



The Mental Health Act –

Five years on

A talk by Graham Morgan from the Highland Users Group

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Hello

My name is Graham Morgan; I work with Highland Community Care Forum which, means that I work with the Highland Users Group or HUG. HUG represents the views of people with a mental health problem in the Highland area.

To talk of the changes that have occurred since the implementation of the new act is so daunting! So instead of giving you a comprehensive version of the users' vision and evidence of change let me tell you a little of my story and the views and feelings of some of my friends and acquaintances.

Just before the new act was implemented I chose to change my medication; I was fed up with putting on weight with 'Olanzapine' which was the medication I was on, fed up with a blurred life and worried about all the other side effects it might have. So with the blessing of my psychiatrist I switched to 'Abilify;' at the time regarded as one of our new wonder drugs.

Initially life was rosy indeed; I found vibrancy and energy and began to spend time with my family in a way I hadn't before. I was glowing with the healthiness of life and, whilst smiling at this transformation in my doctor's consulting room, my wife said with huge happiness that at last after 12 years she had finally regained the husband that she had originally married. Oh a time of smiles and, yet, I stopped sleeping and couldn't stop thinking and all the warmth of the new world shrank in the cold of the New Year until all I could think of was good and evil and battles within me between the two. The need to reach a spiritual nirvana and the need to lay to rest the spirits of all the patients floating restless from their abandoned lives at the old psychiatric hospital in Inverness.

In this altered world it seemed to me totally logical that the only way to provide peace to everyone was to slash my wrists and it was the mechanism of the old Mental Health Act and my subsequent detention that probably saved my life. It was also the lack of choice about medication that meant that I had to go back on the Olanzapine and become yet again the stranger my wife sometimes despaired of being with.

It is strange then to be writing this talk on the train some years later having yet again gone back onto the medication 'Abilify' that to a large part was responsible for my detention. The people who work with me are again fully supportive of my decision, my family is happy, my friends are looking out for me and yet I feel an emptiness; my thoughts are veering into set tramlines and I am having increasing difficulty in sleeping.

If things carry on as they have in the past I may begin to become psychotic and will find my health once again in danger. So why on earth should I be doing such a dangerous thing and what does it mean about my life and the act today?

First of all I have always hated 'Olanzapine' a few months ago, as part of the physical health checks that we are now encouraged to have, I discovered that I had extremely high cholesterol which is probably partly caused by my medication. It was so high that I was told that I had a one in ten chance of a heart attack or stroke in the next ten years.

For this reason alone the risk of switching to 'Abilify' seemed worth it but equally, like so many others, I prize my autonomy, I prize and value the ability to lead my own life, to find my own paths and ways of being and as with anyone that can mean taking risks; even those risks that may be very harmful. However in contrast to the last time this was tried, I have a team of wonderful people both professionals and others looking out for my welfare, I have Relapse Prevention Plans and bundles of Diazepam to help me sleep and I have been told that if I get into trouble to phone the Mental Health Team in Aviemore and they will phone back to help wherever I may be.

So what am I saying? First of all people are said to despair of people like me who stop taking medication or who insist on taking medication that is unlikely to work, but I would say that whatever trouble it causes we do things like this for very good reasons; to enhance our health, to assert our identity, to really find out who we are and live the lives we had hoped we could lead.

Getting into situations like the one I might be facing is often the result of soul searching and the desperate need to find something in a life that sometimes seems leached of the joy so many of us expect from it. We do not leap into madness, especially when faced with the lessons of the past, but we may have to take risks in the hope that we can maintain a level of wellbeing that we need so much to aspire to.

And the changes? I feel so supported. I feel the worst is planned for and the best expected. I know if things go wrong that I will get help and I know that if everything collapses then maybe I'll be sectioned again and maybe I will have to be put into hospital again.

I give a rosy story; I talk of my views being respected, of having a say in what happens to me, of being treated as a true equal with the expectation that if anything goes wrong, as much as can be done will be done to support me. I talk about being encouraged to lead my life and supported to take the risks and steps that we all so routinely take.

