

## Chapter 13

# A Recovery Approach in Mental Health Services: Transformation, Tokenism or Tyranny?

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*Question:* Name something that originated from and was developed by mental health service user/survivors ... and was subsequently taken up by mental health services, redefined and re-structured to meet *their* needs rather than those of their service users?

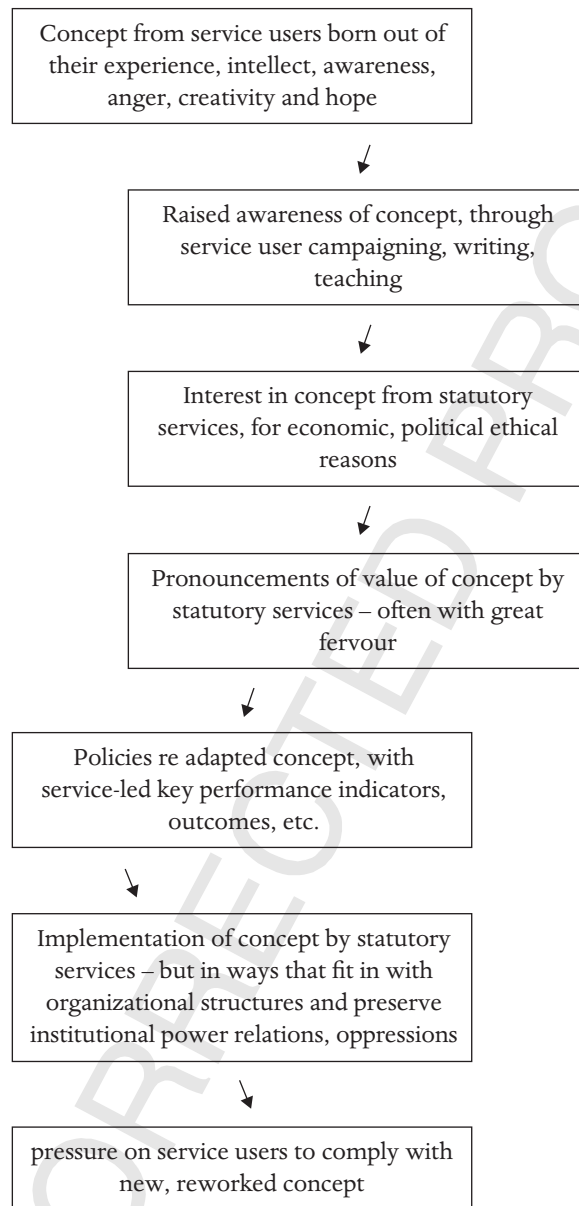
What did you answer? User involvement? Self-management? User empowerment? Recovery? All fit the bill admirably. So what happens when our concepts get taken up by mental health services, which then proudly lauds them (and itself for taking them on) but at the same time seems unable to implement them in authentic ways? In Table 13.1, I have laid out a flowchart of how service user concepts may become distorted when taken on board by mainstream mental health services.

As a Black service user who has tried for many years to work with 'the system' (Trivedi, 2008) I have often struggled with this question, most recently in relation to the concept of personal recovery, born out of service user/survivors experiences, anger, hope, creativity, intellect and wisdom (Repper & Perkins, 2003) but increasingly appropriated and adapted by the mental health system in order to fit in with their pre-existing structures and already established service-led quality standards (Shepherd et al., 2008; Future Vision Coalition, 2009).

In this chapter, I discuss some aspects of this worrying trend. This will be neither an academic discussion nor an evidence-based treatise, nor even perhaps a well-informed argument, but just me trying to make some sense of two of the many confusing experiences I have had over the last couple of years in my encounters with the recovery approach. My aim here is certainly not to knock sincere and well-intentioned proponents of recovery (both service users and mental health

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**Table 13.1** Flowchart to show how service user concepts may become distorted when they come into contact with mental health services

workers) who are working tirelessly to bring a more human, holistic and hopeful approach to care, but rather to consider why concepts such as recovery, which have such tremendous potential to be transformative, too often end up being either tokenistic or tyrannical when taken up by mental health systems.

