

# Getting better... Who decides?

Mark Hayward, winner of the Society's Award for Distinguished Contributions to Professional Psychology, joins with Mike Slade to discuss the recovery movement

**Readers will be familiar with the issues and complexities related to the processes of defining and diagnosing emotional and mental distress. In last year's special issue ([www.bps.org.uk/may07](http://www.bps.org.uk/may07)), arguments were put forward for the damage that can result from the categorisation of people's difficulties, and a more individualised process of definition and exploration was advocated.**

**A process that is complementary to that of defining and diagnosing distress is that of defining wellness. Having decided that someone's distress can be categorised or understood in a certain way, who decides that a given individual is getting better?**

## question

Can people who experience psychosis lead satisfying lives despite the persistence of their unusual beliefs and/or sensory perceptions?

## resources

Basset et al. (2007). *Psychosis Revisited: A recovery-based workshop for mental health workers, service users and carers*. Brighton: Pavilion

Care Services Improvement Partnership, Royal College of Psychiatrists, Social Care Institute for Excellence. (2007). *A common purpose*. London: SCIE [www.scie.org.uk/publications/positionpapers/pp08.pdf](http://www.scie.org.uk/publications/positionpapers/pp08.pdf)

Imagine that you have had a mental health crisis. Let us make it an extreme one and suggest that you have experienced a psychotic episode involving, for you, extreme suspiciousness about other people. You have spent some time in a psychiatric hospital and feel as if things are improving. You continue to feel suspicious of the intentions of others, but the medication has reduced the intensity of these feelings. Despite feeling a little bit fuzzy in your thinking, you seem more able to concentrate and to hold a decent conversation. You are hoping to be discharged at the forthcoming ward round.

You feel increasingly nervous as the ward round approaches. You have been placed last on the list so have to wait all morning to be seen. By the time your turn arrives, you feel anxious and quite exhausted. The prospect of trying to put your best foot forward and create an impression of being well feels daunting.

When you enter the ward round you see an array of faces – some familiar, others not. Everyone is looking at you. The consultant psychiatrist asks how you are feeling and you speak honestly about your anxiety and exhaustion. You want to put this in the context of the long wait, to avoid these feelings being pathologised, but you are denied the opportunity as the conversation

is moved swiftly along. 'How is the paranoia?' the consultant asks. What answer should you give? If you are honest and speak of still feeling suspicious, will this be detrimental to your hopes of being discharged? Does the consultant want to hear that your concerns for your safety have abated, or will a reduction of distress be sufficient? Do you have to somehow prove that you are well enough to return to work, or will it simply be sufficient for you to feel able to return home? If you are not considered well enough to return home, will you be told of the criteria by which getting better will be assessed? And what about this diagnosis that you have been given? How will you get rid of that?

Whilst something of a caricature of the conversations between a service user and a consultant psychiatrist in a ward round, this scenario illustrates some key questions

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about defining and assessing wellness. Some of these questions are prompted by the recent focus on the possibility of recovery from severe mental health problems. Other questions concern the ability of mental health workers to tolerate uncertainty, and implicit beliefs about who learns from whom.

### Recovery to...?

'Recovery' is in vogue (Slade & Hayward, 2007). Whether conceptualised as a process, a vision, an outlook or a guiding principle, recovery has prompted debate about mental health care for people with severe mental health problems.

The ability of people to get better following some form of psychotic breakdown is not newsworthy; it has been known for many years that the majority of such people go on to lead satisfying lives (e.g. Harrison et al., 2001). Introduced into mental health discourse primarily by individuals who have experienced recovery, the novel contribution of recovery has been to focus attention on the needs and aspirations of those individuals for whom psychotic experiences and associated distress might be an ongoing aspect of their existence. These are people whose difficulties might previously have been labelled as chronic – for whom the spark of hope may have been systematically extinguished as they were perceived as unable to 'return to health'. For these individuals, the pertinent statement might not be 'recovery from symptoms/illness/distress', as these experiences may continue. Rather, the focus might shift to be on 'recovery to...and by what means?' How to live a 'satisfying, hopeful and contributing life, even with limitations imposed by the illness' (Anthony, 1993).

