

How My Attitude To 'Care' Has Changed

This short article is a written version of the talk I gave to the staff induction course of the Devon Partnership NHS Trust at Langdon Hospital 19.4.07. I'd welcome people replying with their own comments/attitudes/ideas on how to move forward debate around service user involvement and recovery¹.

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Who am I? Sometimes I'm a 'patient', sometimes a 'client', sometimes a 'service user'; some might wish to call me a 'survivor', others someone with 'lived experience' - I'm certainly not a 'customer'! I have a diagnosis of manic-depression, which of course we must now call bipolar affective disorder - the language of mental health is a bit of a nightmare. Why am I here? Because the 'facilitator' asked me and I like her. I am a sceptic, not only towards mental health services, but towards what's known as 'user involvement'; or perhaps it's just the remorseless negativity that comes with a depressive illness!

I first met a psychiatrist twenty years ago. At the time I couldn't explain to myself what was happening to me, and looked to mental health professionals for answers. Every client I've ever met has the problem of explaining themselves to others. Weird things have been happening to you, you can't explain them to yourself, how do you explain them to others? For a start you don't have a language with which to do so. I assumed 'expertise' in psychiatrists and others, and adopted what is known as the 'sick role'; not out of passivity, dependence or deference, but ignorance of myself and the need for answers.

Over the next few years I experienced several periods in hospital; was given first a diagnosis of 'reactive depression', then 'hysteria', then 'schizoaffective disorder'. I knew I was ill, but sceptical and not a little confused! But what I remember now as having made a real difference when in hospital, was not my contact with professional mental health staff; but the 'normal' encounters I had with catering and domestic staff, and some nursing assistants. People who treated me as an ordinary bloke, who showed me simple human kindnesses - people who hadn't had the normal human responses trained out of them.

It was not until seven years after my first admission that I was diagnosed as manic-depressive. This is a label I'm prepared to accept as useful in certain circumstances. It is the best approximation to the way I am - it has some meaning to me, some explanatory power. It helps to make sense of the long periods of depression, the quite long periods of normality, the shorter periods of hypo-mania and the few weeks of psychosis, before I crash back to depression. A cycle which is only partially flattened out by medication.

¹ Please send any responses via Janet Hooper / Pennie Evans, South-West Devon Service User/Carer Network, at the Lescaze Offices, Shinnars Bridge, Dartington, TQ9 6JE, tel. 01803 861974, email janet.hooper@nhs.net / Pennie.Evans@nhs.net

Over the years I have also sought answers in various talking therapies; 'one-to-one' and in groups. But again what seemed to make a difference was not the therapeutic approach, but the personality of the therapist, how well I could get to know them and make a 'connection'.

In the last few years I've been encouraged to get involved in 'user involvement', I resisted at first thinking it would make me more pre-occupied with my own illness and reinforce the sick role. But that has not proved to be the case. I'd come to know that mental health professionals weren't very good 'experts' in my care, but neither did I believe I was. I have periods when I rapidly lose insight, and need to be monitored by others. There seem to be three strands to user involvement. Those individuals and groups who, though recognising the limitations of the experts; nonetheless lobby for better experts and services from the NHS. Secondly those who seek to 'take care into their own hands' such as self-help groups comprising people with a shared condition; the difficulty being that though they can share their own strengths, they also have the same weaknesses. Finally there is the approach which I favour, of seeking co-operation with mental health professionals, but in a 'spirit' of equality and partnership; in which care is negotiated on the basis of each person bringing different skills to the encounter.

Whatever the causes of mental disorder, its principal consequence is the breakdown of the client's relationships with others and the inability to form new and lasting personal relationships with others. Its all about fear of others. Yet those who seek to help those with mental problems are trained to remain emotionally detached. Unless I like, respect, look up to, feel emotionally attached to, or care about someone, I'm unlikely to either take their advice or seek to change my own behaviour.