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Recovery in England: Transforming statutory services?

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Abstract

English mental health policy has explicitly supported a focus on recovery since 2001. More recently, this has been elaborated through policy support for social inclusion, employment and well-being. We review several drivers for this political orientation, including a refocusing of the role of health services as a whole from treating illnesses to helping people to make the most of their lives, the shift to greater power for the individual, reflected in personal social care and personal health budgets, and the evidence informing clinical guidelines issued by the National Institute for Health and Clinical Excellence (NICE). A disjunction remains between policy and practice, with organizational policies espousing a recovery orientation and teams re-branding as 'recovery and support' teams, whilst pursuing clinical practices which prioritize symptomatic treatment rather than recovery support. The next phase of development in English statutory mental health services is therefore bridging this gap, through organizational transformation in mental health services towards a focus on recovery. We describe two funded initiatives to support this process of organizational transformation. The first (ImROC) is a national initiative to develop a pro-recovery organizational climate. The second (REFOCUS) is a multi-site cluster randomized controlled trial (ISRCTN02507940) investigating a team-level pro-recovery intervention.

What does 'recovery' mean in an English context?

In England, probably the most commonly used definition of 'recovery' is one imported from the USA: 'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness, recovery involves the development of a new meaning and purpose in life as one grows beyond the catastrophic effects of mental illness' (Anthony, 1993, p. 17) (see Shepherd et al., 2008; HM Government, 2007). However, 'recovery can be seen through different lenses' (O'Hagan, 2009, p. 16). Even a cursory look at the burgeoning recovery literature shows that the concept has been understood, and misunderstood, in many ways (Slade, this issue, Editorial).

Individual journey versus service intervention

Some English authors, often those with lived experience, have described recovery as the journey of an individual as they grow within and beyond what has happened, for example (Coleman, 1999; Repper & Perkins, 2003; Reeves, 1998). A journey in which

professionals, and the services they inhabit, are not at centre stage, but may (or may not) have a marginal, supporting, role 'The most challenging decisions ahead are not how to increase access to professional services but how to maximise life chances and enable people with mental health conditions to make the most of their lives. The real challenge is how to do things differently and use resources differently: recognise the limitations of traditional professional expertise, the value of the expertise of lived experience and rekindle the belief that citizens hold most of the solutions to human problems' (Perkins, 2010, p. 36). Such authors locate the origins of ideas about recovery not in the work of professionals, academics and services, but in the US civil rights movement and the work of people with lived experience of surviving and thriving with a diagnosis of mental health problems.

However, in England, ideas about recovery in mental health services have been driven by professionals and policymakers (see, for example, DoH, 2001, 2009; HM Government, 2011; NIMHE, 2005) and transformed from the journey of an individual to a model of service provision. We have seen the introduction of special 'support, time and recovery workers' (DoH, 2003) and 'recovery teams', and

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'recovery interventions' such as the 'Recovery Star' (McKeith et al., 2010) with its prescribed dimensions of recovery (living skills, addictive behaviour, managing mental health, etc.) and progression on a ten-step ladder from 'stuck' to 'self-reliance'. All a long way from the 'deeply personal, unique process' of which Anthony spoke.

As mental health services have taken ownership of recovery, its origins have been sought in the development of services rather than the journeys of those individuals whom they serve. For example, Davidson and colleagues (2010) trace the origins of the 'recovery movement' in psychiatry to the work of pioneering reformers such as Pinel and services such as The Retreat, York, established in 1979 to replace the chains, shackles, intimidation and neglect of the traditional 'mad house' with respect, friendship and kindness (Tuke, 1813). However, 'humanitarian psychiatry' continues to place services at centre stage and the focus is what professional services can do to put right that which has 'gone wrong'.

'Recovering from an illness' versus 'recovering a life'

Too often the term 'recovery' has been taken to mean 'recovering from' illness or impairment. Longitudinal studies of 'recovery rates' are cited as evidence that more people with a diagnosis of, for example, schizophrenia, 'recover' – are free of symptoms, medication and services – than has historically been assumed. Such arguments may be useful in counteracting the 'therapeutic pessimism' that abounds in many mental health services and to remind us that the small section of the population whom professionals see in services do not offer a representative picture of life following a diagnosis of mental health problems.

