being strong and look on your weakness with shame, when you are so independent and private that you refuse to seek help, would not dream of going to the GP or phoning a helpline, then maybe there is a cultural dimension to stigma in rural areas.

As I said I work for the mental welfare commission and over recent weeks have been meeting service users and carers in their local communities and in these meetings people highlight some of the issues they experience. Whether they are highlighting discrimination or inequality I do not know – those of you who are academics will know far better than me, but my heart does sink when I hear that in some communities such as Tomintoul there are only two buses a week that people can get to town. I wonder what that means for people who have to use public transport to get to services, as would be the case with many people with mental health problems. Using Tomintoul as an example, the fact that the library is closing is another sign of disintegrating community facilities made more poignant by the fact that people who struggle to get online to apply for benefits are now encouraged to get help or to use library computers to do so and now of course will not be able to.

As far as I know many of the people with the severest of mental health problems have limited access to and ability to use the internet and of course in some rural areas there just is not an internet connection to be made. Is this discrimination? I

don't know it certainly means that many people in rural areas with mental health problems are worse off than if they lived elsewhere.

And budgeting I remember speaking with someone on the west coast fairly recently who said that when she is ill she cannot budget properly, that sometimes sense goes out the window and sometimes the need for something that might cheer you up like a drink or even a nice piece of clothing can take precedence over the basic necessities but in a rural area this is made even harder: if you cannot face public transport because of your social anxiety, and yet cannot afford the price of petrol at the pumps for your car because it is so expensive then you are pretty stuck; have to rely on local shops if they are there, which again tend to be more expensive.

Again an inequality where the high cost of living in a rural area is combined with the difficulty of managing a life with a mental health problem while on benefits.

And equally services for mental health are few and far between, I hear that in Lochaber people are now encouraged to come into Fort William to see their CPN, so again we go back to public transport and that fact that for some people that is difficult, as is just getting the energy and motivation to attend appointments when getting more ill and I suppose the seal is laid on this when people desperate for services are discharged because they cannot attend appointments.

Thinking of Skye and Mull I hear of very few services that people can access and even fewer that people can use if they are young, I hear of young people who are lost in their illness, losing out on education, losing out on friendships with nowhere that they would naturally turn to; drop in centres and meeting places are worth their weight in gold but if the average age of people using such places is over forty it is likely that most young people will not attend such places. Is this discrimination or the choice people make by living where they do?

Do young people who have to travel to Inverness for children's mental health services and have to leave school for the day to do so have any privacy and vestige of confidentiality and was it their choice to live where they did? Was it their fault that young people's services are so hard to access from so many rural areas that inpatient units can be many hundreds of miles from their friends and family and home, I do get that we are restricted by resources and geography and population but to me this is clearly discrimination; maybe a discrimination we are still happy to accept but discrimination none the less.

We try to say that there has been an increased investment in mental health services but when I look at rural areas I am familiar with I do not see the evidence of that, the third sector struggles and many statutory services seem now to be geared up to short term goal orientated services tied into the mantras of recovery and resilience and responsibility; all very well in its place but when will people planning services recognise that many people with mental health problems will have them all their lives and that efforts to make some people productive and better can be deeply offensive, that some people need the sanctuary and safety of somewhere to go when they are up to it and when they feel like it, with no need to fill in forms or set targets but

instead the very human need to have somewhere to go with something to do, someone to talk to and something to eat.

It was on Mull that we pondered this issue of discrimination and stigma – we knew fine that stigma exists and that in some ways it can be worse and different in a small community but we were unsure about discrimination: is the fact that people with mental health problems tend to be without much money, without cars and can struggle even more to make ends meet than some people in urban areas discrimination or a choice they have made? Is the fact that you can travel for a day to get to therapy sessions that leave you shaken and ill and that you still need to keep it together on the bus journey home to Wick or to Gairloch? Is that discrimination – well of course it is, people with mental health problems are discriminated against because of their mental health problems but there is the additional discrimination that comes with living in a rural area which can heighten it. At the moment even people like me accept that some discrimination is inevitable – I could weep at the loneliness I have occasionally experienced and which my friends and acquaintances have because of our mental illness but I can understand why it happens, I yearn for friends. I love to hear the knock of friends on the door but I also know that, confronted with actual real people I clam up, leave all the talking and entertaining to my partner, so it is no wonder that it takes years and years for me to make friends when I move to a new areas, it is wrong but life is wrong and in some ways I accept this is just how it is.