### The Emperor's New Clothes

As a service user, in the early days I felt both excited and hopeful about the way in which government departments, mental health organisations and services in the UK were hailing recovery as the new way forward in care. However, my lived experiences over the last couple of years have caused me to seriously question whether recovery can ever retain its authenticity when it is translated and structured into a recovery model/approach/paradigm by mental health systems. For example, I have come across systems and organisations that claimed that recovery is about:

- A social not scientific concept – but they then started looking for proof of its efficacy using standard scientific methodology and even randomised control trials!
- Individualised, personal journeys – but they then set up structured models and approaches with clearly defined stages and standardised outcome measures!
- Hope – but they then skipped over exactly how hope can be generated and self-actualisation achieved when basic needs such as decent housing and enough money to live on are still not being met!
- Challenging the stigma and discrimination against those with a mental illness diagnosis – but they then paid lip service to other oppressions, such as institutionalised racism (both within society and services) which may have had a much more profound effect on someone's mental health!
- Social inclusion – but they then focused on getting individuals back into the mainstream (i.e. work) and did very little (if anything) to tackle the structural social inequalities which will continue to result in large numbers of people being denied access to opportunities, resources and economic and political power on the grounds of their race, class, gender, sexual orientation, etc.

Mad or what? Certainly it seems very worrying that such huge contradictions are not being discussed more openly within the mad fervour (? hypo-mania) currently surrounding recovery within mental health services. To me it seems a bit like the Emperor's new clothes, where everyone gets very excited and hails the new clothes (the new recovery approach) as indicative of a radical and positive shift while all the time knowing that the power base and control remain very firmly embedded within the corpulent body of the Emperor (mental health services) and any shift can only happen on his terms. Even if people wanted to, they could not do anything except be positive because if they did express doubts it would not

only undermine the authentic concept of recovery, but also their personal investment and position in relation to it (Baker, 2000).

However, two years ago, Social Perspectives Network held a study day entitled 'Whose Recovery is it Anyway?' (SPN, 2007) which did enable service users and others to express their doubts about the Emperor's new clothes. It was a buzzing, vibrant and sometimes painfully raw day. I gave a presentation, using my personal experience to raise some fundamental questions about the ways in which some mental health services implement a recovery approach (see Table 13.2).

In particular, I was concerned with how the mainstream recovery agenda related (or not) to those service users from Black and Minority Ethnic (BME) communities, an area of particular concern since there is such a massive over-representation of certain BME communities within mental health services, particularly at the 'hard end' (Fernando & Keating, 2008). Whether the concept of

**Table 13.2** Crucial questions about recovery and the mental health system

1. What precisely is the role of mental health services in recovery? Can they recognise which areas of recovery they have expertise in and can make a useful contribution, and which areas they should not get involved with but enable others with more relevant expertise (particularly service users and community organisations) to have take control of.
2. How can the mental health system (which is directed by the Department of Health and works according to central government guidelines using highly standardised systems to achieve service-determined outcomes under the strictures of clinical governance) take on a recovery approach, which is essentially about personal, individualised and very diverse journeys of recovery?
3. How does a mental health system, which claims to be based on service user control and empowerment, also respond to other pressures – for example, the focus on public safety, risk, the Mental Health Act, practitioners and pharmaceutical companies who believe medication to be the first-line treatment for mental distress?
4. Does the mental health system really value individual journeys of recovery as defined by users themselves, or is recovery still defined according to service-determined outcomes (e.g. how many go on to employment, independent living, referred back to GP)?
5. How does the system (which has traditionally disempowered, coerced and excluded people with mental health problems from society) now gain the trust and confidence of users (particularly those from discriminated against communities who often fare worst in services) and prove they are now committed to empowering, giving control to and socially including service users?
6. Is the system able to address issues of power or is it interpreting recovery in a way that enables it to retain power, authority and access to resources? Can the system work towards and practically enable a shift of power from itself to other social agencies, in particular to service users?
7. Is the system prepared to shift its focus radically and prioritise the infrastructure, resources and support necessary to implement a recovery approach over traditional priorities?

personal recovery (derived almost entirely from White service users) is applicable to them is still a matter of conjecture.

### **Black Service Users – Personal Recovery or Liberation?**

Some focus group studies have suggested that Black service users may have very similar notions of recovery to White service users, though it is not always clear exactly if and how difficult issues like racism and internalised oppression which are known to impact heavily on mental health were raised. In my experience, Black users often discuss recovery in broad contexts which invariably include a lifetime of personal and institutionalised racism and the limitations and disadvantage that this has imposed on them in terms of education, work, access to economic and other resources and forced them into spirals of oppression from which it can be almost impossible to escape (Trivedi, 2002). Recovery for BME service users often therefore involves finding a way of overcoming social and political factors as well as personal mental health-related issues that White service users may be concerned about (Fernando, 2008; Griffiths, 2008). In discussing this, Suman Fernando, a Black radical psychiatrist, has queried the use of the word 'recovery', suggesting it may be far too mild to encompass a Black person's personal, social and political journey towards a fulfilling life in a society still riddled with institutionalised racism and exclusion for those regarded as 'other'. Instead, he proposes the word 'liberation' as being more applicable (Fernando, 2008).