However, such a perspective continues to place recovery within the paradigms of traditional psychiatry: the purpose of mental health services is to 'cure people' and to contain and care for them unless and until this is achieved (Perkins, 2012). They have also proved popular in an era of diminishing resources, justifying economic imperatives to reduce reliance on services as a means to reduce costs (Beresford & Bryant, 2008). A cynic might argue that it is this, rather than a desire to improve the lives of people with a diagnosis of mental health problems, that underpins the current popularity of ideas about recovery in current English mental health policy (HM Government, 2009, 2011).

However, such a conceptualization of 'recovery as cure' has been contested by other authors (Perkins, 2012; Repper & Perkins, 2003; Shepherd, et al., 2008; Slade, 2009) who describe recovery as the

process of 'recovering a life'. Ideas in keeping with the user/survivor originators of ideas about recovery: 'the lived or real life experience of people as they accept and overcome the challenge of disability. They experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability' (Deegan, 1988, p. 11).

An individual journey or a journey that occurs in a social and political context: Treatment and rehabilitation or civil and human rights

Many ideas about recovery are highly individualized in nature, born of the culture of individualism in the USA from whence they were imported. Explorations of discrimination and exclusion exist but have typically been separated from ideas about recovery. 'Recovery' and 'social inclusion' were quite separate work streams within both the Royal College of Psychiatrists (Boardman et al., 2010; Roberts et al., 2006) and the National Institute for Mental Health in England who described recovery as improvement in the persons' condition and/or experience and the importance of the person assuming an active and responsible life (NIMHE, 2005). An essentially individual, rather than a collective process that fails to acknowledge the political and social reality of prejudice, discrimination and exclusion (Beresford & Bryant, 2008; O'Hagan, 2009; Perkins, 2012; Repper & Perkins, 2003).

Sayce, in her ground breaking book From Psychiatric Patient to Citizen (Sayce, 2000), talked not about treatment and rehabilitation as routes to inclusion and citizenship but of breaking down the barriers to participation within the social model of disability adopted by the broader disability rights movement. Such an approach argues that the barriers lie not within the individual but within the environment the focus is then on removing the environmental barriers that prevent participation: 'If we remember that environments are not just physical places but also social and interpersonal environments, then it is clear that those of us with psychiatric disabilities face many environmental barriers that impede and thwart our efforts to live independently and gain control over our lives and the resources that affect our lives' (Deegan, 1992, p. 3).

Examples of a disability rights perspective in relation to mental health can be seen in the work of the Mental Health Action Group at the Disability Rights Commission (Mental Health Action Group, 2003). An increasing amount of work around the broader disability rights agenda explicitly includes those with mental health conditions and the UK's cross-government advisory group on disability issues is now chaired by a mental health service

user/survivor. Following the work of US authors (Chamberlin, 1993, 1995; Deegan, 1988, 1992), some UK authors have argued that considerations of recovery should be framed within this broader rights-based context (Beresford et al., 2002; Beresford et al., 2010; Perkins, 2012; Repper & Perkins, 2003; Sayce, 2000).

These differing perspectives on recovery have all been played out in the development of mental health policy in England.

Recovery in English mental health policy

'Recovery' as the stated aim of government policy in England first emerged in 2001 – The Journey to Recovery: The Government's Vision for Mental Health Care (DoH, 2001) – and was to be achieved via the creation of 'safe', 'sound' and 'supportive' services as detailed in the 10-year modernization programme outlined in the Mental Health National Service Framework (DoH, 1999). This National Service Framework used the term recovery only three times, all in an exclusively cure-based clinical context; however, it did acknowledge that services should be based on service user and carer aspirations, that a place to live, meaningful occupation, further education and training were important and that stigma and discrimination too often prevented people achieving these.

Following the Mental Health National Service Framework a new mental health strategy was produced: New Horizons. A Shared Vision for Mental Health (HM Government, 2009). This was a crossgovernment strategy recognizing that promoting mental health and improving the lives of people with mental health problems required action across government departments, not just within mental health services. New Horizons went beyond traditional treatment approaches in describing its four underpinning principles as 'equality, justice and human rights; reaching our full potential; being in control of our lives; valuing relationships' (p. 9). It said that mental health services should be recovery-focused (adopting the Anthony definition) but with the demise of the Labour Government in 2010, it was rapidly superseded by the Conservative/Liberal Democrat Coalition Government strategy No Health Without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All Ages (HM Government, 2011).

