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 **Foresight**

**Mental Capital and Wellbeing:  
Making the most of ourselves in the 21st century**

**State-of-Science Review: SR-B9  
Factors Influencing Recovery from Serious Mental Illness and  
Enhancing Participation in Family, Social and Working Life**

Bob Grove Ph.D.  
Director, Employment Programme  
The Sainsbury Centre for Mental Health

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any Government or organisation.*

## Summary

Over the past 10-15 years there has been a refocusing of the aims and purposes of services for people with severe and enduring mental ill-health, designed to include and give greater priority to interventions that promote integration into society (which in the days of the old asylums used to be known as rehabilitation and resettlement). Alongside this has come a conceptual shift towards a rights-based framework increasingly referred to as 'recovery'. Recovery is a disputed and often loosely defined term incorporating within its meanings entitlements to basic human rights and social inclusion in all the domains that constitute a life well lived. This review does not attempt to enter the philosophical debate about the recovery paradigm but rather assumes that the next 10-15 years will see continuing emphasis on enabling people with severe and enduring mental ill-health to lead lives that include a decent home, work and, perhaps most importantly, a full range of relationships built on shared interests and affections and not blighted by stigma, exclusion and poverty. The review scopes and summarises the scientific evidence on how these facets of a life well lived can be achieved and concludes with some informed speculation on the barriers and supportive factors that will influence this agenda in the coming years.

### 1. Recovery from severe and enduring mental illness

In England, the starting point for the definition of severe mental illness is contained within the National Service Framework for Mental Health (DH, 1999). Based on history of service use as well as diagnosis, the purpose of this definition is, *inter alia*, to aid determination of eligibility for specialist services. It excludes a group of people who, while not meeting the criteria in terms of severity or service use, are nonetheless impaired in their ability to function day-to-day and in terms of social participation. This group is large – including perhaps two-thirds of the *circa* one million people with mental health problems on Incapacity Benefit – and managed, where at all, predominantly within primary care. This review concentrates on those who meet the NSF criteria but does not exclude studies that include people experiencing long-term disability, that is, one year or more (the definition used in the UK Disability Discrimination Act, 1995).

Recovery is an increasingly popular (RCP, 2007) but contested term, often associated with the work of Professor William Anthony (Anthony, 1991) and colleagues from the Center for Psychiatric Rehabilitation in Boston. It is derived from the experiences of service users who may continue to experience periods of severe mental ill-health but still manage to lead productive lives with satisfying levels of social participation and optimism (Deegan, 1988; Chamberlain, 1995).

Recovery is predicated on principles of self-management, self-determination and therapeutic relationships with treating clinicians that are as collaborative as possible within the constraints of personal and public safety. The issue of medication is always a thorny one, but proper, collaborative management is, for many who experience severe mental illness, the 'foundation' of successful recovery (Edward Francell, Treatment Advocacy Centre website). The term is contested because it is difficult to operationalise for research and service design purposes, being used to cover both states of mind and a very broad range of individually determined outcomes (Davidson et al., 2006).

This review does not attempt to enter the debate about recovery, but rather focuses on the main features commonly associated with a life well-lived<sup>1</sup>, making the assumption that, whatever the meaning and lifespan of the term 'recovery', the shift of emphasis in mental health services towards a much broader range of

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<sup>1</sup>"Social inclusion must come down to somewhere to live, something to do and someone to love. It's as simple – and as complicated as that." Charles Fraser quoted in *Creating Accepting Communities*. MIND, 2003

service outcomes that include work, housing and social relationships in non-protected settings will continue well into the present century.

## **2. The dimensions of 'living as well as possible' (South London and Maudsley NHS Foundation Trust, 2007)**

There are many ways to describe the dimensions of 'living well'. Some are framed negatively, referring to aspects of social exclusion (SEU, 2004a) others positively, talking about life domains of social inclusion or equalities (NSIP, 2007; Cabinet Office, 2007). The problem in selecting the most important dimensions is that priorities are different for each individual and they change according to an individual's circumstances and time of life. However, it is possible to select a manageable number of items that appear in all lists and are reasonably discrete.