Fernando also discusses how focusing on personal, individualised journeys may not resonate with people from non-Western cultures where communality and interdependence (rather than individuality and independence) are emphasised and aspired to. He poignantly illustrates this when he states:

In the world of twenty-first century Britain, the reality for many black service users is being stuck in the system with heavy diagnoses and 'sectioning' as dangerous people; their journey from darkness into light (as the recovery approach envisages), if it ever takes place, entails circumventing or overcoming many barriers of a social and political nature where family, religion and community are important.

Furthermore, he raises the point that even in focusing on the individual, the current discourse seems to see recovery in reductionist, scientific ways, i.e. in terms of different and separate aspects of the self (e.g. personal psyche, social networks, status, role status) rather than as an integrated whole, something which again may not resonate with people from cultures where there is no such clear divide between body, mind and soul. Finally, Fernando concludes that unless the current recovery discourse is changed substantially, it may well marginalise BME people service users and impose on them service defined identities rather than their own (Trivedi, 2004). Which takes me on to one of my lived experiences.

### **A Warning Note about ‘Lived Experience’**

Lived experience is another concept currently lauded by mental health services – in my experience until it becomes unacceptable and is dismissed as biased, subjective and born out of bitterness rather than factual accuracy! But narratives, by definition, can only be written from one perspective using information available to the writer. For the narratives of lived experience included in this chapter, it was virtually impossible to obtain any information on the mental health system’s perspective of the situations so they are, by necessity, one-sided and subjective.

### **A Tale of Marginalisation and Tokenism**

Recently, I was invited to be a member of a service user/carer advisory group to a huge national research project on recovery. Keen to be involved in such an influential project, I eagerly read through the project proposal but was completely shocked when I came across the following under the section ‘Risk Management’:

This is a challenging programme, so we have a number of approaches to maximising the likelihood of success:

To reduce complexity, some important aspects, including BME and carer perspectives, will not be addressed.

My initial response was incredulity. How could such a major project say they would not address BME perspectives when in many urban areas more than 50 per cent of service users are from BME communities and fare so badly within services (Fernando & Keating, 2008)? How could a project which hailed inclusion as a key tenet purposely exclude the perspectives of people whose whole life experience has often been one of exclusion? How had the statement passed the scrutiny of project collaborators and workers, ethics committees and service user researchers who I assume must have gone through the project proposal with a fine tooth comb? How did we, as BME service users, once more end up at the bottom of the pile, as people not worthy of having our very real issues addressed but rather as barriers to success, adding unwelcome complexity to (what is often viewed as) the nice, White, middle-class notion of recovery? Was this due to individuals who are purposely trying to marginalise us, or more to do with the mental health systems/organisations within which they work? I knew those involved in the project were basically sound

people whom I liked and respected, so initially I accepted the explanation that the statement about BME perspectives had to be included as part of standard procedure, research methodology, technical necessity dictated by the systems of funders, research bodies, services, and so on. But then I got caught up in a maelstrom of feelings at what to me seemed to be exclusion, marginalisation of our issues and clear institutionalised racism.

In anger, I wrote to those involved in the project, very clearly expressing my distress. The result was an immediate and thoughtful response from many of the service users involved (most of whom I had not known previously) but, with one exception, absolute silence from the professionals (several of whom I knew and I thought respected me from previous user involvement work I had done in the Trust). To me that was like annihilation – an almost total blanking of my distress by people who were busy telling the rest of the world how to understand, make sense of and work with distress and move towards recovery. The outcome was that, like many before me who have been disturbed by user involvement work, I retreated into the safety of my bunker trying to fight off the experience of being made invisible and consequent overwhelming feelings of rejection, self-hatred, guilt and a longing to really disappear from the world. Of course, my (?over-) reaction was more to do with my past than the present, but nevertheless it reminded me of how close to the edge we are even when we think we are well sussed and recovered.

