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**A USERS VIEW OF THE MENTAL HEALTH ACT
- 9 MONTHS ON - JULY 2006**

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Hello,

As has been said my name is Graham Morgan and I have been asked to give a users view of the mental health act and how it has been operating in Scotland over the last 9 months.

I have a diagnosis of schizophrenia but generally live a fine and satisfying life. I was sectioned twice about a year and a half ago and apart from that have only once been subject to compulsory treatment but that was many years ago.

I am the Advocacy Project Manager at Highland Community Care forum and spend nearly all that time working with the Highland Users Group (HUG) which represents the views of people with mental health problems in the Highlands. HUG was involved with the review and development of the Mental Health Act. If you want to see our member's views on it do visit our website at www.hug.uk.net.

I am going to give a selection of views about the Act that I have gathered over the last few months and then I will reflect on my own ideas and thoughts and how I believe that the act will hopefully come to signal a cultural change in our treatment.

I always struggled with the work of the Millan Committee which initially reviewed the Act. At its heart was the debate about our right to freedom and our right to treatment even if we do not want it.

I have never come to a comfortable view on this subject. I have witnessed too many of my friends being kept safe and secure through the use of detention to glibly accept the arguments of some of my fellow users that a section can only be seen as an abuse of our human rights - being sectioned does save many lives, mine included.

And yet, I am an articulate confident person with as much right to live an autonomous life as anyone else, even if my thoughts do seem strange at times, maybe they are an aspect of my existence that no one should have the freedom to interfere with without my consent.

Maybe people like me have a right to the sort of unconventional erratic but unsafe lives that psychosis can produce. Sometimes I yearn for the

liberation that comes when respectable thought and responsibility is abandoned, it can be such a struggle trying to remain normal and respectable - maybe the risks that we lead when we try to remain true to our own personal visions should be accepted despite the pain they cause those around us.

When the Act was launched I felt, despite my confusion over the restriction of our freedom, that we had produced an Act with a good balance between the principles that promoted our rights to respect, equality and participation in our treatment whilst acknowledging that at times we do need intervention against our will from those who care for us.

Over the last 9 months we have all been keen to see its effect. The things I have heard are not particularly surprising but some of them include the following:

First of all there is no getting away from the fact that to be sectioned is a blunt, intrusive and traumatic way of dealing with mental distress. To be in the extremes of emotion where there seems no way out of the confusion of life; where the tethers of reality have stretched to leave us abandoned in our own strange country, to be lost in an alien world and surrounded by people who say that they want to help but whose help we do not trust or desire, to be frightened and alone and then to find that people are going to force us to conform to the treatments that they say are good for us and which we have already rejected, - then this can be truly shattering. We do not understand and we feel that we are being coerced and forced and channelled and bullied and in our minds is the refrain of "what have I done wrong" - "What rules and laws have I broken to deserve this?" "Why is it happening?"

And there is no denying that this resounding shout at the perceived injustice of it all has not changed at - the central message is that in some ways little has changed - we still get sectioned - in fact, in the name of improving our ability to exercise our rights it is beginning to become more common now to be treated on 28 day sections than the 72 hour one; this seems, to some of our members confusing - the perception we have is that in the past we could look forward to just three days detention and now are expected to endure four weeks so that our rights can be

protected. A section is still a section; our freedom has still been taken away, despite all the safeguards and principles of the new Act.

But then again, there is no denying that when we rejoin conventional reality many of us can see the benefits of having been sectioned and may, in retrospect feel deep gratitude at what had once seemed to be an unwelcome and unwarranted intrusion into our lives.

Apart from that we all wish that an act such as this will run smoothly and allow for better treatment and an improved quality of life for all of us - what I find confusing are the numerous reports of how much more bureaucratic the Act is; with forms having to be filled in left, right and centre.

We hear that this makes it harder to provide direct services to us because our Psychiatrists and Mental Health Officers are so busy writing about us or attending tribunals.

This seems to be the exact opposite of what an Act such as this one is trying to achieve. It is easy to see that if we need to enhance and preserve our rights and treatment that more needs to be written down but surely not to the extent that we find the services we want and need harder to get. We need to be sure that the effort to prove that our rights are protected and our care provided doesn't detract from the daily support and advice so many of us need.

In Highland we have lost some mental health officers partly because the focus of their job has changed and partly because there is no increased remuneration for the increased responsibilities and work that they have to do. This means that there is a greatly reduced service in hospital but has also led to one of the things we really feared when the Act was being developed. The increased pressure on social work to deal with the act means that some of our members who are not so seriously ill have been told that they can no longer have the service they used to have because there is a greater requirement to deal with people who have been detained. This is very wrong and makes us wonder why the Executive didn't forecast it and allow for it when allocating resources for the implementation of the new Act.

There were a number of new measures in the act that we welcomed.

