

HUG
Cromwell Villa
23 Lotland Street
Inverness
IV1 1ST
Tel: (01463) 719366
Email: hug@spiritadvocacy.org.uk



**Self directed support and mental health
Inshes church
Inverness
19 november 2012**

Hello

My name is Graham Morgan. I work with Hug (action for mental health), which is a group of people with a mental illness that campaigns for better lives and services for all of us. I have a diagnosis of schizophrenia and am detained under a compulsory community treatment order.

Today Heather and I are going to speak from differing perspectives about self-directed care. If feel a senses of unease because many of the things Heather will say I agree with and vice versa.
Let me make a start on some broad issues.

To my mind, at its philosophical heart, self directed care has key messages of

- Control
- Independence
- Choice
- And autonomy

These are mantras that we are bought up to believe should underpin all services and all notions of care and, for many years we, as people with mental health problems, have said and still say, that one of the problems we face is the lack of say and control and autonomy we have in the way we live. So something like self directed support should surely fulfil our aspirations.

I am going to spend a few moments talking about why I think this is not what we always want and then I will go into more detail over the issue of self directed support.

To be in control and to be independent are fine sounding words but are they aspirations we all want to achieve?

Take illness or even impairment due to mental illness. One of the features of mental illness is that we do on occasion, lose control, we do lose the ability to make decisions, to argue rationally, to see clearly to the goals we might want to achieve. When we cannot make even the

HUG (Action for Mental Health) is part of SPIRIT* Advocacy

***Strengthening People In Raising Issues Together**

SPIRIT Advocacy is a Company limited by guarantee. Registered in Scotland no. 404409

Scottish Charity no. SCO42513

Registered Office: Cromwell Villa, 23 Lotland Street, Inverness, IV1 1ST. Tel: 01463 719366

simplest decision about what to eat and when to get up and how to do the shopping, when we seek oblivion or even death, when we are bewildered by a whole legion of conflicting memories from our past and anxieties of the present we can find ourselves uncertain and vulnerable. We can hesitate and shrink inside ourselves from the mechanism and reality of daily life.

At these times which may be temporary or longer term we may desperately hold on to the last vestiges of control in our lives in an attempt to preserve our identity and reality but often we seek a place to lay down our burdens.

When we cannot see a few hours ahead let alone a week ahead we may say; give us the sanctuary and safety of hospital where, whatever its failings, we can feel safe for a time and looked after and protected and cared for, or we may throw up our arms and say to our c.p.n. or our support worker or the drop in centre or our friends; I am tired, I cannot go on, please, please, give me respite from responsibility and control.

Please let me come to that place where, for a time, I no longer have to make decisions or strive to succeed or be responsible.

At these times being forced to be in control of our treatment, our lives and our destinies can be the last thing we want.

At other times, when faced with the complexity of the worlds we have entered, where we do not understand the benefits system, the care system, the illness system, where even the names of the people and medicines and treatments that help us are alien. Where our diagnosis is fraught with confusion. In this world we may reach out to understand and make sense and cope with the multitudes of bureaucracies with their worlds of rules and attitudes that we do not understand and at these times we may say, above all, listen to me as an individual, as a person with needs and views and opinions, but to be in control at these times?

At these times we often look for partners and guides and allies to whom we look to, for advice and direction. We do not necessarily want to determine for ourselves the best thing to say to get d.l.a or even to find out that we are entitled to dla, we do not necessarily want to decide what our support needs and goals are with our tenancy or our compliance with medication are. At these times we can want a guide who will support us to speak out for what we wish but at others we can be content and keen to rely on the knowledge and expertise of other people. At these times we want control when we are sure of our views but often we want to give up this control and to have the security of walking alongside a helper to find out and achieve what we want.

And in terms of control, some people like me, after 30 years in the psychiatric system are well aware of how it works and what we want and are familiar with our own views and interpretations of our lives but many of us, when we try to make sense of our world are beset by a whole mythology of the mental health system and, at these points, being in

control can be something we regret later. When our understanding of mental illness is based on 'one flew over the cuckoo's nest', articles in the Daily Mail, thrillers on television and late night, drink fuelled conversations with friends our initial reactions and views can be distorted misinformed and misguided. They may send us down routes of destruction we would not have ever chosen if we had been given the right information and it is at these points where we are desperate for control that we often need to pause to listen, to discover and learn from others what is the most sensible thing to do and here we share knowledge and information and decisions.

At these times we may cry out for experts to give us clear unbiased information and on occasion advice about how to approach our lives. It is at these points where we may say do not give me all this responsibility, give me the tools of navigation but don't send me on some unknown mission of self-fulfilment filled with choices and control when I have neither the knowledge nor the skill to reach it.

And that brings me to independence. The mantra seems to be that when we become known as service users we are meant to be guided to the point where we live independently, where we control our destiny, where we make our own decisions and reach the destinations we have chosen.

This is in marked contrast to reality. Sometimes I think that it is more the vision of workers and policy makers to make us these fully functioning, fully autonomous, self-reliant and non-dependant people and yet I would pause.

When you go to the pub with a group of friends how do you make that decision? Do you all split up for your different destinations when you don't agree? or do you reach consensus often guided by the most charismatic or outspoken of your friends? When you live with another person do you insist on having the final say in everything that happens of being in control of everything you do as a couple or do you seek co-operation and negotiation and an ebb and flow where first one person then the other has more or less influence and between you, you muddle through a shared journey where at some points you rely on your partner and at others they rely on you. When you work in a team, do you, in the name of independence insist that your views are sacrosanct and cannot be altered or do you sway and swirl around the subject until you are as close as can be to agreement.