And yet there are a host of other stories, stories that are maybe not heard so clearly because we shy away from them. There is nothing whatsoever that can stop the fact that many people find themselves detained, confined, treated against their will, locked in places they never dreamed of staying in and their offence. What crime have they committed? Of course we all know the crime, the crime is not one of wrong doing but one of simple everyday illness and however much we may praise the humanity of our new Act, however much we may say it saves lives, it still takes away freedom and liberty and it is easy to understand the bitterness of my friends who scowl at what they

see as the forgone conclusions of an establishment that seems to have so casually imprisoned them.

I personally have always agreed that sectioning is needed as a last resort and have had no problems with an Act that supports this, especially with the backing of the Milan principles; and yet sometimes I wonder whether this reflects a poverty of my imagination.

Someone once said that we have a first class piece of legislation in a land of second class services and I wonder about this. Someone close to me wrote in an advance statement that time, patience, respect and dignity when she is deeply distressed do more to bring peace and co operation than any imposition of force.

And when you think about things like this you can begin to wonder can't you? The casually blunt restrictions of detention can perhaps be offset with time and resources and the right surroundings. I don't know what the ingredients are, but perhaps its being known by someone we trust, having somewhere to go to where we feel comfortable and having that space for decisions to be delayed and delayed and delayed until the desperate anxiety about what is being done to us diminishes and finally, if nothing else can be done, for that imposition to be carried out with as much respect and dignity as possible rather than having to witness a collection of police walking up our garden path.

But look wider; what are the ingredients of confrontation and desperation? It's when life becomes unbearable, when our destiny is miles away from our control, when other people know what is best for us and when hope is a forgotten promise and activity; something we forgot about months ago. It's when we feel threatened by the people around us and when we feel that we belong to no community of our own.

You know this feeling. It is when life grows dark and bleak and desperate and then we lose the will to live or we develop the anger to hate. And the causes? Well of course, the obvious - when our synapses snap our mind, when genetics create their own sad destiny, when the slide of chemicals tips us into illness. but much stronger in my mind is the feeling of alienation, the fact that 85% of those of us with a serious illness are unemployed, that most of us live on benefits that prevent all sorts of activity or opportunity for enjoyment and that in our lives on benefits we are vilified by the media as frauds and feel inspected and victimised in our medicals. It's loneliness and no one to hug and kiss, it's being told, with the best of motives, not to mix with other people with a mental illness, it's being shunned and ignored and feeling an overwhelming sense of guilt and shame for where and who we are and what we have done to those that we love and care for. It's feeling perpetually at the bottom of the heap and in that alienated world losing all faith in those supposedly normal people who we are supposed to emulate. And when this happens, when the society and culture that we are a part of rejects us, dismisses our talents and humanity, illness beckons with redoubled force and the crash of the law becomes an inevitability and however good

the law is, it is not the least restrictive because our world is the one that developed the law and our society the context in which we suffer.

So the Act needs to be seen within the cultures we inhabit. If we look at sections 26 to 28 then I am a model of their effectiveness; employed, confident, healthy, occupied, socially engaged and yet I think I am the exception rather than the rule and that is why I am almost always well and so many of my friends so frequently despairing.

Yesterday I broke the news to one of our HUG members that a friend who provided inspiration to many of us had taken his own life. The person I told had just been detained in hospital himself. The Mental Health Act certainly protected our HUG member and those around him but it didn't protect my friend and it doesn't provide comfort to the HUG member who is locked behind the doors of the ward unable to even get into town to get money out of the bank for cigarettes and all the other things we need for our daily living.

....As I write I stare over the fields but I feel a swelling sadness because it is just not acknowledged how absolutely awful illness is, days of torture that spread through your whole being until there is nothing left at all and so, if we are in time, we rescue those that are lost, and hope that care and space will restore their will and energy to them but sometimes that is not enough and we lose those who are so desperately valuable and however much we reach out however humane and bright our carers may be, we lose those that we love, their being becomes lost in a twilight world I have lost too many dear friends in this way to celebrate the Mental Health Act. Yes it saves lives, but too many of our lives are just hollow echoes of the visions our parents had for us as children for us to say what we have works well.