No Health Without Mental Health identified six outcomes to improve mental health outcomes for the population as a whole. The second of these makes recovery an explicit goal and the focus is on people's lives rather than symptom reduction: 'More people with mental health problems will recover. More people who develop mental health problems

will have a good quality of life - greater ability to manage their own lives, stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education, better employment rates and a suitable and stable place to live' (p. 6). The five other core outcomes are better physical health, improving people's experience of services, reducing avoidable harm, and decreasing stigma and discrimination as well as improving the well-being of the population as a whole. Public services that empower those whom they serve, increasing choice and control (including the development of personal budgets so people can make their own decision about what support they want and who will provide it), social action and human rights, as well as greater diversity of support/service providers, are all seen as key to achieving these outcomes. Some have argued that these pose a threat to the NHS and universal public services, while others have seen it as offering an opportunity to develop peer-run, peer-controlled services (Brown & Floyd, 2011).

In parallel with these developments within mental health policy, mirrored in other countries (Piat, this issue), two further sets of ideas underpin UK policy development in relation to mental health, both of which derive from a broader disability rights agenda.

Personalization and self-directed support

Originating in the demands of disabled people for greater choice and control over their lives and the help/support they receive to live them, these efforts initially resulted in the development of 'direct payments' in social care. These allow people to elect to receive money to purchase the social care/support of their choice, rather than be with a service determined by the Local Authority Social Services. Although people with mental health problems could, in theory, elect to have a direct payment, in practice few know of this possibility and even fewer receive them (NIMHE, 2006) thus denying the control that they afford. In the social care arena, Putting People First (HM Government, 2007) and Transforming Social Care (DoH, 2008) extended direct payments in a major strategic shift requiring that everyone have a 'personal budget' (which people could receive as a direct payment, have managed for them, or some combination of the two). This personal budget allows people to exercise choice and control over the shape of the support they receive to achieve their self-defined goals. Self-directed support and personal budgets form a central tenet of government policy across the disability spectrum, including the mental health strategy (HM Government, 2011). All social

care will be provided in this way by 2013, and the remit is being widened to encompass personal health budgets for those with long-term conditions, including mental health problems. Personal health budgets are currently being piloted in a number of different mental health teams across the country (Alakeson, 2011; NHS Confederation, 2011).

Ideas about recovery and self-directed support/personal budgets have developed separately, but are entirely complementary and share common objectives (Mind, 2009). Both are about enabling people to participate as equal citizens; to exercise choice and control over their lives and the help/support they receive to live them; and pursue their own ambitions and aspirations rather than those determined for them by professionals and services (Alakeson & Perkins, 2012; Perkin & Repper, 2007). Personal budgets might best be described as 'control with money attached'.

Many mental health professionals remain deeply suspicious of personal budgets and the choice and control they might afford those who use services (NHS Confederation, 2011). As one psychiatrist said: 'I'm a highly trained, highly expert specialist in a field which has involved many, many years of training, many years of clinical experience, and my job is to know the best evidence and the best practice for the kind of presentations that I'm expected to see within my field. It would be completely against my code of conduct to say . . . yes, go ahead and spend money on something that has no evidence base' (p. 14).

Although expressed in rather extreme terms, this type of attitude reflects one of the major barriers to both personalization and the implementation of recoveryfocused practice within mental health services. The imperative of 'evidence-based practice' owned by professionals and based on population research (Deegan & Drake, 2006; Perkins, 2012), and failure to recognize the importance of the 'personal medicine' found in 'those activities that gave life meaning and purpose, and that served to raise self-esteem, decrease symptoms, and avoid unwanted outcomes such as hospitalization' (Deegan, 2005, p. 29). Recovery-focused practice requires equal recognition of the expertise of lived experience based on personal narratives, values, preferences and ambitions. Unless these can be brought together in a genuine process of co-production, mental health services can never assist people in their journey of recovery.

Disability equality and rights based legislation

Anti-discrimination legislation in the form of the 1995 Disability Discrimination Act, and 2010 Equality Act that has superseded it, outlaw discrimination on the grounds of disability and require that

employers, education providers and the providers of goods and services make 'reasonable adjustments' to allow access for disabled people. The UK government is also a signatory to the United Nations Convention on the Rights of Persons with Disabilities. In both instances, the definition of disabled people encompasses those with mental health conditions, rather than in some other countries which have mental health specific legislation (Roe, this issue).

