



A USERS VIEW OF THE MENTAL HEALTH ACT

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Hello, as has been said my name is Graham Morgan and I am meant to be talking about the Mental Health Act from a users perspective.

I work with the Highland Users Group and am myself a user and have a diagnosis of Schizophrenia. However it is many years since I was last in hospital and I have never been sectioned, so I feel a bit of a fraud today. I expect many of you know considerably more about this subject, either from personal experience or as professionals, than I do. However I will do the best I can to pass on some of the ideas that I have gathered and those of my friends and acquaintances.

It is hard to be positive about a piece of legislation that, although it is meant to deal with a much wider subject, has, at its heart, those times when we have exhausted our resources, found our identity fracturing and the professionals around us at a loss of ways to help, except for the extreme of taking away our freedom and our control of our own destinies.

It is also very hard to see how legislation can deal with what sometimes seems like weariness in the system. As professionals many of you will be tired of constant reorganisation and the demands of work that require new and innovative and inspired ways of working, but often without the time and resources to support this.

As users we too can get dispirited by the yearning to speak out, to improve things, to comment on the latest ideas, the latest proposals, to say from our hearts what we know we and those around us need. Many of us put huge effort into such processes. We, who may struggle to carry out the simplest of tasks when the days have become grey and dreary, may put our soul into speaking out, into the prospect of the joy and lightness of change, and yet this change, this new life for our community, happens painfully slowly, so slowly that we become disheartened, and find it hard to see the positive in any new initiatives.

When I think of the Mental Health Act I think of the words one of our members. She said that she saw present mental health services as grey and dull like a concrete city and said what we needed was colour and vibrancy what needed was warmth and respect and love and care and brightness and hope.

Now if legislation could kick-start such things we would have wonderful prospects. If we, in the users movement, could have the confidence provided by seeing change for the better occurring, so that we do not have to speak out ever more shrilly and angrily, if workers in mental health, instead of feeling burdened by their jobs and got at and blamed, if they knew, in their hearts, that they were happily involved in a cause that is so important and makes such a difference, if

they worked with faith in the importance of their worth and could rely on the support and respect of the users and carers they are meant to serve, then, in that world, where we worked together, where we believed and knew how important our collective voices are, then we would have something special.

Maybe the legislation will provide some of this. I am told it has a much greater emphasis on rights and autonomy and respect for users and carers than ever before. Maybe that is something that we, as users, can happily celebrate. But equally I hear that some workers worry about how they can deliver the services which will now be expected of them.

I intend to refer to some of the Millan principles that provided a backdrop to this legislation and which I feel are a vital and vibrant set of statements. But before I do that, let us have a little reality check on what we mean by a piece of legislation that gives the authority to the actions of a society that accepts sectioning.

Here are the quotes of some of the people I know who have had to experience such a blunt and intrusive form of treatment:

“It’s like you lose trust from others so that they don’t trust you or your opinions are no longer valid. You feel outcast.”

“You fall into feeling that you are a reject – even if you had a real life before – the real life doesn’t seem important to them – how do you get back to your real life? This is not real life, we are not participating in life, you are put on one side and don’t feel that you are a participant any more because you have been sectioned and neglected.”

“It can be a very negative world, you lose optimism, you lose hope that you will get well.”

“The routine chores – children, work that keeps you busy – in our world people don’t work and the simple things that used to take up your time stop and this lack of things to do removes you from life.”

“It may be good to have a car but I have no reason to drive it anywhere,”

“It’s pointless ... to have a phone as I don’t need one – no one would call anyway.”

“I am often trapped in my house – it can be very hard to get out – it can be really hard to get to a drop in centre or a group.”

I think these statements convey the hopelessness and despair that can come after well intentioned treatment, even when that treatment has been acknowledged by some users as having liberated them from even more horrendous situations. That is really our starting point and should be the reference point for those who have to carry out legislation such as this.

As is said before I am going to refer to some of the Millan principles for the rest of my talk. I do think that principles that give a vision and statement of respect for the lives that we lead are vital and hope that their humanity can inform and influence the new act as it is implemented across Scotland.

However I intend to illustrate some of the principles from my life and the lives of my friends to show the immensity of the task that we all face.

Let's start with the **principle of non discrimination.**

Discrimination is a daily reality for some people, and although the stigma of mental illness is beginning to change and reduce (as we saw with the response to the coverage about the experience of Frank Bruno), it can be a harsh reality. It is a year since a stranger told me, on hearing that I had a mental illness, that the world was too good for people like me and that we should be put down. I know of people who have been avoided, had stones thrown at them, been abused verbally, and been spat at.

85% of people with a severe mental illness are unemployed. I am sure that is not just a result of the condition; part of the reason is that people still don't want to employ us and part of the reason for this is that the employment market has not adapted to the needs of people with a mental illness.

