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Recovery: Bringing service users in

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Abstract: *We introduce the new meaning of recovery and reflect on its potential to develop current thinking and practice in mental health with adults, and look at its implications for service providers and service users. We analyse the relevance of this concept to the context of the UK government's policy to move disabled people, including mental health service users, from 'welfare to work'. The social and economic climate that drives this policy agenda and the implications for society of the focus on employment are outlined, as we reflect on the role of work in supporting or hindering the recovery process and identity re-formation, in part through the experience of the first author. We conclude by suggesting how practice can enable a process of returning to ordinary living, including employment, that supports recovery through a process of shared responsibilities.*

Keywords: *recovery; providers' role, returning to work; service user's role and experiences; mental health policy; mental illness and health; identity.*

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Introduction

The language of recovery is now widely used in mental health policy, services and research. Yet the term has disparate antecedents, and is used in a variety of ways. It is an ever evolving concept and emanates from two traditions: the medical model of recovery and the psychosocial personal model of recovery. The former emphasises the achievement of symptom reduction and ability to function as measurable outcomes by which the success of a service user's recovery can be measured. The latter emphasises the journey or process that leads to a more valued life for service users, one controlled by them, and has emanated from the service users' movement in English speaking countries.

The focus in the new meaning of recovery has been on the improved quality of living despite the illness (Anthony, 1993), or on the ability to live well with the illness and to live beyond it (Davidson, 2003). Deegan (1996), a service user and a clinical psychologist, has introduced the emphasis on the journey of recovery and the increased control of service users of their own journey as the core issues of this process. She has provided several useful examples from her own life to illustrate the meaning of being in control, such as the difference between being hospitalised following her own decision, or due to the decision of professionals.

This definition reflects a considerable move away from both the dictionary definition of the concept as well as from that of traditional psychiatry. In particular, the new meaning has discarded the notion of cure and a generic definition of recovery for an individualised one (Slade, 2009). However, research based on analysing service users' narratives highlights the importance of interdependence and positive interaction with other people in terms of mutual support, having someone who believes in the person's potential for recovery as central to re-building their self identity following the traumatic impact of developing a mental illness (Roe and Davidson, 2005). Thus a personalised approach needs to be accompanied by consideration and action concerning the social existence of the service user. Working for the World Psychiatric Association, Amering and Wallcraft (Wallcraft et al, 2011) have established three years ago an international group of service users that works on issues of user involvement and recovery, funded by the association, indicating the world wide growing interest in this issue, and especially in service users' perception and involvement. The varied definitions of the new meaning of recovery detract from its clarity and from translating it into operational definitions, yet the variability highlights that the meanings attached to it are still being discussed and are open to further change.

Without using the term recovery, the Italian Psychiatric Reform (Ramon, 1989) and the Social Role Valorisation approach (Wolfensberger, 1983; Ramon, 1991), developed in the 1980s, also left behind the cure from symptoms as a core target for service intervention, and focused instead on leading a more fulfilling, socially inclusive life, even with the symptoms and the disability remaining. Similarly, the focus on users' own strategies of living with voices, developed and nurtured by Romme and Escher to become a successful network of local self-help groups in the Netherlands, Italy and the UK has enriched the recovery approach (Romme and Escher, 1993).

We would argue that the new meaning of recovery departs radically from values and knowledge of traditional psychiatry, and hence presents mental health professionals with a considerable challenge within a policy context, such as in the UK (and most other English speaking countries, as well as continental Europe) where a recovery oriented practice is expected to follow.

The existing evidence presented by the longitudinal studies, many of which were developed in continental Europe (e.g. Huber et al, 1980; Ciompi, 2005), have highlighted that recovery from long term mental illness is much more prevalent than was believed within psychiatry. Likewise, outcomes were found to be less linked to diagnosis than to psychosocial factors; the prevalence and intensity of symptoms diminish over time; the justification for staying for life on anti-psychotic medication is much weaker than has been thought, and the regime of mental health services – whether they are residential or not – matters in terms of the likelihood of recovery being pursued and achieved by both service users and providers (Harding, 2003). This analysis has led Harrison and his colleagues (2001, p. 515) to conclude at the end of the longitudinal study he led that there is no justification for the prevailing belief in the chronicity of illnesses such as schizophrenia.