In England there is widespread recognition of the importance of opportunity in recovery – the chance to do the things you value and participate as an equal citizen (Boardman et al., 2010; Perkins & Repper, 1996, 2003; Shepherd et al., 2008) and of the barriers imposed by discrimination and exclusion (DoH, 1999; HM Government, 2009, 2011; ODPM, 2004). Despite this, those with a diagnosis of mental health problems and the services that support them have not always recognized this rightsbased agenda or demanded the rights to which people are entitled under legislation. This may be a consequence of people with a diagnosis of mental health problems not seeing themselves as 'disabled' or because mental health services have remained rooted in an approach to recovery based on individual change. Nevertheless, anti-discrimination legislation and human/civil rights agendas are important in enabling people to access the opportunities that facilitate recovery.

Where rights in relation to mental health have been considered, this has generally been in relation to the right to treatment and the right not to be detained and treated against one's will, rather than positive citizenship rights (Sayce, 2000). The discriminatory nature of English mental health legislation has been repeatedly emphasized (Dawson & Szmukler, 2006; Disability Rights Commission, 2007; Szmukler et al., 2010), as has the ways in which it contravenes the United Nations Convention on the Rights of Persons with Disabilities to which the UK is a signatory (High Commissioner for Human Rights, 2009). It is particularly alarming that, at the same time as we have seen ideas about recovery and the need to break down prejudice and discrimination appearing in mental health policy, the number of people forcibly detained and treated has increased and the powers of compulsion extended. Care Quality Commission data shows that the number of detentions in hospital under the Mental Health Act increased from 23,982 in 1989/90 to 41,828 in 1999/00 and 45,755 in 2009/10, with an additional 4,017 uses of the new Community Treatment Orders' (introduced in November 2008) (Care Quality Commission, 2010). Some have questioned whether it is possible for English mental health services to become genuinely recovery-focused while such legislation exists (Perkins, 2012).

Supporting recovery-focused practice: Changing mental health services

There can be no 'blueprint' for recovery – each person must find their own way. However, a number of authors have identified key factors that may be important in the journey. Andresen and colleagues identified finding and maintaining hope (including a sense of personal agency), re-establishing a positive identity, building a meaningful life and taking control and responsibility (Andresen et al., 2003). In England, Repper and Perkins have reviewed people's accounts of their own recovery journeys (Repper & Perkins, 2003; Repper & Perkins, 2009, 2012), and suggested three similar key factors:

- 1. Hope. It is not possible to rebuild your life unless you believe that a decent life is possible and have people around who believe in your possibilities.
- Control. Taking back control over your destiny, the challenges you face and the help you receive to overcome them.
- Opportunity. The chance to do the things that you value and participate in as an equal citizen in all facets of community life.

Turning from individual accounts to services, Le Boutillier and colleagues performed a qualitative analysis of 30 different practice guidance documents on recovery-oriented practice in six countries (USA, England, Scotland, Republic of Ireland, Denmark and New Zealand) (Le Boutillier et al., 2011). These showed considerable variation in document type, categories of guidance, and level of service user involvement. Inductive, semantic level thematic analysis was used to identify dominant themes, and interpretive analysis was then undertaken to group the themes into practice domains. The conceptual framework which emerged identified 16 dominant themes, grouped into four practice domains:

- 1. Promoting citizenship –supporting people who live with mental illness to reintegrate into society and to live as equal citizens.
- 2. Organizational commitment a demonstrable commitment to ensuring the work environment and service structure is conducive to promoting recovery-orientated practice.
- 3. Supporting personally defined recovery supporting individuals to define their own needs, goals, dreams and plans for the future to shape the content of care.
- 4. Working relationship demonstration of a genuine desire to support individuals and their families to fulfil their potential and to shape their own future.

In England, the reality is that mental health services continue to be organized around three "C"s: cure, care and containment. The overarching paradigm guiding the work of services is one of cure: the reduction/elimination of symptoms or problems. Unless and until a person's problems can be eliminated they are "cared for" and, should they be a threat to their own health and safety or that of others, contained (Perkins, 2012). It is widely recognized that, if English mental health services, whether they be statutory or non-statutory, are to promote the recovery of those whom they serve, major changes in culture (attitudes, values and practice) are required (Repper & Perkins, 2003; Sainsbury Centre for Mental Health, 2009; Shepherd et al., 2008; Slade, 2009). Perkins has argued that two key issues need to be addressed: the purpose of mental health services and the balance of power between services and the individuals and communities they serve (Perkins, 2010, 2012).