One of these was the creation of mental health tribunals which we had hoped would decrease the trauma and formality that people used to experience when they had to appear in court. We are very happy that some of our HUG members are lay tribunal members; this is a sign of a change in attitude to us as users and what we can do to contribute. However we do hear that, on occasion, some tribunals can be quite confrontational which may defeat their purpose - anecdotally - we hear that the legal people who chair the tribunals can sometimes be one of the causes of this and that they have maybe brought in the culture of the court room to what was meant to be a safe space. However at other times we hear that users feel glad that they have had an opportunity to have a genuine say about their treatment.

As the Act was being developed we were very pleased to hear about the development of advance statements. Our members are very, very happy that they exist; the idea that we can have a great influence, when well, on our future treatment is so appealing and reassuring but, when we look at our membership, we find that very few users have adopted them.

I certainly haven't, even though I know that it could be very useful for me if I did. I would hope that in the future they become a key task for workers to encourage us in when discussing our treatment.

Advocacy is now a right which is great. So many of us can reach states where we feel that not only do we find it hard to express ourselves but that even when we can speak out that we are not heard. When we look at our network we find that there is a wide knowledge and appreciation of Advocacy Highland which is our local Advocacy Service.

To have legal representation when your freedom has been taken from you is a basic right and yet, it is only now, 9 months on, that we have found one solicitor within the Highlands willing to represent people subject to the Act. I believe that this situation has occurred across Scotland.

Hopefully it is just a blip with a complicated Act but it is a pretty bad blip to have occurred and has deprived people of a voice at crucial times in their lives.

I would hope that these are all teething problems to an Act that needs to flex itself and settle into a routine where its operation becomes easy and

manageable. We all need to learn and grow with it whether we are users or professionals.

The bit that really intrigues me is the cultural changes that the Act may signal.

When I was on the Millan Committee I gave a talk saying that the idea of impaired judgement was something that we need to be careful with. When we are very ill we may be completely incapable of making decisions on some aspects of our lives. For instance it may be obvious to us that everyone can read our thoughts and that we need to protect ourselves from them. Other people may disagree with this but they may not disagree with the fact that we do know what we want to eat, we have clear ideas about what treatment we do and don't want. We know who we want to visit us and who we don't want to see. Our judgement varies according to the subject being discussed and with the hour day and week that we are in. It must be very hard to decide how impaired our judgement really is especially when we look at some of the eccentric views some of the sane members of our society hold about life and so on - I remember a recent newspaper article that reported that some of the more extreme Christian faiths believe that mental illness is caused by demons and possession and can only be solved by God. That attitude fits quite neatly with my own beliefs when I am regarded as psychotic.

What I really want to talk about is the act of detaining someone.

It seems to me that it is seen as something that professionals *do* to us as users.

We are seen as passive recipients of an action that we have no control over.

By entering an altered reality we are seen as incapable of making sensible decisions; we are often seen as unaware of the effect of our actions, as people lost in an alien dimension whose voice is suspect and, for some of us, on some occasions, this is no less than the truth and, because we are in a frightening unsafe world, someone with the right to make such judgements about us, assesses us and decides that we need detained. We have some rights but I would guess that the attitude of many professionals is that they are intervening because we have lost the capacity to make any sort of reasoned judgement.

They are taking control of our lives, hopefully for a short period, before we are back in a place where we can resume normal life again.

However we all know that it is not as simple as this - when I was sectioned a year and a bit ago I had been put on a new drug that didn't work and had, as a consequence, stopped sleeping for any more than two hours a night.

After a few weeks the ideas that I had became more and more confused, and by some strange inversion I began to become frightened that I would die if I did finally sleep, I started to think that I would reach a clarity and purity of vision if I could resist sleep and I also gained a strong desire to cut my wrists in a cemetery of our old hospital.

I had a grand plan which involved persuading my Psychiatrist to let me do this in the company of a nurse who could bandage me up so that I didn't bleed to death.

It seemed to me to be the height of common sense; by letting out my own bad blood I thought I would lay to rest the sad spirits of all the lonely people from the old hospital. The psychiatrist I saw begged to differ and I ended up in hospital.

We could say; silly old me, the things that you do when you're ill - and it was, it was silly to hope for that but equally, I knew in my mind that my preferred option was only one option, I knew that there was a risk that I would be asked to go into hospital and even that there was a risk that I would be sectioned.

When I talk to some of my fellow users they also say that there are times that they are aware that there is a possibility that once they have said or acted on their feelings that they know that they might be sectioned. Not all the time but some of the time.

When I become ill I lose my grasp of what is healthy and unhealthy and I become consumed by strange and unwelcome ideas that I usually manage to keep submerged and hidden from myself but it is not like my brain has completely crashed, I still make judgements for good or worse and I still

have intelligence and awareness - it has just become distorted in some areas. I am a relatively intelligent and articulate person who is used to living in a world which is generally full of equality and respect.

I feel that, occasionally we become partners in our own detention; perhaps we haven't signed up to it with our souls and our hearts but we can have a fairly good knowledge of what could happen when we spill the strange visions that we have.