For Pat Deegan, one of the champions of the service-user movement in America, recovery is about taking back control:

To me, recovery means I try to stay in the driver's seat of my life. I don't let my illness run me...being in recovery means I don't take medications. Just taking medication is a passive stance. Rather, I take medication as part of my recovery process. In the same way, I don't just go into hospital... Rather, I use the hospital when I need to.

(Deegan, cited in Repper & Perkins, 2003)

Deegan's recovery did not involve a move away from services; instead, it constituted a change in attitude towards the use of services. Ron Coleman, a significant figure in the UK service-user movement,

## Re-covering recovery by Ruth Chandler

For me, recovery is re-covering traumatic events in more and, sometimes, less hopeful ways. Getting better looks forward hopefully and looks back less fearfully. Hope would become hopeless, getting worse, if I uncovered the full fear of my experiences. Hope re-covers an unspeakable time and is intimately linked to forgetting.

In hospital, I believed I would die in my sleep and was too medicated to move my mouth. I was in permanent panic and locked inside. I pretended not to be there to survive. Memories of ward review still force speechlessness. I was always last to be seen and desperate to go home. Anxiety knows no patience, and I always presented with a panic attack. The chair was in the middle of a semi-circle of strangers. People spoke about me not to me. My distress was described as a chemical imbalance, making it unnecessary to look further. I wrote to say I was there but nobody responded. I was studying for university but was also a low-paid, single parent in social housing. Expectations reflected popular prejudice – 'If she makes a full recovery she might make it back to care assistant'. These words marked a turning point. Anxiety made room for anger. I showed competency with laundry and cooking. Eventually, I went first in review and presented as 'getting better' in these terms. I was 'safely contained'.

After discharge, I faked compliance and went through cold turkey. I experienced myself as inhuman entities but presented to the expectations of the community psychiatric nurse. Faking gave enough structure to really take back my life and the delusions subsided. I had forgotten how to write, so I did Adult Literacy. A different delusion started at university where my body was invaded by the dead, bubbling up under my tongue. My degree helped to deconstruct the evidence base and trace the sources of the voices. They were my displaced 'self' returning. This hopeful realisation gave strength to breathe the fearful voices out and draw myself in. It did not feel safe to tell anyone. I did postgraduate research on the non-being of women in philosophy instead. I have had no delusions since and remain un-medicated. My delusions were indispensable to getting better at re-recovery – far better not to have needed them.

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corroborates the need to take personal responsibility for recovery:

We must become confident in our abilities to change our lives: we must give up being reliant on others doing everything for us. We need to start doing things for ourselves. We must have the confidence to give up being ill so that we can start being recovered.

(Coleman, 1999, pp.15–16)

What each of these approaches emphasises is the ability of the individual in distress to cope with and manage their distressing experiences, then turn attention to further processes that may facilitate moving on – processes that may be directed towards defining the self in relational, social and occupational (rather than illness) terms.

In this sense, the 're' (meaning *again*) part of recovery can be misleading. For some people, reclaiming aspects of previously valued quality in their lives will be sought after. For others, there may never have been any discernable quality, so sources of quality may need to be

claimed (or discovered) for the first time. Yet others may move to a position of greater understanding and compassion (as a consequence of their distress) that allows them to look back on previously valued quality from a different perspective and acknowledge its limitations.

The bottom line? The process of getting better is defined relative to the experiences and expectations of each individual, rather than through the imposition of an explanatory model that 'privileges' symptom reduction as a necessary dimension of improvement.

### Implications for individual practitioners

If the individual in distress defines their process of getting better, how might this impact upon the practitioner – the psychologist? Sheehan (2002) describes recovery as 'an uncharted, unpredictable and personal journey'. At the extremes of such anxiety-provoking circumstances it would be understandable for the practitioner to impose their knowledge and expertise upon the situation and act

with compassion to ‘take care’ of the individual in distress and reduce possible risks – ‘you are not well and need to be admitted to hospital/increase medication/reduce exposure to stress’. Yet acting in this manner may deny individuals opportunities for learning (possibly resulting from failure) and the enhancement of self-efficacy (possibly resulting from success).