Recovery-focused services must start by considering not 'the patient in our services' but 'the person in their life', with a primary goal of helping people to live the life they want to live and do the things they want to do. 'We do not build our futures on the basis of our deficits and dysfunctions – ambitions are realised, and dreams pursued, on the foundation of our strengths and resources. Symptoms, diagnosis, prognosis, treatment, support and services must be considered not in terms of how much they reduce problems but how far they enable (or impede) the person to do the things they want to do and live a satisfying, meaningful and valued life' (Perkins, 2012).

If they are to aid people in this journey, services must move from centre stage to the margins of people's lives. Professionals need to move to being 'on tap', not 'on top': making their skills available to people who may need them rather than prescribing what people should do; supporting self-management rather than fixing people. Recovery-focused services need to bring together the expertise of lived experience and professional expertise on equal terms in a process of genuine co-production. At the heart of such co-production lies a fundamental shift in the balance of power at all levels (from service design and delivery to shared decision-making at the level of the individual) and changes in the workforce to include the expertise of lived experience. The existence, and increasing use made of, powers of compulsion afforded under mental health legislation severely jeopardizes such transformations.

Nevertheless, across statutory and non-statutory sectors, attempts are being made to create the cultural transformations necessary if services are genuinely to promote recovery (Mental Health Strategic Network, 2009). Within the statutory sector, two major programmes are in progress. The first,

Implementing Recovery - Organisational Change (ImROC), forms one of the key work-streams supporting implementation of the new Government Mental Health Strategy No Health Without Mental Health (HM Government, 2011). This 3-year programme is delivered via a partnership between the UK Department of Health, the NHS Confederation and the Centre for Mental Health and is based on work conducted at the Centre for Mental Health (formerly Sainsbury Centre for Mental Health) and focuses on transforming mental health service systems at all levels (Shepherd et al., 2008, 2010). The second is the REFOCUS study, a research programme funded by the National Institute for Health Research and delivered by a team based at the Institute of Psychiatry. This programme focuses on changing the interactions between workers and the people they serve via the development of a manualized intervention and associated training.

The ImROC programme

This programme is founded on a framework of 10 key 'organizational challenges' developed via a process of co-production in five workshops involving a total of over 300 mental health and social care workers across statutory and non-statutory organizations, managers, people using mental health services and relatives and friends who support them (Sainsbury Centre for Mental Health, 2009). This process identified 10 key changes that are needed if services are to better support the recovery of those whom they serve:

- 1. Changing the nature of day-to-day interactions and the quality of experience of both people with mental health problems and their relatives and friends. This includes a change in the relationship between those professionals and those whom they serve. To support these transformations a series of '10 top tips' for recovery-focused practice were developed (Shepherd et al., 2008).
- Delivering comprehensive, service user-led education and training prigrammes for staff. The expertise of lived experience is central in achieving the changes in values, attitides and behaviours necessary if mental health workers are to promote the recovery of those they serve.
- 3. Establishing a recovery education centre/recovery college in order both to promote the recovery of individuals and drive forward changes in attitudes, values and behaviour across the organization. Recovery colleges bring together the expertise of lived and professional experience via co-produced and co-delivered courses/workshops in which staff and people using services can learn together (Perkins, 2012).

- 4. Ensuring organizational commitment and creating a recovery culture at all levels. Training alone is not enough, it needs to be supported by embedding recovery principles in every management process at all levels: recruitment, supervision, appraisal, audit, planning and operational policies and the mission or purpose of the organization.
- Increasing personalization and choice, including personal budgets. Choice and control over treatment and support are essential if people are to take control over their own lives and recovery journey.
- 6. Changing the way we approach risk assessment and management 'The possibility of risk is an inevitable consequence of empowered people making decisions about their own lives' (DoH, 2007, p. 8). Recovery-focused services need to move from 'risk assessment and management' to co-produced safety plans: plans designed to enable people to pursue their aspirations and where responsibility for safety is shared.
- 7. Redefining service user involvement. In recovery-focused services it cannot be the case that one group (staff) involve another (service users) in 'their' services. The challenge is genuine co-production at all levels. 'Co-production goes well beyond user involvement . . . It promotes equal partnership between service workers and those intended to benefit from their services pooling different kinds of knowledge and skill, and working together' (New Economic Foundation, 2011).
- 8. Transforming the workforce. If the expertise of lived experience is to be valued on equal terms to that of professional expertise, this must be reflected in a workforce that includes peer support workers (Adams, this issue): 'We recommend that organisations should consider a radical transformation of the workforce, aiming for perhaps 50% of care delivery by appropriately trained and supported 'peer professionals' (Sainsbury Centre for Mental Health, 2009, p. 3).
- 9. Supporting staff in their journey of recovery. The creation of services that promote recovery involves major changes for their staff, including the erosion of the traditinal 'boundaries' that have been erected to protect 'us' from 'them' (Perkins, 2010).
- 10. Increasing opportunities for building a life 'beyond illness'. Participation is central to recovery (Bradstreet, this issue). If people are to rebuild their lives they must have the same choice, control and freedom as any other citizen at home, at work and as members of the community. This involves supporting both individuals and communities to recognize their own resources and resourcefulness.