Eventually, I got myself under control and started venturing out from my bunker. Catching up with e-mails, I found two from the Recovery research project, one stating that there was still a place for me on the Advisory Group if I wished to attend and one offering me a meeting to talk about my concerns with the chair of the Group. Scared of getting myself into a state again I declined both and tried to forget about the whole thing. Then, several months later, I met one of the main people in the Project at a meeting and he told me that my input about BME issues had had a significant effect on the Project and there would now be a PhD student looking at BME issues! I wasn't sure whether to laugh or cry at what to me was a very tokenistic response to a major concern, but tried instead to be polite and grateful, just as a good service user should be. But then that night, angry with myself for being so compliant, I got thoroughly confused trying to work out what was going on. I could not honestly believe that the professionals involved in the whole fiasco were bad people trying to deny us BME service users our identity and our issues, so the only conclusion I could draw was that there must be something very powerful going on which is maybe not so much about individuals but more worryingly about systems, power relations and the structuring of institutionalised oppressions within the systems in order to maintain the established power relations and preserve the status quo.

Which brings me to the second lived experience re recovery and mental health services that I would like to relate.

## A Tale of Tyranny

Ashwin is a 61-year-old Asian male service user who was diagnosed with schizophrenia at the age of 18 and has lived in a culturally appropriate group home for the last 19 years. Apart from monitoring his medication, mental health services have played little active part in Ashwin's day-to-day life for the last few years and he is on his own path to recovery, with establishment of meaningful social relationships, increasing involvement in mainstream leisure and community activities and early intervention by staff in the group home who recognise his relapse indicators and how best to respond quickly and effectively.

The local mental health services then adopt a 'recovery approach', review all residential placements and decide Ashwin has been in his group home long enough and needs to move on to next step of recovery – independent living. When Ashwin is informed (out of the blue and without any lead-in) he becomes very distressed as he sees his established security being taken away from him. Staff from the Recovery team talk purposely of recovery and Ashwin's best interests, but fail to make any real connection with him or understand his distress at his sudden change in prognosis and the focus on him 'moving on'.

The situation turns acrimonious. The Recovery team insist on the need for Ashwin to move on since he has had no hospital admissions for several years and needs to become more independent. Staff from the group home stress Ashwin has made (and is making) good progress from the stable base of the group home. Ashwin's family express their concern at Ashwin being suddenly disrupted and try to introduce a broader, family and cultural context so that Ashwin's needs are assessed in these terms and not simply in terms of Eurocentric norms and values. Ashwin himself withdraws, intermittently showing his distress in displays of anger and aggression.

The Recovery team attempt to meet Ashwin on his own but, terrified of being moved, he refuses to attend any appointments.

Persuaded by his family, he does eventually agree to meet a worker from the Recovery team but after three or four meetings complains to his family that he is feeling bullied because the conversation always focuses on him moving out of the group home, in spite of the fact that he has clearly and repeatedly said he does not wish to. Suddenly, an Independent Mental Capacity Worker (IMCA) is brought in (without the knowledge of the family) to assess Ashwin's capacity and concludes that Ashwin has capacity but doesn't know how to use it! Presumably, he will when he agrees with the Recovery team! The situation then gets stuck, with Ashwin's previous recovery journey being disrupted as he lives in a constant state of anxiety that any moment he will be 'moved on'. Attempts by the family to clarify the situation are unsuccessful.

A stable situation for one service user is completely disrupted with the arrival of the Recovery team. So what on earth was going on to make the situation go

so disastrously wrong? In spite of all the trauma caused (and as in my first narrative), I really do not believe the staff involved with Ashwin were bad people. I'm sure they were all well-meaning and would claim to have Ashwin's best interests at heart, but something was obviously going on that turned the approach of individuals within the Recovery team from one of potential transformation to one of tyranny and coercion when their unilateral plan was not complied with. So if it was not the individuals themselves, we once again come back to 'the system'.

### Systems, Organisations and Power

Many of us (as I have done above) talk about systems and organisations as tangible objects which have a separate existence from the individuals who comprise them. But Ralph Stacy (2005), using group analytic concepts, describes organisations as being derived from the individuals within them; communicative interactions and relationships between those individuals forming patterns of activity, which create the experience of organisation. Relationships, by their very nature, inevitably have power structured into them and so power relations become established within the organisation, sustaining a version of reality in which certain identities and differences are privileged and accorded higher status within the system while others are subjugated into lower positions according to their degree of 'otherness' (Dalal, 2003). At the same time, specific beliefs, values and norms evolve within the organisation which individuals are compelled to conform to if they are to be included within the organisation. Furthermore, they must be seen to do this and participate in the organisation's dominant discourse, the ideology it reflects, the power relations it sustains and the patterns of inclusion and exclusion it upholds if they are to continue to be part of the organisation. Once this pattern is established, ideology does the work of sustaining the power relationships within the organisation by convincing all that this is the natural order of the world (Dalal, 2003).