Analysing service users' stories about recovery, Ridgway (2001) stated that they are viewing recovery as the reawakening of hope after despair; breaking through denial and achieving understanding and acceptance; moving from withdrawal to engagement and active participation in life. These are central elements of what needs to be reinforced in recovery led practice. Deegan (1994, p.19) reminds us of how much effort is put into being in a state of apathy:

> *The professionals called it apathy and lack of motivation. They blamed it on our illness. But they did not know that giving up is a highly motivated and goal directed behaviour. For us, giving up was a way of surviving. Giving up, refusing to hope, not trying, not caring, all of these were ways of trying to protect the last fragile traces of our spirit and our selfhood from undergoing another crushing.*

It is this phenomenal challenge of moving in the opposite direction that both service users and providers who believe in the value of recovery have to face.

To follow the new meaning of recovery into everyday ways of working, new knowledge and skills have to be achieved, including:

- Believing in the strengths aproach (Saleeby, 2009, Rapp & Goscha, 2006), according to which service users have strengths and abilities, and not only weaknesses and disabilities.
- Applying the strengths approach to assessment, personal development plan of

individual service users, and motivational interviewing (Kelly and Gates, 2010),
- Enabling the person to rebuild a positive sense of self in a self-directed way alongside peers (Davidson, 2011).
- Moving to a coaching style (Slade, 2009) and shared decision making way of working with individual service users (Deegan, 2007), in which it is accepted that shared, calculated, risk taking is a necessary part of enabling service users to move towards recovery (Ramon, 2005),
- Involving service users and carers collectively in service planning and auditing.

This amounts to a fundamental shift not only in the way professionals view service users who experienced mental illness, but also in the way many service users view themselves, and in the power relations between users and professionals. Service users' self identity, especially following the trauma of experiencing a severe mental illness, is greatly impacted by the views of the significant others in their lives, including professionals. The continuous stigmatisation of people with mental illness, especially those experiencing schizophrenia and personality disorder, and the ongoing belief of many professionals and carers in the inevitability of the chronicity of such an illness, accentuate the poor self esteem they have and leads to a further internalisation of their self image as failures. The personal examples of service users who have managed to live beyond the illness, to become activists in the user movement and transformational leaders of our mental health system, indicate to all stakeholders in mental health, but especially to the service users, the existing scope of recovery and of a re-emerging new and more positive self identity (e.g. Deegan,1996; Copeland, 1997; Repper and Perkins, 2003; Coleman and Smith 1999).

Bringing in service users into the context of recovery would therefore imply considerable unlearning and relearning by both groups, not only in terms of self-perception and role perception, but also in the degree of trust and a re-shaped agenda for collaboration, as well as in organisational change (Shepherd and Boardman, 2009; Ramon, 2011). Each of the components listed above is crucial for the purpose of bringing in service users, albeit from different angles. Without the acceptance of the strengths approach both users and professionals would find it impossible to move away from the chronicity model, to envisage a life with new possibilities, or to take a calculated risk necessary to break out of the cycle of low expectations, low social image, low self image into one in which all of these components can change. Indeed the belief in the value of the experiential knowledge that service users bring with them is a step further, as it implies that not only knowledge codified as scientific or as professional is of value to the development of a shared understanding of what service users are experiencing, one that compliments professional knowledge, and at times corrects the latter. Furthermore, accepting the value of service users' expertise may reduce the high level of uncertainty that is one of the hallmarks of psychiatry.

The new meaning of recovery as described above heralds a new dawn where opportunities for service users to lead a valued and fulfilling life are provided. They no longer live in a world of hopelessness, but in one that accepts that they can develop to their potential. These components also pose a considerable challenge and require that service users will take responsibility for their lives. In my recent experience, I (Joanna) described how work was important to my journey of recovery (Fox, 2011). It enabled me to find a sense of purpose giving a structure to my day and a sense of self esteem. Without having a reason to get up for the morning, it is very difficult to get up; without having a reason to go out, it is easy not to go out. One of the most difficult things to do is to fill a day that has no structure, no purpose. Motivation is lost and inactivity is characterised by doing nothing, sleeping a lot, and not going out. Thoughts can fly free and can go down tracks of paranoia, unfettered by the need to apply them to useful things. The only worse thing than not having enough time to do things is having all the time to do things. Life lacks meaning and structure; thoughts and inactivity become personally self destructive. For me work was – and is - an important and necessary part of my recovery.