Mason (1993) offers a framework for understanding the possible benefits of working with uncertainty. Emphasising the value of not knowing, expressing curiosity and respectfully listening, Mason suggests that individuals in distress seek help in one of two states: unsafe uncertainty – where options for change are perceived as absent and they want somebody to make it better; and unsafe certainty – where the required change is known and needs to be actioned by someone else. A more productive state is safe uncertainty, whereby new explanations can be collaboratively developed and people can ‘fall out of love with the idea that solutions solve things’.

Mason’s framework is not dismissive of the practitioner’s expertise. Rather, the practitioner is seen as travelling alongside or slightly behind the client (as opposed to leading), ‘using expertise to open up space to allow new meanings to emerge’. However, this nuanced approach is often difficult to communicate to practitioners from other professional backgrounds, especially those who are less familiar than psychologists with the idea of multiple models. The exhortation to not just listen to but act on what the client says is, we observe, often experienced as de-professionalising and therefore threatening – ‘Why did I train all these years if I’m just going to do what they say?’ In combination with the lack of hope and low expectations of change which pervade mental health services (ODPM, 2004), this produces a toxic combination which results in unchallenged paternalism (‘duty of care’), high use of coercion (46,700 compulsory detentions in 2004/5 in England), and the use of psychological manipulation techniques to impose an explanatory model (or ‘improve insight’). For psychologists working in multiprofessional teams, this can create a painful experience of divided loyalties – with apparent tensions between the interests of the team and the client.

### Implications for services and the research agenda

So what does this mean in practice? Applied psychologists working with clients experiencing psychosis and other long-term mental health problems are

often well placed to undertake three classes of action which promote recovery.

First, psychologists can be advocates for individual clients. Most psychological therapies are idiographic – concerned with individual differences in preferences, values, interpretations and goals. The focus of psychologists on individual difference rather than group-level similarities not only leads to ambivalence about diagnosis, but also provides the skills to crystallise key characteristics that are specific to an individual client. Psychologists are (in the main!) articulate, and can negotiate with the team about what actions will be most acceptable and useful to the client.

Second, psychologists can support or lead local recovery-focused developments.

We list here some of the initiatives we and our colleagues have undertaken:

- | developing learning sets within teams, comprising staff and clients from the team tasked with developing a within-team change to promote recovery;
- | shaping policies of the team and the Trust, to legitimise recovery-focused initiatives;
- | providing/organising training, such as Psychosis Revisited – a recovery-based workshop for service users, carers and mental health workers (Basset et al., 2007);
- | piloting recovery-focused action planning, by amending the Wellness Recovery Action Plan approach developed in the USA (Copeland, 1997);
- | modelling joint working with service users, by co-facilitating a hearing voices group;
- | constructively challenging stigmatising or hopeless language, by identifying embedded assumptions;
- | supporting social inclusion initiatives focused on developing friendships, employment opportunities and meaningful daytime activities – domains identified by many recovered service users as vital;
- | supporting initiatives focused around

“The process of getting better is defined relative to the experiences and expectations of each individual”

spirituality, sexuality and cultural capability – key areas of self-identity and personal growth which are taboo topics in many mental health settings; and

- | changing staff recruitment policies to require meaningful service-user involvement in recruitment – not because it’s politically correct but because it provides a means of assessing personal qualities, in addition to the competency-based recruitment approach encouraged by Agenda for Change.

Third, psychologists can shape the evidence base, which is currently very limited (Slade & Hayward, in press).

If resources (i.e. staff and teams) follow the evidence, then randomised controlled trials of interventions to promote recovery need to feature in NICE guidelines. Medical and psychological researchers provide nearly all of the contents of NICE guidelines, and medical research shows little indication of interest in developing interventions whose primary aim is to engender hope, promote well-being and resilience, or exercise choice and self-management skills. If applied psychologists don’t focus their efforts on these areas, drawing on the expertise of organisational and positive psychology colleagues, then who will?

### Returning to you

Returning to the scenario that began this article – what would you say to the consultant psychiatrist in the ward round? Would you disclose your ongoing difficulties with an expectation that practitioners would nevertheless assist you to engage in a process of recovery defined by you? Or would you keep quiet through fear that a narrow definition of return to health may be imposed upon you, with the resulting negative expectation if this is not achieved? What sort of patient would you be? What sort of practitioner would you like to be supported by?



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