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PERSONALISED CARE AND THE CONTRACT CULTURE.

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Hello, thank you for asking me to speak to you today. As has been said, my name is Graham Morgan and I work with the Highland Users Group or HUG as we prefer to know it.

Hug is a network of people with a history of mental illness spread across the Highlands. We have 380 members, which, considering the number of people with a mental illness is not many but when you think of those who are happy to join in with changing the world one tired step at a time is quite a lot.

We have two parts to our work; HUG 'speaking out' where we look at those elements of our lives that we find important and want to comment on and HUG 'stopping stigma, raising awareness' where we try by working with; young people, the media, by providing mental health awareness training and promoting creative expression we hope to reduce the unbearable weight of the anxiety and prejudice that so much of the rest of society has about us.

It is good to be part of a group that we know without a shadow of a doubt is having results and making the world closer to the one we think we want and it is good to come to conferences and talk and try to get the voice of our members heard.

HUG is a project of: **Highland Community Care Forum**  the voice of users and carers

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But personalisation and contract culture? I think I first heard those phrases as an accepted vocabulary on the same day that I was asked to give this talk.

I am not going to be so clever as to pretend that I am so immersed in the policy world of our future services that I can give you acres of wisdom about concepts that are relatively new to me but maybe I can give a few perspectives that my friends and acquaintances might feel comfortable with and you can draw whatever conclusions you want.

Last night on the train I was reading some British Government paper. It had lots of fine words and numerous references to the bright new future of personalisation and throughout it, it kept on saying:

“you told us that and so we did” whatever it was they did

and I pause here, because I wonder who it was that told the government these things. Who represented my views and who decided who I was? I suppose that there is a body of evidence that people like me said various things to the Government and researchers and the various consultants who occasionally come out to trawl us for our opinions but frankly ‘personalisation’ it may be a good thing but I would guess only a couple of other people in our entire network have heard of the word ‘personalisation’ and that, like me, they have only a hazy notion of what it means and yet we get this fine new future because, without knowing that we had, we told the government that that is what we wanted, and I am sure that this is right because you are all very important people here and you all know about ‘contract cultures’ and ‘personalisation’ to your back toes and it is in places like this that the debates about our futures as users and carers are dealt with and settled.

But, and I hate to keep labouring this point, who among my friends, acquaintances and colleagues across the mental health user movement in Scotland have been the catalysts for ‘personalisation’?

In the back of my mind, I have inklings, that there may be a disability lobby that speaks on behalf of people like me, but I pause a little here because, whilst I have no doubt that there is a mental health community I know that it doesn’t speak on behalf of the learning disability community and it wouldn’t dream of knowing the issues and cultures that affect the deaf community. Is it possible that the ‘personalisation’ debate found its roots in the world of physical disability and personal assistants. Things that I have such a sketchy knowledge of that it is a universe from my experience of schizophrenia, or maybe it’s the voluntary sector is that it? Or the academics? Or the politicians?

I am just intrigued, as we have a whole new realm of social care developing and it may well be just what I want and it may be just what I would have asked for but I

really am not aware of anyone in the mental health community of users being asked whether they wanted it and yet the documents say its what we want when we never knew we asked for it. It's just a wee bit perplexing.

However, of course, in many ways it is what we may want. I have a friend who has learning disabilities and mental health problems. He comes to visit me in hospital when I am ill and worries about me when people put me on constant obs. He is always taking trips in to town, wandering around the hospital, attending conferences, just generally joining in with the world, having his say, getting to know people. Being him. Soon he will have a house all of his own and in it he will have 24 hour care provided by a voluntary organisation.

I sometimes wonder to myself how many thousands and thousands of pounds it has cost to build him a house and provide all this vital support and then I pause, because hang on! How much money is he allowed to spend as he wants each week? £5.00. If you squeeze it out, he could maybe afford a coffee in a café three times a week, its just as well he doesn't smoke or drink or buy music or books or nice clothes , it's just as well his friends don't expect him to ever put money in for a biscuit or cake to go with the coffee he gets in the café three times a week.

Then another group of people who all live in a residential home run by a voluntary organisation, a really nice crowd of people, ranging in age from their thirties to their sixties. Some of them have held paid jobs for years in the past, some of them do voluntary work and some go to college. But if ever they go out for a social time at night they don't have their own wallets or money, they are given money between them in a bank bag and one of them is made responsible for paying for everything and getting receipts for everything that is spent. Buy a fish supper or a pint of beer then panic sets in as the search for receipts goes on to prove that they spent the money in the way that they should and I'm sure that if any of you go out to the pub after this conference or buy a bag of chips on the way home you will faithfully collect the receipts to show to your husbands and wives on your return just like they do any time they go out for some fun.

Lastly there is a nursing home near me for people with a mental illness. It's a private one and when people with a certain reputation come to stay their bank cards are taken off of them and kept by the staff just to make sure that their bills are paid at the end of their stay. This means that if a grown man wants to go to the pub in Inverness because he likes a drink and he has the money to pay for it he is stopped from doing so because the home wants to be certain that they will get their money whatever this does to his dignity or quality of life and of course we expect this when we go to a hotel or a restaurant don't we? The staff will decide what we can and can't drink and eat and where we can go to eat it, before agreeing to serve us.

So yes, to be in control, to have a say and autonomy, to have that precious freedom to make decisions for ourselves, to sit back and say;

“its my life, my service, my rights , my freedom, my voice.”