So this really is the central message of my talk; however good our Act, however much life has changed, life for most of us remains much the same; the ache of an empty day, the lack of a cuddle, the monotony of another cup of coffee, the *cruel balm of too much* ... much alcohol does nothing to inspire hope in our lives. The continued suspicion of the public and the sometimes, though hopefully rarely, negative attitude of some of our professionals, does nothing to inspire our self confidence. A culture that alienates does nothing to help us feel connected to the world. Being desperate for help when life is at its most tenuous and being told that hospital is not appropriate supposedly because of the diagnosis you have or yearning for warm words on the weekend from those that help does not make us believe in our service, however committed and well intentioned our helpers may be.

But we do have our Recovery Network, our 'see me' campaign, our Breathing Space, our sections 26 to 28, our Mental Health Delivery plan, all of which aim to change these sad realities and they are so clearly making progress. So, why I am so cross?

It just feels so cosmetic; little layers on a web of suffering that stretches back centuries and will carry on for centuries to come. I want my friends to stop dying of despair. I want to stop picking up the phone to the sobs of someone filled with guilt because

their sadness is now obvious to everyone. I don't want to see people barricaded into their own houses, placed in prisons, not seeing any reason to get up in the morning.

...And I am sorry, but instead of a reasoned account all I am saying is let the people you and I work with and love so much have some respite, something to believe in and look forward to, it is a shout of "why can life be so terrible?" and why can't someone, somewhere find a way of stopping the pain? And I am sorry, but legislation however proud we are of it, doesn't take away the agony that just being alive can carry with it.

In some little way 'recovery' embodies many of the answers I yearn for; this way of celebrating our own journeys, however rocky they are, the values of hope and optimism, the refusal to be defined by impairment, the reaching out for solutions and self-determination and self-definition. Yes, it's a buzz word, a trend and maybe a phase, but there are days when I walk into the HUG office and see our members laughing, supporting, drinking those interminable coffees but gaining that huge sense of belonging and community and value. There are times when I walk into a drop in centre, a training centre even a hospital ward and feel so welcome and so buoyed up with optimism and shared experience that I do feel hope. I meet workers who will not be confined by the barriers of professionalism but reach out daily with that most precious of gifts; love. I meet users who see every day as another tiny step forward; who refuse to see illness as their essence or even as illness at all. And of course there are those with the wide lives of sadness who find messages of hope offensive but if I were to change the Act today it would be to incorporate the values of recovery.

It would be an Act that, of course, never could be an Act because we cannot truly define recovery,... an act that changed our culture, that celebrated the thousands and thousands of us that go through illness, that built on our rights and values and sense of community and belonging. That looked beyond the stale words of "work good, unemployment bad" and sought other ways of valuing the contribution that so many of us make but don't get paid for. That celebrated our diverse experiences and views and above all looked for strong visions and solutions that we can all share *whether they be **chemical** or social or, spiritual, that could bring comfort and support to so many who no longer expect it.*

And in conclusion I suppose that it would be good to refer to some of the tangible aspects of our Act. First of all it does seem strange to say we are taking away your freedom but you have a right to participate in this process. A sort of a contradiction of offensiveness and yet I do know that many of our members do feel that they have a greater say nowadays and that this really does need recognised and celebrated.

Tribunals; yes they are better than the past system but too many people still believe that it is the setting for a fight in which they are hopelessly outnumbered. Named persons - well I haven't time to cover this now, but however much we may love our families we do not always want them to become named persons by default even if as our main carers they should so clearly have that right. Advance statements - well we know we are not making them - how many of you in this room have an advance

statement? We all know we should, I know I should, I just don't get round to it but it is good that one day I can if I wish. Mental Health Officers - can we finally have enough of them? Legal help - why do we rely on lawyers from Glasgow to represent us in Inverness? I could go on in a number of areas but I won't as I've said too much.

Many years ago I served on the Milan Committee; it was a privilege and an honour and each meeting filled me with dread because I didn't feel I was up to the task intellectually or philosophically but I am proud of what we did. I do think with tweaking our Act is, and will, work well but I have to say, as I have already spent the last twenty minutes saying, we need also to look at our culture, our society, our values, our need for hope and faith and love for it to be anything more than the mechanism that deals with a minority in the sad extremes we can sometimes reach. Maybe when we no longer wait well over a year for talking treatments, don't see brand new wards for older people built on the second floor of hospitals but do celebrate the staff who daily seek out fresh flowers for patients on that same ward, and in those values realise what this is all about, we will find a vision we can all believe in.

Thank you