The ImROC methodology is based on the principle that just as there can be no 'blueprint' for recovery, there can be no 'blueprint' for developing recovery-focused services. Both are individual journeys of discovery, but ones in which we can learn from others who are travelling a similar path. The 10 organizational challenges form a framework for an internal audit loop or ongoing Plan-Do-Study-Act cycle. Services are assessed by those who provide and receive them against the 10 organizational challenges. Participants then agree the key proprities for action that they consider will have the most impact in achieving local service transformation, draw up a local action plan for moving forward, evaluate progress and identify new priorities (Shepherd et al., 2010).

Mental health services and their partners across England were invited to apply to become one of six pilot sites within the 3-year ImROC programme. These organizations are assisted by a small project team and a group of experienced peer trainers. The project team have extensive understanding of both recovery principles and service transformation — most have lived experience of using mental health services as well as professional and managerial experience. Each site has 30 days consultancy tailored to their plans and preferences. In addition, six learning sets enable sites to come together, share experience and gain peer support from one another.

Although each pilot site has selected different organizational challenges and developed their own local plans, most are, or have already, developed a programme of co-produced, co-delivered training (at board/executive team, middle manager and front line levels) to change the organizational culture and nature of day to day interactions; are establishing 'recovery colleges', training and recruiting peer support workers and peer trainers, and addressing the way in which they approach risk. (Further information about ImROC can be found at www.nhsconfed. org/networks/mentalhealth/ourwork/imroc or www.centreformentalhealth.org.uk/recovery/supporting_recovery.aspx.)

The programme is being evaluated in a number of ways: a peer researcher is employed to conduct qualitative research among peers and staff involved in the transformation process, progress towards self-identified objectives is being evaluated, and each site is required to develop ways of evaluating the experience of those using their services together with national data from the Care Quality Commission survey of the experience of people using community mental health services (www.cqc.org.uk/public/reports-surveys-and-reviews/surveys).

Demand to become a 'pilot site' in the ImROC programme was higher than expected (there were 35 applications for the six places). The six sites selected by the programme steering group demonstrated a

good understanding of the challenge, clear organizational commitment and full involvement of people using services/partner agencies. In order not to waste the evident enthusiasm, the project was extended beyond the six pilot sites in two ways. First, there were a number of sites who were further on in their journey and did not require such intensive assistance from the project. These sites were designated 'demonstration sites', offered (at their discretion) up to 10 days input from the project team and peer trainers and attendance at the learning sets. They were required both to employ the ImROC methodology and share their learning with other sites. Second, 16 of the remaining sites who applied were invited to join the six learning sets.

The REFOCUS study

This research programme has adopted a different approach to increasing support from mental health services for recovery, by focusing directly on interactions between workers and service users. The aim of the broader REFOCUS programme (described at researchintorecovery.com/refocus) is to develop a recovery focus in mental health services in England. One component of the study is the development and evaluation of a manualized complex intervention.