Discrimination is subtle too. It can be a matter of perception. People generally don't see mental illness as important as they do other illnesses. They don't acknowledge its severity or the fact that 10% of people with Schizophrenia die as a result of it. The fact that 20% of people with Anorexia also die is hidden and unremarked by the media and although the government has long recognised that mental illness is a priority in the health service, has that really translated into substantially enhanced mental health services across the country.

In most situations, the siting of a new hospital for the most needy and the most vulnerable and the most sick would be celebrated in the local media and hailed as a great step forward and the politicians would be queuing up for photo opportunities. In mental health the siting of secure units can cause the local communities and the media and even some politicians to mobilise in opposition.

In most other areas of health care, the recovery of the most severely ill would be celebrated; communities would open their arms to welcome the newly well back, and yet, as we all know, there are people in the state hospital who are acknowledged to be as well as can be expected and ready to return home, and yet they can't go home. They have to stay incarcerated because the facilities are not there or are unable to accept them.

This is another aspect of discrimination. We can go on and on, looking at housing, benefits, friendships and inclusion, look at the need for crisis services and out of hours services, look at the need to be valued and loved and needed and occupied; these are all aspects of and consequences of discrimination in the lives of the mentally ill.

Let us look at the **principles of equality and diversity**. To have this would be great, but let us remember that, along with the rest of society, we have a long way to go.

Have the mental health services really acknowledged, responded to and accepted that the very concept and perception of mental illness varies across different cultures?

Have the intensive psychiatric care units responded to the isolation and fear that many women feel in such a places; being the only female patient in a disturbed and frightening environment must sometimes be a horrendous experience.

Have we responded to the different sexualities of different people? Are they genuinely welcomed by mental health services and their clients? Is there not still a touch of medicalisation of the distress caused by the everyday prejudice such groups can face?

Lastly let's look at faith and religion. For many of us faith is a sanctuary and a salvation, especially when we reach points in our lives where it is hard to see meaning or joy or hope.

For many of us, our illness involves a distorted but still important aspect of faith; we may feel that we are possessed, we may feel that there are spirits around us and yet how much training do our spiritual leaders have in this aspect of our lives? How do some faiths react to suicide? How do some religious communities react when we fail to see joy in our salvation? How do the medical professionals react when we gabble about our perhaps confused view of our own spirituality? Do they listen and counsel and refer to those that can help or do they dismiss this as an embarrassing aspect of illness?

Reciprocity is of course the big principle. It is painfully self-evident that if you deprive someone of their freedom when they have committed no crime and not been at fault that you are obligated to them and need to make some form of fair provision to them.

I would take it further and say that we have to look at the present attitude of society to people with a mental illness. Society seems to be content and to find it convenient to accept that a large proportion of the mentally ill will never work, will spend most of their lives on benefits, will live in poor housing, will be seen as antisocial neighbours and a threat to communities, will have little to do and few opportunities to use the abundance of talents they undoubtedly have. We often have little to look forward to or to hope for, for many of us life is not a place of joy it is a dry and arid land which we struggle through; many of us are alienated marginalised and discriminated against.

In my mind reciprocity should really be an obligation by our society to rectify and provide restitution for this unnecessary and harsh reality.

In my mind, the fact that it is only relatively recently that the long stay patients started to finally leave hospital seems to be glossed over. Where are the records and the public history of the abuse of the lives of the people who spent decades of their lives in hospital? Where is the compensation for the lives that were ruined by ill conceived principles of treatment?

At the very least look at the lives many of us lead; twilight lives, lives where our expectations are so low that a coffee can be the big event of the day, lives where it is so hard that to think of hope at all can be a dangerous thing. At least when we look at reciprocity, at least, when we have been discharged from hospital and possibly our sections, don't put the effort into just maintaining and containing us in the community, look to recovery, look to our talents, help us create our own opportunities and liveable lives.

There is a principle that we should get access to care without the need for compulsion. Well, of course, but for many of us this seems laughable at present and a great thing if it were to become a reality. Where do we go to in the dark hours of the night? Who do we turn to when life is desperate and yet the joys of a Friday evening beckon for those that usually help us? What do we do when we need to talk? To find understanding for what we are going through and know that the wait to see a psychologist will last over a year? What do we do when we have built up a trusting relationship with a psychiatrist, someone we have faith in, and they move on yet again and we have to start all over again?

The paucity of what we can access, the lack of continuity and alternatives and a widespread distrust of such services by the wider community mean that we often don't get help when we need it or how we need it, and can only lead to situations getting worse and detention becoming more likely.

The principle that we should be involved as much as possible in our treatment, have our wishes respected and be given the information we need; this is so good and in a reasonable world would seem to be a matter of common sense and common courtesy, but let me give you some simple quotes that outline the task this principle involves.

"I do have problems but not all of my experience is meaningless – I want a chance to make sense of my experience rather than have it dismissed."

"Conventional psychiatry doesn't acknowledge my reality and yet Joan of Arc heard voices and she's a saint."

"I dress and look different; my clothes are good quality and in good nick but staff interpret this as bizarre behaviour."