Having recently given birth to a baby I took on another identity, that of a mother. To the maternity services, I was no longer a social worker, an academic, a researcher, or a PhD student. My predominant newly imposed identity (albeit with the best intentions of helping me and my baby) was that of a service user who needed ‘additional support from an enhanced service’. As a mother I no longer had the value of being all the important identities that my work and study brought me, making me feel disempowered and devalued. I also absorbed a lot of these negative values associated with being perceived as a ‘service user’ and ‘just a mother’. Not only was I carrying the identity of being just a mum, perceived as a socially non productive role, but it was just a mum who was also a service user; a doubling of devalued roles. This made me empathise again with the identity of feeling separate and different. It was difficult to fall back on professional values and project a safe professional image: I became a service user again, not in needing services but in my projected image. I had forgotten how valuable the life of work was in providing structure to my day and a sense of self esteem, and it had played a very important role in my recovery.

I am not alone in finding that work is an important part of the recovery journey. Research highlights that for many service users employment is an important and necessary part of their recovery, even though taking that first step can be frightening. Many disabled people want to work, and people with mental health conditions have the highest ‘want to work’ desire (Perkins et al, 2009). Work has many benefits for people from all backgrounds and can play an enormous role in the recovery journey. A recent comprehensive review of the research (Waddell and Burton, 2006 p xiii) illustrated that overall work for sick and disabled people:

- is therapeutic
- helps to promote recovery and rehabilitation
- leads to better health outcomes

- minimises the harmful physical, mental and social effects of long-term sickness absence
- reduces the risk of long-term incapacity
- promotes full participation in society, independence and human rights
- reduces poverty
- and improves quality of life and well-being.

Although the benefits of work have been strongly promulgated, work needs to be fulfilling and enable the worker to have some control over their working environment to promote good health and well being. Good jobs improve mental health whilst bad jobs can have an inverse reaction on good health (Coats and Max, 2005, p. 5).

Working is often assessed as an outcome of recovery and may be the beginning, middle, or pinnacle of this journey. For some people with mental health needs their relationship with the world of work reflects my experiences, for others it may be a difficult and at best an ambivalent relationship. Indeed many people with mental illness conditions have not had opportunities for a fulfilling and rewarding career. Perkins et al (2009, p.7) noted how people had been so stigmatised and institutionalised that they have lost all but the identity of being a mental patient. They had also been so demoralised that their once held ambitions and aspirations have disappeared under the burden of failure, segregation and disappointment. This is both a personal tragedy at the lost potential for the individual and has far reaching consequences for the national economy. The former has been well documented: people living under a benefits regime are more impoverished, increasingly socially excluded, experience worse health, less well being and increased morbidity, and there are poorer outcomes for children of workless families (Black 2008; Department of Work and Pensions & Department of Health 2009; Department of Health, 2001). The latter effects have been shown to cost the UK national economy £15.1 billion of lost productivity (Sainsbury's Centre of Mental Health, 2007; 2010).

The difficulties of participating in the world of work for those with mental health problems cannot be denied: gaining employment despite of the stigma of mental ill health can be hard and the fluctuating nature of a mental health condition may impact on the ability to maintain employment. The belief in recovery plus the rejection of the notion of chronicity of schizophrenia and other mental ill health conditions creates a climate where it is believed that work is possible. Government policy is driving an agenda that work is considered desirable for all members of the community. In the past the social systems perpetuated the workless-ness of service users: it was governed by a "passive benefit regime" (Black, 2008) that meant that once claimants established an entitlement to incapacity benefits there were few interventions to help them to return to work, and little expectation that they would. However, is government policy the best way to drive the recovery of service users? For many returning to work is a complex and difficult journey. Work may be characterised by an overwhelming experience of stress or fear. Competitive employment cannot be equated with recovery as each individual's story is different and hence recovery journeys differ. For some service users, a compulsion to participate in the world of work can resemble a sword of Damocles hanging over their head, frightening them and hindering their recovery.

Government policies have consistently been aimed at creating conditions to enable and incentivise disabled people to access work. (Black 2008; DWP & DH, 2009, DH, 2011). This policy agenda is manifested in the new Work Capability Assessment (WCA) (instituted in 2009/10 with a continuing momentum under the current Coalition Government) where the emphasis changed from assessing people's incapacity to evaluating their capability to work. Many claimants however complain that the WCA process is unfair: stating that the assessment is too inflexible, not enabling them to explain the fluctuating nature of their conditions or the subtleties of their impairments. People with mental health issues fear that their needs will not be recognised and that they will be discriminated against. Indeed, a recent review by Harrington (2010) on the Work Capability Assessment highlighted these concerns, but supported the premise that work is a positive experience for most people and that the WCA programme should continue.