On admission to hospital I agreed to give over my razor blades and made a commitment not to cut myself for three days. This was reached by listening to my key nurse who said that if I trusted the staff for this amount of time then I would surely feel better and stop wanting to harm myself. However at the end of the three days I still felt betrayed because, feeling that I had kept my part of the bargain, I felt that the staff should surely let me proceed with my desires now that I had proved that my ideas were still solid. The feeling of betrayal was real and bitter but equally there was the background hum in my mind that said they had no option but to put me on the section that they did. In a way I had to make a point of principle that would allow me to keep faith with my beliefs however unpalatable they were to others.

After the initial days of restriction I was given more and more freedom until eventually I came off of my second section. During this time I remember leaving the ward on a particularly stormy night to buy some razor blades from the shop.

It is a sign of how obedient I usually am that I walked back into the ward some time later soaked to the skin after the police were about to be called and minus any razor blades because the shop was shut.

Here, I suppose I have to say that all the section had done was to give me some fairly clear rules of conduct; I had so much freedom in the ward that if I had really wanted to then it would have been very easy to damage myself. It gave me a cocoon that allowed me to keep myself safe.

However we are all aware that it is almost impossible to prevent people from damaging themselves when in hospital if they are determined to. I

certainly succeeded in the past despite having a nurse within arms length of me for two weeks.

For me a section sets certain boundaries - it gives *you* freedom to intervene in certain ways and it tells *me* what is expected of me - you may be able to change these boundaries but, in the main, you need cooperation from people like me who are being sectioned or else it becomes impossible to enforce. I am an active partner in the process and have, in a way, to silently agree, without admitting it, to the section that you have imposed.

I may do this because I am ordinarily a very conventional person who usually obeys the orders I am given,

I may do it because I am proud and need to be given the dignity of acting out strange beliefs in a safe environment, I cannot reject those alien frightening thoughts, they may be a large part of my self image but equally their consequences may frighten me.

I may be in the position where again pride and autonomy comes into play again and it is just too embarrassing to ask for help, it is better for my self esteem to have it imposed on me.

I may need to refuse help for my situation to be recognised for what it is.

I may just be negotiating the best deal in an uncomfortable situation.

Whatever my reasons and they may not always be apparent to me at the time, I am also setting boundaries and rules with which I will either co operate or not.

The section itself is sometimes meaningless, it is the unspoken and unequal contract and agreement that I make and my carers make, to make treatment occur in the way it does. We are learning and acting out new and sometimes alien roles in our hospital stay and without a shared understanding of what we are trying to achieve when we all agree to remove my liberty, we may all get it wrong. To see us patients as completely passive is a mistake, we may not understand what is happening to us, we may find life totally bizarre but in some fashion we are participating in what is being done to us.

We are active partners and sometimes in an incredibly inverse perverse way willing partners when our liberty is removed.

This is where I think that the new Act will have far reaching implications for our treatment. Once we realise that we are all participants in the event then we need to establish a dialogue.

This happened with me when I was about to be released from my section; by then I had grown used to it and felt safe and protected by it, but I didn't feel safe in myself - it was only by keeping the section alive unnecessarily for a couple more days that I found myself back at ease with my regained liberty. On occasion that much derided smear of paternalism is actually valuable - it allows us to be looked after and protected when we have lost the ability to do so ourselves.

I suppose that I see this new Act as enhancing this dialogue and partnership.

The principles that underlie it reinforce and make crystal clear the need to respect us and treat us as fellow humans deserving of dignity and respect entitled to participate and have a say in what happens to us at all points in our treatment.

I have no idea how to measure this change and it is not just legislation that causes it but I have seen it happen to me over the years, nowadays I see my psychiatrist as someone that I trust rather than fear or feel suspicious of.

When I was last in hospital I was given such a degree of freedom that at first it felt scary but equally it gave me responsibility and autonomy which you lose and miss so dreadfully when all your control is taken away. I think that giving me freedom and taking risks with my safety contributed greatly to my quick recovery. I don't know how much that applies to my friends and acquaintances but do know that some at least would share those views.

The shift in expectation is complex and difficult for me to grasp solidly I suppose that it means having faith in each others expertise and believing that with this faith we will all have better outcomes and be less suspicious of each others motives.

To illustrate the complexity; one of the Millan principles says that we should have the least restrictive intervention. On the face of it that seems completely reasonable and understandable - but who decides what is the least restrictive? Some of us, as users, can reach states where we

want, for whatever reason, more than our helpers think we need. Should we get what we want or what the professional experts feel we need? Equally we should all be able to participate; but what we, as users, think of as participation and what we want to participate in, may be very different to what our helpers believe we need.

It is this belief in us and in our need to be listened to and respected in the whole variety of states that we get into that will determine the success and changes our act may stimulate. That and making sure that the bureaucracy of it and the resources allocated to it allow its precious vision to become a standard part of its practice.

Thank you