

I think it's a good paper which covers current thinking and your work to date on recovery. You have touched on many issues in a paper that isn't long or just 'talk.' I will go through it and share my thoughts:

The aim of the paper is clear (page 1) There are some words/points I picked up on:

I always want to hear about what helps - (inspires, motivates, encourages, protects) others on their individual journeys. Not everyone will see themselves as having entered into recovery. For many users living with their mental distress can feel like just about surviving. It can be hard to see a progression, only 'another day over with'. A suicide attempt may be the antithesis of recovery but if survived there is a long rehabilitation and possibly an acceptance of living. From my own experience, different forms of distress can be all consuming. It's only years later I can see these most acute times as on a continuum of recovery. The 'doing whatever I can to survive' stage is still valid and there is movement back but then forward.

I do worry that services may give up on users who don't seem to be moving in the direction of recovery soon enough. Often it takes years to change - which goes against brief interventions that may be all that is on offer. The Strategies for Living project highlights 'control over one's life' and this also applies to decisions around recovery process and pace.

There are concerns about recovery and how it is applied. I think organisations such as yours need to voice concerns where users are unable to express them or be heard.

Definitions

I agree with the consensus about the key elements of the definition. I don't, personally, tend to discuss too much the language of recovery or the fact it has been accepted by services. I think it's more important to make sure that care is taken over the practice of recovery and that users, not political/financial agendas, lead it. It would be concerning and wrong for services to close, claiming that users in recovery shouldn't need them. I think in some day centres there's been lots of changes around introducing compulsory group activities which may not be what all users want. A group of centre users with severe and enduring needs may have used the place for social contact and their only meal of the day for some years. Since the purpose of the centre has changed it could lead to another form of exclusion.

I think it would be of great concern if employment numbers become a measurement of how well recovery is working on the ground. It isn't only the changes in the work place that are necessary, it's confidence and ability of the individual to sustain work that's appropriate and self-selected. There have been recent announcements around welfare reforms with the use of private companies to move disabled people into employment. I doubt that these companies will always have regard to individual recovery; the payment by results could introduce other motives.

Strategies for living (page 2)

I feel this is relevant. I would want the common themes in my life. These can sustain a user during setbacks as there's the memory that such an experience (e.g. pleasure) is possible.

Rethink research (page 3)

I think this is also interesting. I don't have personal experience of schizophrenia but think self management applies across all mental health. This diagnosis has possibly the greatest stigma.

Essentials of recovery (page 4,5, 6 and 7)

Hope, strengths, belief in the person are all extremely positive and powerful.

I understand about finding a separate identity. The illness one has been true for me of being a self harmer or an anorexic. For instance, treatment for anorexia depends on whether the individual hits a low enough weight, then once re-fed she is left alone to regain some kind of normality. Then the identity becomes a way of being taken seriously and a sense of self is lost with the need to 'recover' the anorexia once again.

I realise that within strengths there is the focus on health and wellness - you also need to accept that sometimes this can be threatening or feel inconsistent with subjective experience to a user. It depends on how much that person is struggling as to whether they can engage in education/activity or build on existing strengths. If there is the threat of services being cut then there's the fear around improvement.

Being believed in is vital and then nurtures a self-belief and hope.

With spiritual/religious faith this can feel distant or challenged in times of acute distress. It's hard to engage with, even sit through, meetings if the mind is elsewhere (I can only, through experience, refer to churches). Reading text is also difficult if concentration is reduced though groups/services are based on this. But I think it is an important and meaningful area.

Meaning - I think understanding our experiences, interpreting them, is also key. It's likely that we emerge changed but possibly stronger, more reflective and able to correct problems leading up to crisis.

Coming to terms with the past - I think it's important not to repeat patterns. But examining the past ('developing a better relationship with past traumas') may be significant for the individual. What I understand with CBT it is about current thinking and behaviour, although also how this is developed. Sometimes we do need to take a more thorough look at our lives, deal with the emotions this evokes and then move on. I think practitioners working within mental health, where trained and skilled, should be prepared to do this work rather than always making a psychology (with waiting list) referral. Past difficulties shouldn't be avoided as problems can recur. The impact of an illness/severe distress may well have been life changing. There may be losses that resulted and these need to be worked through not dismissed. Moving on then may be about reinventing oneself.

Positive identity - yes it can be a long arduous journey to build a more solid sense of self. Some people will have first experienced illness in teenage years. It is hard to remember what you were like before that time and what 'normal' is. There can be uncertainty about sexual identity or any identity at all (unfortunately this is one of the criteria for BPD).

Social inclusion - social roles in society. These are not only about being an 'employee'. I think a user needs to have many aspects to life or else if one thing such as work goes wrong then mental health suffers.

I realise the momentum of individual budgets, direct payments or In Control. However, what is offered in one authority may be very different than another in terms of cost and range of activity. A user in one area may be able to use allocated money for an Indian head massage and in another would be refused.

Empowerment and responsibility - There is a shortage of advocacy especially for the community. There are usually advocates in hospitals but it's after discharge that a user may be left alone to try to deal with all agencies. Advocates including volunteers need training and sufficient resources.

I think the notion of self responsibility mustn't be used to take away support. I saw a support worker who left to train in social work. We had different views on recovery as well as social work which she saw as 'getting clients to do things for themselves, not taking over.' She didn't understand the true meaning of 'appearances can be deceptive' (I think this is true of how I may present not conveying the problems I go through) and said recovery is about paid work,

normal life with a family. The worker didn't seem to see the value of long term work pointing out it didn't happen in other areas.

Mental health system - though not all experiences are bad ones. There are very good practitioners with the right qualities, who honour 'duty of care' and take a person centred approach.

I have had a diagnosis of BPD, but have always resisted it. I think that recovery in BPD is seen in terms of how much money the NHS is saved (emergency admissions and A&E) after intervention. Since diagnosis determines referrals then it can be difficult to find someone to work holistically.

I think the cultural contexts are also important, though I don't feel it's an area I am able to talk about with personal experience. The same is true for carer's issues. I would hope there is a strong voice from those directly affected.

A mental health worker I met recently said she had a problem with the word 'disability' for mental health. There's the opinion 'we tell people what they can do, not what they can't.' But I think mental distress can be impairment and limiting but then there should be supports to overcome obstacles, living out personal potential.

Another issue with recovery is the acceptance that it applies universally. I would have doubts about someone in prison or a long stay ward feeling that they are on a recovery journey when their environment is dispiriting. I think places and surroundings also need to change.

Recovery seems to apply currently to adults but I'm unsure about older adults or young people. More work may need to be done to develop this area and see if according to those living it, recovery has meaning. The stronger emphasis on primary care mental health also needs attention paid to how users, traditionally called 'patients', perceive treatment and their own personal development.

Recovery involves ongoing work, support through setbacks and recognition of hard work. It's about finding the life I want to live and at my own pace.

Alex Williams

March 2008