How can we support service users to enter employment within the best conditions of supporting them in the working environment? The former Labour Government sought to provide such an environment by tackling the wider environment of stigma and misunderstanding surrounding the myths of employing people with mental health conditions. The new Equality Act (2010) establishes the responsibilities of organisations and employers towards people with disabilities, including those with mental health needs, making it illegal to discriminate against people on account of their disability. Amongst these reforms, it became illegal to compel people with mental health needs to disclose their condition in a medical questionnaire before job selection and job offer; this could only be used in best practice situations to support the employer to make reasonable adjustments to enable the disabled person to undertake their role effectively.

Often paid employment can provide this opportunity for empowerment; conversely it can also hinder this process where the work environment is unsupportive and hostile. Many people want to work, whilst some are unable to do so and need the opportunity to occupy other socially valued roles. Sometimes entering education or unpaid work can provide meaning for a service user's life and give them a sense of purpose. If recovery is only equated with the ability to work, then recovery has been appropriated by professionals, by politicians, and by policy makers. If recovery is seen as providing the opportunities and an environment to support and promote good health and well being, which may include work of different types – paid, unpaid, part-time or full-time – then recovery retains its value as something that supports a service user to engage with and on their journey to lead a life where they feel more valued by themselves, their family, and society.

The recovery process may be very separate and different from the world of work.

It may be a process where the service user learns to live their life effectively and with purpose. Recovery may constitute a process of self awareness learning to self manage a mental ill health condition. The new meaning of recovery emphasises this process and indeed the Expert Patient Programme in the NHS focuses on teaching self management strategies, learning to be an expert in the management of one's own condition. Many service users indeed lead a fulfilling life without entering the world of work. Hence there is a potential conflict: if a service user does not wish to work but has a fulfilled life with a variety of unpaid activities and hobbies, should they be entitled to benefits? If a person is a member of society and is a citizen in that society, there are responsibilities as well as rights. Does one have the responsibility to contribute economically to that society as well as benefit economically from it? Is this part of the social contract a citizen makes with the society in which they live? This may be very different from the journey of recovery and may be separate from the 'system' and 'position' of being a service user. Working when a person is able may be part of the responsibility to play a genuine, full and contributing role in society. This expectation is very different from the role of being a service recipient, which implicitly states that one receives and uses services from the state. A person can be and is legally and morally a citizen of society when being a service user entitled to be supported under the benefits system. However if that person is deemed well enough to work, when do they stop being a service user and become someone who is a non contributing member of society? Who should decide or assess this state of 'being recovered', the state of being able to work?

A similar issue may be related to the experience of making decisions about choosing to take or choosing not to take medication. Service users have a right to be involved in decision making about their health. A service user can choose to not take medication (unless under certain Sections of the Mental Health Act 2007), even if it is assessed and recommended by the psychiatrist as the most effective treatment to manage his/her mental illness symptoms. While service users need full information to make an informed decision about the efficacy of different medication treatment procedures they have the right to choose what are acceptable side effects for them. It may be perceived as good for their health and well being to take medication, but they know best how it affects and drives their recovery. If recovery is only equated with taking medication as prescribed without discussion and a process of shared decision-making, then it devalues the language and practice of choice. Can returning to work similarly be equated with the journey of recovery? Do people have the right not to work and to receive benefits? This is not only a fundamental paradoxical tension between rights and responsibilities, but encompasses the very fabric of our society in deciding who is a 'sick person' entitled to receive benefits and who is 'well enough' to contribute to the economic well being of our society. The question that follows from this is how and when is it assessed that a person is well enough to return to work? Can this be a process of shared decision-making or must there be an element of coercion and compulsion? Can that premise play a part in the language and process of recovery?

We believe that the language and practice of recovery are best expressed when the responsibilities for deciding different treatment courses are shared between the professional and the service user. In such a process the service user should receive full and unbiased information about the proposed course of action to make an informed choice to accept or decline the treatment offered. Where treatment is declined, there should be frank discussion about the possible adverse consequences; however, the right to choose should be retained by the service user (while capacity remains) (Drake et al, 2010). This process promotes a feeling of mutual respect and presumes the mutual autonomy and independence of both the service user and the practitioner. The language of shared decision-making enriches the process of dialogue in a mutually respectful environment rather than emphasising the outcome of accepting or refusing the treatment (Drake and Deegan, 2009). This should provide a model for the process of shared decision-making about returning to work too. Working on shared decision making in the context of psychiatric medication management has barely began in the UK, even though it focuses on a central issue for service users, providers and carers and a crucial element of bringing service users in. Several projects are now to chart shared decision ways of working, such as the one based in Cambridgeshire & Peterborough Partnership Foundation Trust in collaboration with Anglia Ruskin University, in North East London and University College London, and in South Devon. The first two projects are funded by the National Institute of Health Research, indicating the beginning of the recognition this issue deserves within the NHS.