Following this line of thinking, we can see, for example, that in mental health services, systems have evolved to focus on public safety and control, minimising risk, compliance with medication, scientific, evidence-based treatments, quality assurance and clinical governance and staff must comply with this if they are to remain and be valued within the organisation. However, individual staff may also have their own important values such as patient safety, positive risk-taking, individuality, empowerment, personalisation and recovery, and these may clash with the organisation's dominant values and cause inevitable and sometimes unbearable conflict for those who hold alternative values (Stacey, 2005). In order to remain true to themselves (and also credible to service users and their families who will benefit from these values) they must be seen to uphold their own values while still complying with the dominant values of the organisation. If

these values can then, through iterative interactions, become functional while still upholding the dominant values, then the latter may eventually diminish in importance. But this will depend on the power relations within the organisation and the way in which these enable or constrain functionalisation of alternative values (Stacey, 2005).

### **Making Sense of Lived Experience – or Not**

Maybe this can help me make some sense of the two lived experiences of recovery I have described in this chapter.

In my first example, it could be that the Research team were starting with values allied to a recovery approach but within the power relations and constraints of the Research Institution and its allied bodies were compelled to comply with their more dominant values – in this case scientific reductionism, rigid methodologies, objectivity and proving hypotheses through maximising chances of ‘success’, sure they displayed their recovery-focused values too by setting up the project in the first place and by having a service user advisory group. But it seems to me that their inability (or unwillingness) to carry through their recovery-focused values in their dealings with me not only alienated me but missed an important opportunity to ‘functionalise’ these values and exposed flaws in their commitment.

In the second narrative, it may have been that the Recovery team too were starting with values allied to a recovery approach but within the power relations and constraints of the system were compelled to comply with more dominant values, such as financial pressures to move people out of high-cost supported housing into less expensive accommodation. By insisting that Ashwin’s proposed move was nothing to do with saving money and only to do with his best interests, and by transferring the pressure put on them into pressure on Ashwin, the Recovery team failed completely to communicate meaningfully with him and his family and made a mockery of the principles of the recovery approach they were claiming to be advocating.

### **Conclusion**

I’m not sure where any of that leaves me. The concept of personal recovery in mental health is self-evidently a ‘good thing’ and to knock it would be tantamount to heresy, but it certainly needs to be broadened out to take into account the different perspectives and experiences of those who are involved with services, particularly those from seldom heard and marginalised groups. The focus on individualised personal recovery also needs to be broadened, since for many,

recovery is not just a personal journey but also a social and political one. Finally, much more attention needs to be paid to the ways in which systems and the individuals who comprise them operate, the ways in which power and authority operate within those systems and the glaring contradictions which seem destined to disable any meaningful progressive move towards improving services for all service users. If mental health services could take recovery on in authentic ways, it would undoubtedly be hugely beneficial to users of services, but at the present time I fear that rather than being transformative, it could very easily end up being tokenistic at best and tyrannical at worst.

Throughout this chapter I have made a very conscious effort not to apportion blame directly to any of the individuals involved in my examples of lived experience and to give them the benefit of the doubt that they are all committed to the principles of recovery. I suspect I too am (for whatever reason) compelled to see the Emperor's new clothes and maybe am doing my best to ignore the painful reality that the problems with the Recovery approach may simply come down to the fact that:

Despite the new discourse of listening to users' views, a tension remains because of privately held and so undisclosed professional assumptions about patient irrationality. This implies that private pessimism might co-exist with optimistic public rhetoric in professional mental health work. (Pilgrim, 2008)

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UNCORRECTED PROOF

A deep sorrow and regret,  
That we never met,  
And yet,  
I loved you still.  
Thoughts, memories,  
Of what could have been,  
A strong belief in the unseen.  
I longed to hear your soft voice,  
To feel your warm embrace  
Or a gentle kiss on the face.  
You were always part of me,  
There was no escaping that.  
Creating a delusion,  
Which in turn would  
Cause more and more  
Confusion.

Mariam Maule, 'To What Could Have Been'

UNCORRECTED PROOF