The intervention is based on a number of reviews. For example, a systematic review and narrative synthesis investigated published descriptions and models of personal recovery, with the aim of developing an empirically based conceptual framework (Leamy et al., 2011). A total of 97 papers were included, from 5,208 papers identified and 366 reviewed. Quality assessment included double rating of eligibility, quality ratings using established scales for both the identified qualitative and quantitative studies (with robustness of the synthesis established through thematic analysis to reach category saturation with higher quality studies only), and expert consultation (n = 54). The emergent conceptual framework comprised three inter-linked, super-ordinate categories. Thirteen characteristics of the recovery journey were identified, which provide conceptual clarity about the meaning of a recovery orientation. Five recovery processes comprising 'connectedness', 'hope and optimism about the future', 'identity', 'meaning in life' and 'empowerment' (giving the acronym CHIME) were identified, which informed the valuation strategy in the REFOCUS study. Finally, recovery stage descriptions were mapped onto the Transtheoretical Model of Change (Prochaska & DiClemente, 1982), giving a framework for guiding stage-specific clinical interventions and evaluation strategies. Studies focused on recovery for black and minority ethnic (BME) individuals showed a greater

emphasis on spirituality and stigma, and identified two additional themes: 'culturally specific facilitating factors' and 'collectivist notions of recovery'. This emphasis on individuality informed the REFOCUS intervention.

The resulting manual (Bird et al., 2011) involved substantial input from people with lived experience of mental illness (Slade et al., 2010). A key insight which informed its contents is the central importance not only of what a mental health worker does (in providing evidence-based treatments and interventions) but also how they do it. This points of course to the strengths and limitations of disorder-specific clinical guidelines approach to mandating treatments to be provided. The intervention involves a complex intervention with two components: three working practices which support recovery (the 'what') and a range of approaches to enabling recovery-promoting relationships between staff and service users (the 'how').

The working practices involve:

- Understanding the individual's values and treatment preferences the person's values and preferences are understood to be central, incorporating both their own dreams and aspirations, as well as their preferred mechanisms of recovery. Without this knowledge, it is difficult to avoid clinical assumptions dominating the care planning process. Three approaches are suggested in the manual: having a conversation informed by a topic guide, undertaking life story work to generate a narrative, and supporting the individual to create visual life maps, covering for example relationships, background, 'Who am I?', preferences, choices or respect.
- 2. Assessing strengths a key insight from the wellbeing (O'Hagan, this issue) and positive psychology (Slade, 2010b) literature is that amplifying strengths may be more beneficial than ameliorating deficits (Oades, this issue). Strengths are the internal and external resources available to the person. An internal resource is something positive about the person, including personal qualities (e.g. hopefulness, creativity), outlooks (e.g. a positive cultural identity), and life experiences (e.g. strategies that previously worked for the individual, or having experienced periods of wellbeing). External resources are anything which helps or could help the person in their life, such as respected role models, a supportive family, being well-connected in the local area, having a friend, undertaking voluntary or paid work, having a decent place to live, and involvement in collective activities (e.g. singing in a choir). External resources may also include ways in which

- mental health and other services can help the individual, either in the way they work with people (e.g. holding hope for the person) or in the content of care (e.g. offering effective treatments). Identifying and then harnessing strengths provides an opportunity for people who feel 'stuck' to find a way forwards in life. A strengths worksheet provides a framework for this assessment.
- Supporting goal-striving the attainment of personally to "valued goals - is a positive experience which beneficially impacts on hope, agency, resilience and empowerment. Goal-striving is supported by six principles:
 - i. Goal-striving is supported by coaching;
 - The person's goals are the primary focus of action planning;
 - iii. Approach goals are more achievable and sustainable than avoidance goals;
 - iv. Goal-striving is based on the person's values and treatment preferences;
 - v. Goal-striving builds on strengths;
 - vi. Actions should focus on supporting the person to do as much as possible for themselves.

In addition, the intervention develops recoverypromoting relationships in several ways: providing consumer-led training to increase knowledge about recovery; providing training and reflective practice follow-up sessions to develop coaching skills in staff, as an interpersonal style to bring to interactions with service users; a partnership project involving staff and service users working together to do or learn something jointly (Amering, this issue); and raising expectations held by service users about how mental health workers will interact with them.

The intended effects of the intervention are described in the REFOCUS manual (Bird et al., 2011), which outlines the impact on staff values, knowledge, attitudes, skills, behavioural intent and behaviour, and the consequent impact on the experience of mental health service users. This manualized intervention is currently being evaluated (2011-2014) in the REFOCUS randomised controlled trial (RCT) (ISRCTN02507940) (Slade et al., 2011). This cluster randomised controlled trial is taking place in London and Gloucester, involving 30 mental health teams with over 500 mental health workers. The evaluation involves collecting outcome information from 15 randomly chosen service users from each team, and from their involved worker.