This is fundamental to our sense of who we are and what we do with our destinies. To sit down and say

“with this budget I will pay for this and this and this”

and, with the rational sense of being a sensible individual or even a not very sensible individual I will make my existence and my life will be truly mine. I will get up when I want to, go out when I want, buy the therapies and services that I want and it will be embedded in my individuality because who better than me to know what I want or need.

And yet in my world there are times when I am not sensible. If I were ill I would spend all my money on exorcisms not on my own detention. If I were ill I would sack my helpers and if not fail dismally to instruct and manage them and, to be honest, even when I am well, I would spend a budget; not on company and nurses and talking treatments but on alcohol, literature and sailing.

Silly examples of course and, to give us all opportunities to take risks is fine indeed, but some of our risks and our pleasures in a world where insight varies would land me smack into the world of psychosis and breakdown again.

I don't know, there is something uneasy in my mind, its knowing that there are services that are vital and hugely important but not the first choice for our income. Just as the public doesn't want to spend money on mental illness but does on children with horrid illnesses, so can I see us avoiding drop in centres, forgetting the bright light that company gives us.

I have this horrid recollection of people with learning disabilities who in the so called liberal name of inclusion are housed away from their friends. Somehow it is wrong for us to mix with people with similar experiences and needs to us, having friends who share our views and experiences is somehow being put into our own well meaning ghetto, so those that know better than we do make sure we get support away from our old acquaintances.

People wake up when their support worker arrives, get taken to the shops, watch telly, get help to cook a meal, watch telly, go to bed wonder whatever happened to Sandy or Alex or Danny. Wake up, watch the telly, think how nice it would be to meet some friends in the pub, watch the telly, get taken out to do the shopping. This makes us independent, this makes us individuals like everyone else.

I just have this disinclination in my soul. We all have to be independent, make our own decisions, control our own lives, speak our own mind of course we do that is right and proper. But this assumption that independence is the be all and end all of everything that someone with a disability should aspire to fills me with qualms. Surely we are all interdependent, we make decisions together and have obligations to each other, we are parts of communities which rely on and support each other. We pay tax so that different things can be done on our behalf, because we are part of society and I worry about something that hives us off, takes away our mutual reliance and obligation we all have on each other, on acquaintances, friends and even enemies. We are part of a community and we need to balance the needs of our community with the needs of us as individuals in that community.

Now a sudden change of discussion; the contract culture, and I agree there must be a huge tension here because personalisation is seen as so good and contracts as far as I can see are yuck.

It is easy to see our Commissioners in Health and the Council as the baddies but they aren't, I wish I knew who the baddies really were. Maybe it's us in the voluntary sector for unrealistically wanting so much when there is nothing to give.

When I think of the contract I work to, I think of commissioners I see regularly, who in other existences are paragons on the side of users and carers, whose ethics and experience and understanding of what we go through outshine my paltry understanding of our lives. It is not that the people who draw up our contracts are out to get us or do us down or exploit us, it is not as though they are these hard, hard negotiators there only for the complete exhaustion of the voluntary sector.

It is the simple, horrible, undeniable fact that there is far too little money for us to do the job and with a voluntary sector full of idealists for the changing of the world and social workers and nurses and doctors in the statutory sector also desperate to change the world too we find contracts that get tighter and tighter and tighter. If only we could do this and this and this and if only we could provide that, and then there is the horrible, horrific understanding that the money to let us willingly work to the limit will never be enough.

In those circumstances you can see how people like me can grow to hate our funders maybe without good reason but with very understandable reasons, not being able to afford the paper to send out the latest report, not being able to buy our members sandwiches when they spend a day working with us, not being able to attend conferences or training or to pay the expenses that will allow our members the time to spend days doing voluntary work with us makes me sick to my stomach and even more.

Having so much nailed down, measured, demanded. Targets and outputs and outcomes that are so strict and all encompassing that they stifle our creativity, our innovation, our joy, our ability to deliver because we have always done our jobs for the love of them not for the money or the reward of an easy job. This makes me so, so sad and angry.

When you ask what our members say about personalisation I don't really know because they have never heard of it but I have given some examples of the restrictions that they face without it and some of my half formed thoughts.

When you ask about contracts I know our members are weary and unfortunately our funders are not familiar as people to them. They just assume that our existence will always be precarious, that we will have to fight for every penny and that every activity we manage to do is a hard won privilege in the face of the statutory sector.

This is not healthy as it pits good people against good people and allows tension to grow where ideally it should have no ground to take root in because, as far as I can see, most people in this field are dedicated in their own way, whatever their background.

My biggest worry is that we will drive hugely important voluntary organisations to the wall with the contract culture we have developed and the recession we have inherited and where we don't drive them into the ground they will be forced into the route of poor practise because they need to continually cut the worth of what they can offer purely by being the voluntary sector with all its ideals and shared values just in order to survive.

My dread is that as personalisation grows and individual budgets develop into major forms of expenditure that the harsh negotiations of the commissioners we face will be replicated or even replaced by harsh assessments and negotiations on individual people who are often not in a position to bargain with the resources that keep their lives liveable . That the scourge that is hitting the voluntary sector may be carried on into a brutal bargaining over the lives of vulnerable people that may ruin the principles of personalisation and make life harder and harder for those that want so much to live lives of autonomy and control and self direction.