I think many people also feel the same about discrimination in rural areas, a sort of: 'I choose to live in north west Sutherland so how on earth could I complain that the nearest hospital that will care for my young child is hours and hours away in Dundee. Well that is discrimination; the young people of Dundee can have family travel just a short distance to see them, not so the young people of Durness but then you would never accept the need for an in- patient young people's unit in such an area – it might only take one person every five years or so; a degree of discrimination that at the moment we accept and do not really question.

Maybe one day we will do, maybe technology will make some of this obsolete, maybe the Scottish social security agency with its emphasis on face to face contact will make some of our benefits more accessible and we will have to travel less and will see more people in a more approachable way.

I am really only pondering and musing. I will finish though, with some examples of how we can tackle stigma, nothing beats a good story and when it turns out to be true that is even better, nothing dispels fear and misunderstanding better than being confronted by the person that you fear and finding out that they are pleasant and reasonable and when feeling wounded by another person then understanding why a person has acted the way they have done and realising that no hurt was intended can make all the difference.

That is the basis of the mental health awareness training we carried out for many years in HUG, the group I used to work with, with hundreds of people.

In addition we worked in schools across Highland with mental wellbeing days and visits to PSE classes, for many years we took dramas alongside Eden Court into schools; probably working with about 9000 young people and consistently getting great evaluations. That sort of thing was wonderful, I still sometimes meet young people who now work in mental health who were inspired to do what they now do because they were part of this.

We have created films and animations, have participated in the mental health and arts film festival, we have held painting, exhibitions, given poetry performances, created creative writing books, participated in walk a mile events, appeared in the papers on the radio and on TV. We produced post cards and beer mats, spoke at conferences and so on. It is slightly different now and I am not too sure what happens now in the Highlands but that visible unashamed yet honest presence did for a time, make a big impact on the conversations that went on in rural communities about stigma. We were fortunate in having a worker whose job was almost entirely about challenging stigma and sometimes it is this small investment in a post that allows amazing things to do be done.

With the bits about discrimination I am less certain of the solution or even if there is one, as a volunteer I wrote an article about austerity, using the Highlands as an example, for the Lancet, and, also as a volunteer, gave a talk to the National Farmers Union which then appeared in precis in the Farmers Weekly. In some small way having the Rural Mental Health Forum might make changes that we could not and in other ways the work I do in the Commission makes a difference : in the Commission we are all about the rights of people with a mental illness, learning disability, dementia and autism. I actively seek out the views of people from remote and rural areas and as people highlight the difficulties they experience then we can, in turn, raise such things at our yearly meetings with Health Boards. We have an advice line which is free for people with lived experience and carers, which, as it says can offer advice to anyone around mental health and care and treatment and rights. Being about rights we are of course on the verge of dealing directly with discrimination. We have films and a booklet called rights in mind which relates the experiences we go through in the hospital and the community to the rights we have in law – all of these can make a difference. We sometimes take on casework with our local practitioners dealing with some situations and we also have a role in influencing policy at a national level – we are about the whole of Scotland but that of course includes areas such as Argyll, the Western Isles, Dumfreis and Galloway and the Highlands.

I used to think change would only come about if people with lived experience are at the forefront of speaking out and campaigning for a better world, I still think that to some extent but I also think the growing recognition that mental health and mental ill health has across society, that it is us and our families and friends who experience it, I think there is some hope in this, that between us we know that tackling subjects such as this is something we all need to do; that it is no longer a niche subject but a matter for all of us.

Thank you for listening.