Careful attention has been paid to outcome evaluation, since this is challenging in recovery research (Slade, 2010a). Five approaches are being used. First, standardized measures for recovery are

administered, including hope, empowerment and well-being. The sample size calculation is based on finding a change in personal recovery, assessed using the Questionnaire about the Processes of Recovery (Neil et al., 2009). Second, change in service support for recovery is assessed using a new measure called INSPIRE (researchintorecovery.com/inspire). Third, two approaches to individualizing outcome are used. The standard trial approach of specifying a primary outcome in advance has the intrinsic problem that different participants will place different values on that outcome (Slade & Hayward, 2007). This is being addressed by asking participants at the start of the intervention to 1) choose a key outcome domain from a list, where each item in the list is linked to a standardized outcome measure which is then administered; and 2) to identify a goal, with progress towards that goal evaluated at 1-year follow-up as a measure of personal benefit from the intervention. Fourth, a range of standard clinical outcomes (symptomatology, functioning, etc.) are assessed, to allow the relationship between recovery and clinical outcomes to be investigated. Fifth, a pre-planned sub-group analysis will focus on outcomes for people from BME communities, as this group have less positive experiences with mental health service use, and poorer health outcomes.

In addition, data are being collected on fidelity, implementation, and process and economic evaluation. A central scientific challenge concerns whether and how the implementation is implemented, and hence the extent to which it needs modification. Establishing cost-effectiveness of the intervention, including through the use of standardized health economic measures such as ICECAP-A (Al-Janabi et al., 2011), will maximize the likelihood that the REFO-CUS RCT informs clinical guidelines.

Future challenges

In conclusion, the primary challenge facing the development of recovery-focused mental health services is whether NHS services are capable of the major transformation of culture – attitudes, values and practices – that is required. A paradigmatic shift is required (Perkins, 2012; Repper & Perkins, 2003; Shepherd et al., 2008; Slade, 2009).

Worrying signs can already be seen that, in the hands of such a powerful system, and the powerful professional groups, recovery ideas are being distorted and accommodated within existing paradigms. If recovery is interpreted by professionals as 'recovery from illness/deficit or dysfunction' then no change is necessary. If 'recovery' seen as an 'add on' to existing ways of doing things (a new intervention or team), then traditional paradigms remain intact.

Traditional mental health professionals of all hues have a great deal invested in existing structures. Traditional views of 'professionalism' assume that 'experts' have a body of knowledge that cannot be accessed or understood by non-professionals; therefore it is their role to prescribe what is good for people and ensure compliance with these expert prescriptions. Such assumptions are central to professional identity and training. Recovery-focused practice challenges this hegemony. First, it asserts that the expertise of lived experience is as important as professional expertise (Tse, this issue). Second, it argues that there is value in the experience of mental distress - that this may be an asset, rather than a vulnerability - and that 'symptom reduction' may not be the ultimate goal of services. Third, it considers that individuals, not professionals, are the best judge of what helps them in their recovery journey and the direction this journey should take. In an era of diminishing public resources, professionals who feel their jobs are threatened cling to their 'core roles' and oppose any suggestion they may not hold the key. Political imperatives to save money may use ideas about 'recovery' as an excuse for cutting service rather than using resources differently (if people 'recover' then their services can be cut).

The National Health Service remains a major political issue. Each new government has to stamp its mark on services and all are acutely aware of the impact of 'public opinion' on the votes they receive. As well as the ideas about 'recovery' espoused in government policy, parties of all persuasions have other competing political and economic agendas. These include reducing costs and increasing productivity and reducing public anxiety about the threats posed by people with mental health problems via increased compulsion and containment.

Both ImROC and REFOCUS have as their primary aim the transformation of mainstream statutory services. Given the challenges described, there are many in the UK user/survivor movement who question whether it is possible or desirable to do this and argue that the future must lie in alternative, nonstatutory, peer-led provision. However, the NHS continues to be held in high esteem in the English public consciousness. It is politically very difficult to close NHS services even if money is diverted to alternative, non-statutory, recovery-focused provision, and any politicians attempting this risk reducing their chances of re-election. While the vast majority of people with mental health problems receive help from statutory NHS and social services, efforts to fundamentally transform these services may be justified. However, the extent to which programmes like ImROC or REFOCUS can achieve this transformation - genuinely transfer power and leadership to those whom they serve - remains to be seen.

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