Effective practice should promote an enabling environment that allows the service user to explore opportunities and choices to return to work. Practice that promotes and supports choice, encourages autonomy, and enables a sense of shared responsibility is more effective than compulsion. How can practitioners promote such an environment to enable people to return to work without fear and coercion? Perkins et al (2009) recommended that service users be given greater support to access work and retain roles they held when they had become unwell. She recommended that Individual Placement and Support programmes should be further developed to provide intensive mentoring to place service user and ensure that they retained 'good' jobs (as described by Coats and Max, 2005) that promote well being and recovery. Perkins argued that providing sufficient resources to enact the policy decisions of government was more effective than the rhetoric of compulsion or coercion. Many people want to work but are afraid that it would hinder their recovery, rather than not wanting to return to work. Using work programmes to support recovery and promote working is more effective at bringing the service user back into society than forcing and driving them in.

Another excellent example of bringing service users in and utilising their expertise is provided by the peer support workers schemes, an American innovation now in place in several UK mental health trusts (Basset et al, 2010). Training service users to apply their experience as co-workers alongside mental health professionals across the different sectors of the mental health system has demonstrated their capacity to work with service users in need of support in an empathic mode. Furthermore, the existing evidence illustrates the positive impact this has had on reduced coercive work methods, leading to shortened hospitalisation periods and less use of constraints (Ashcraft and Anthony, 2005). In addition, having peer support workers redresses the power imbalance between professionals and service users, and highlights that a number of stereotypes about the latter are incorrect.

Can the government's drive to promote work as an element of recovery have any credence? Although politicians use the language of recovery to promote work and promise greater support in the work place to enable access to employment, they simultaneously use figures to demonise and stereotype sections of the non-working disabled people. News programmes recently reported on the figures released by the Department for Work and Pensions that 81,000 people who were obese, addicted to drugs and alcohol, claimed work related disability benefits. It was claimed by Scope (BBC, April 2011) that the Prime Minister himself used these figures to stereotype and demonise this sector of the disabled population in the run up to local elections of May 2011, attempting to promote a picture of a government tough on the unemployed. This is a misrepresentation of the lives of many people based on stigma and misunderstanding. Can compulsion and stigmatisation through shaming and naming people have any place in the language of recovery? Is this not rather humiliating for people who are already disabled by society and part of the process of de-humanising people who are already stigmatised? This devalues our society and devalues the long tradition of the social contract to provide support through the welfare benefits system.

We have introduced the new meaning of recovery reviewing the development of its history as a concept and as a practice of mental health care, placing the concept of recovery in the context of the current debate in the UK about claiming disability related benefits. The significance of such a move was looked at also from the perspective of the recovery journey of one of us and also for many other service users, but at the same time reflected in the potential disruption this may cause in the recovery of some. The role of government in making policy to at best encourage and at worst coerce service users to look for work has been looked at. We have reflected on the social contract between citizens and the state to contribute in an economically productive role to society and the national economy, and the rights of disabled people to receive welfare benefits from the state. Finally the role of recovery practice in supporting people to find work through processes of shared decision-making and revealed the anathema of recovery practice in compelling frightened service users to enter the world of work was highlighted, alongside examples of bringing service users into the mental health system, as co-workers.

Conclusion

In summary, for one of us returning to work after a major mental health breakdown and subsequent period of ill health was a major part of her recovery journey. Working in a world where her mental health condition was accepted, if not understood, contributed to her recovery, whereas working in a world where it had to be hidden and concealed because of stigma and fear hindered it. It is very difficult to work in a world where someone carrying the label of schizophrenia is demonised and feared, and it is not possible to legislate for this fear even with an Equality Act. We can only change people's minds by participating in the world and fighting discrimination through being ourselves. The new meaning of recovery brings a new take on the language of choice and the language of possibilities, but language and concepts do not change fear and discrimination. Some service users have been so damaged by the world of work they have lost their hope and will, turning work into a terrifying and fearful experience – the WCA cannot evaluate this fear. Some people however need a 'push' but not coercion to re-enter the world of work to become contributing members of society, but how to achieve this tension? To promote recovery, work must be the product of shared decision-making, staged returns to work, and appropriate support and mentoring for managers, work colleagues and the worker. The new meaning of recovery promotes this, but the language of politicians that demonises service users can only create more fear and suspicion. Bringing the service user in requires the language of possibilities and opportunities not the language of coercion from the government, as well as from mental health professionals, and the general public.

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