"They (staff) are a different class of people – their world is mortgages, bills, my one has been where I had to steal for food. There is no meeting of minds. They don't approve of drugs – I think they are no worse than alcohol – mild drugs are ok – there's a complete culture clash"

We do sometimes live in different worlds with different values and different experiences. In order for us to participate and be happily involved in our care and treatment we need to build durable bridges that connect our different worlds. It is really only when we connect and make respectful and honest links with each other that involvement and participation becomes meaningful.

We need respect for carers. This is so important. Most of my everyday life is spent with my wife and son. I live and share my life with them because I want to and they are more important to me than anyone else in the world. They certainly surpass any member of any community mental health team who may be concerned with my care. The professionals that I know are valued assistants in helping me lead my life - my family are the very reason that I still enjoy living and want to remain in this world. They are the people I turn to, - the people I wish to give to, - the people I want to grow old with.

So when it may sometimes be easier for an unknown professional to hear about and influence my illness and treatment than those that are most dear to me, I feel angry.

Of course they should be involved, of course they should get information about me and - of course there are times when those that care for us shouldn't get that information about us, but those times are the exception and not the norm.

Whilst it is certainly changing we do need to move away from those days when carers were seen not only as an irritation, an awkward add on that may occasionally need grudging support and away from the feeling that they are people who were responsible for our illness. We need to move away as far, as is possible, from the atmosphere of blame and exclusion that so many carers have and unfortunately sometimes still do experience.

The idea of the least restrictive alternative is a very dear principle and limits and reduces the agony people may experience.

But let us consider the reaction of the person in crisis whose door is broken down by the police and surrounded by a collection of psychiatric staff, let us feel for the person forcibly removed in front of her family, let us understand the pain of a mother watching her children being taken away from her because someone judges her incapable of providing them a safe home or maybe we should remember those people who, in the confusion of illness, speak loudly, flail around and disturb the neighbours and end up in the cells or even those who cannot be catered for anywhere other than a police station. Or just the feeling of being restrained and injected against your will.

How would they all react on being told that what was done to them was the minimum, was the most reasonable and humane thing to have done; will they understand and forgive?

I have talked about many of the Millan principles, they are good, they do offer us a better and more just life they seem to enshrine respect for the world of users and carers and to acknowledge just how important a step it is to take away a persons liberty.

And, of course, I have interpreted them very, very loosely or even misinterpreted them, but I hope that as we set the scene for what we are faced with we can one day find a way forward.

The realities and the indignities that I have described cannot be laid at anyone's door. They are a culmination of the long and often unpleasant history of our treatment in this country. They are also the stark reality of what we face in our everyday lives because we have unpleasant and sometimes horrific illnesses.

What I can say is that the more I meet people concerned with mental health the more respect I have for them.

The company of my fellow users, is where I feel most comfortable, the camaraderie, the mutual respect, and the willingness to reach for the unattainable and to continue reaching just in case it helps those that come after – this is irreplaceable.

But equally you as workers, most people I meet who work in the various caring professions have not done it for the career and the money and the security, most people do it to relieve suffering, to reduce injustice, to help guide us on the route to a better world. Many of you are also carers or users and will be all too familiar with what I say. What I don't understand is the fatigue that so many of us have when we look to the future, so here are a few final possibly patronising messages:

For the government and the Executive, if mental health is a priority, then let us see it treated that way, let us really see the investment continuing to flow into such a vital service, let us see more and more new initiatives paving the way creating new and exciting ideas, let us see those services that we know work have the freedom to continue to do so without fear about their future funding, let us make investment and services tangible and visible in the very streets and communities we all live in.

For the managers, sometimes I feel that you are caught in the worst of all worlds but I would ask, is it professional to agree to replan and refocus every few months with limited resources to do so? Is it at all fair to try to shift resources in an already stretched world to meet the latest policy? Is it fair to ask users and carers to select priorities for the future when the prospect of change is limited and may adversely affect other groups?

Perhaps one day we will hear people like you saying “no”, saying “I will not agree to plan for the future unless there is a meaningful prospect of the plans coming to fruition and actually benefiting those of us who live and work at the grass roots.”

And for the clinicians and healers and helpers, remember you are working in a hugely important area; to accompany those of us who are journeying out of the deepest despair, to provide warmth and encouragement when we have lost the belief that that is possible. These everyday actions are a unique contribution to make to us and our society. Remember and have faith in your skills and the importance of your contribution and when you see the injustice of our lives join with us in challenging and changing it, don't keep silent. Your work is not just about therapy, it is not mechanical and routine, it is providing a glimmer when we can't even see, and it is about joining with us in one of the great causes for social justice that we face in this country.

And lastly the new Mental Health Act will be a success and will deserve to be celebrated if it becomes possible to section people like me with love, and for people like me to feel that love and, in retrospect, to want to thank you for what you have done on our behalf.

Thank you for listening