I do not want to be independent in the way that services say I should be.

That shouts to me of loneliness and isolation and an arrogance of opinion that none of us should be subject to. I want to be interdependent I want my decisions and my actions to be influenced and guided and adapted and negotiated by all the people in my life and I do not make the workers in my life an exception to this. As fellow humans we have an obligation to each other to interact that may be influenced by our differing expertise

and perspectives as workers and people with a mental illness but this is ultimately built on relationships and maybe our workers may seek to make us independent and sometimes that will be our joint aim. But at other times that is confounding us with dogma and saying dependence is bad and wrong, when in fact dependence and reliance is natural for all of us but we have bureaucracies that are obsessed with throughput and recovery and employability because the longer we have a need for help, the more expensive and inconvenient we are, the more people think of failure and missed outcomes when perhaps they would do better to look at our perception of the quality of life we have and can expect to have.

In a long winded way I have just made a plea for us to listen to what we say, to not take things for granted and to realise first and foremost that we are a community of people, we share control, we share decisions . Opinions and goals are a matter of negotiation and co-operation and choices are made together taking in the needs of those around us and the society we live in. I worry that self- directed support throws everything onto the individual and forgets the needs we have as interlinked interdependant members of the community. No we don't want professionals to decide everything for us but equally we maybe don't or shouldn't have the right to decide absolutely everything for us too.

That is my comment on the philosophy of self directed support. Now for the practicalities – assessment – lets be realistic – if all people with a mental illness were able to get the care they need to help them to a better life, a position of wellness or recovery, then I think we would bankrupt the care system which, to my mind, makes a farce of the whole concept of holding our own budgets and managing our own care.

In the rich western world a paltry 23% of people with a mental illness get any care for their illnesses compared with 67% of people with a physical illness. So, yes, that would be fantastic, lets hand over the resources and manage totally on need, lets make everything person centred but we would have to anticipate a world that is very different to today.

The same applies to social care, do you really think we feel we get all that we want for our care and support? The vast majority of us don't even qualify for social care. I would love it if you opened the system to respond to what we want: respite, holidays, activity through the week, creativity, employment, support, education, leisure, help with benefits, access to what we think is therapeutic rather than what other people think helps us. Yes that would be fab but of course we are at the mercy of an assessment. We will not have control over our care unless the assessment of our needs is in agreement with how we self-assess our needs – we are being given the freedom to administer what other people agree we need - that is not self-directed anything.

On a similar point, as an active group we have often argued that we want to be able to take risks with our lives and for some of us that is so, so important but I find many of us are cautious, we want support, we want

hospital, we are often content, to an extent, with a quiet life with support and help and safety. The world of the mainstream is frightening and full of risk – it is where you as governments and workers may like to see us but many of us are cautious with our lives and content to take the risk free but expensive solution of being supported and looked after. I may be wrong with that but, self directed care may have to acknowledge that we do not all want to move along we do not all want to flourish and succeed according to the measures of others – we may have our own indicators of success that others have not yet acknowledged and that requires different ways of assessing what we want from services and life.

And of course managing direct payments – that will be really easy to do! – When I am busy obsessed with the devils that are telling me to kill myself it will be so easy to employ and direct my care staff , when people like me cannot summon the energy to fill in a benefits form it will be so easy to, to set the hours and determine the way our support is structured . And of course we can hand over this control to another agency – I fail to see how that is self- directed care; it is more like replacing one set of organisations with another – that doesn't seem like anything particularly wonderful.

And getting even more practical how do the organisations that provide wonderful services but to groups of people adapt and react to a system that doesn't acknowledge that a drop in centre or a befriending service or support in our homes needs to cater for a fluctuating group of people, not all of whom will qualify for support and many of whom the system needs to reach out to with all its got rather than asking them to pay for services from their own budgets. It strikes me sometimes that having control of budgets can be as misguided as the government giving housing benefit to us directly.

And again – we are in a world of recovery where our care and our need will fluctuate and change and hopefully reduce as we get better and do indeed gain some sense of autonomy and direction. If we have a budget that pays for a set number of hours for our support how much incentive does that support worker have to get us on the road to recovery? Each hour spent with him or her brings more income to them, each hour we reduce lessens their income – I do not see the incentive in this system, for us to move away from services and into different lives that I would have thought it should have.

I can see a substantial number of people who would like to have more say and control over their treatment than they presently have – I can think of all those people who come to us saying I have just been diagnosed and want to do all I can to get better, people full of energy and enthusiasm for recovery and not getting trapped in a system for year after year. I don't suppose self-directed care will do anything for them; first of all many of them want control of health based treatments and secondly many, many, of them will not be assessed as needing social care – it seems to me that you only tend to qualify for that when you are

already incorporated into the mental health world where your needs are such that it can be very hard to make decisions about what you want and how you want it both as a result of your impairment and as a result of how we are dealt with when we become cogs in a bureaucracy.

And two final points. A substantial number of us are now being charged for services, those of us who have assets such as property can find it almost impossible to afford the costs of support. How do you reconcile charging us for services we can't afford and at the same time handing over substantial budgets to other groups of people.

I hate to finish on a note of intense cynicism but I have been told by people in the council that any new assessment for self directed support will automatically result in around a 20% reduction in the budget allocated to that person. I hope that is one of the wild rumours that circulate in large organisations but if it isn't I fear we are being conned by fine words disguising major budget cuts.

That is the negative view

I am now hoping that Heather can give you a somewhat more optimistic picture.

Thank you