- Freedom from abuse, stigma and discrimination.
- Access to resources.
- Work and employment.
- Housing.
- Social participation.
- Personal relationships.

Within these six dimensions are a number of important sub-dimensions which, some would argue, should be in the list in their own right. Nonetheless, in the absence of any authoritative list, these six are the topics that will provide the framework for this paper.

## **3. Limitations of this review**

One problem for a brief scientific review such as this is that the volume of research into these life domains is very unevenly spread. Indeed, there is more research about work and employment than all the others put together. Another limitation is that, because of the 'real life' nature of the research topics and the newness of the field, well powered, tightly designed longitudinal studies and randomised controlled trials are relatively few compared to the number of exploratory studies and uncontrolled evaluations (eg. see section on Housing below). Inevitably, therefore, much of what appears below is the best evidence available and far from conclusive in its practical implications.

## **4. Predictors of recovery**

Accepting Warner's distinction between clinical and social recovery (Warner, 2003), his finding that 35-45% of people with a diagnosis of schizophrenia achieve good social recovery is not inconsistent with the findings of the 30-year Vermont studies. These found that half to two-thirds of people in the sample who, in the 1950s, looked destined for lifelong institutionalisation, by the end were living reasonably satisfactory lives:

*'... long-term outcome was neither downward nor marginal but an evolution into various degrees of productivity, social involvement, wellness and competent functioning.'*

(Harding et al., 1987 p730).

On the other hand, a study of the development and prediction of social disability across 15 years in six European centres (Wiersma et al., 2000) was less optimistic. After 15 years, only 17% of the cohort had no disability, while 24% remained severely disabled. Interestingly, although disability did improve over time, a small group who did not improve at all were traced to hospitals and sheltered accommodation. Gender, age, onset, duration of untreated psychosis or type of remission during the first two years did not predict long-term outcome of disability. Severity of disability at the first three assessments of the illness contributed significantly to the explanation of its variance at 15 years. The researchers' conclusion was that disability ameliorates, but less than hoped.

In terms of physical health, a cross-sectional study (Chafetz et al., 2006) of 309 residential care clients in 10-year age groups found that the differences in functioning between the study groups and population norms increased with age and that older age groups in the study resembled cohorts 10 to 20 years older. Deviation from population norms started at age 25. Protective factors were: male gender; younger age; having earned income in the past six months; having less life-time smoking; and having an admission diagnosis other than depression or schizophrenia spectrum disorders. Predictors of vocational outcomes have been the subject of numerous studies, with few clear conclusions except that people who say they want to work should not be excluded from programmes on the grounds of predicted employability (Grove and Membrey, 2005). A review of controlled studies (Tsang et al., 2000) found that diagnostic categories and psychiatric symptoms are inconsistent predictors. Mixed results were obtained for age, sex, ethnicity, marital status, residential area, cognitive functioning, substance abuse, previous hospitalisation and premorbid occupational performance. Premorbid functioning, work history and social skills were the most powerful predictors. Of the predictors reported by two or more controlled studies, only education consistently had no predictive value. These conclusions are challenged by an Australian study as failing to factor in local labour market conditions (Waghorn and Chant, 2002).

Other studies have suggested that self-efficacy (self-belief, motivation, mastery of tasks) may override even work history (Regenold et al, 1999) but, as these internal factors are changed by successful employment placement, their value as predictors is limited. Although we are primarily concerned with severe mental illness, we noted earlier that common mental disorders, especially depressive disorders, are associated with high levels of disability for significant numbers of people. The social precursors to onset and recovery from common mental health problems are, therefore, important economically and in terms of service priorities (Layard, 2004). A study using data from the British Household Panel Survey from 1991-8 found that low social support, separation or divorce, becoming or remaining unemployed, health-limiting daily activities and caring for a sick relative all decreased chances of recovery (Pevalin and Goldberg, 2003). Reduced rates of recovery were also associated with severity of distress. The chances of observing a change of state (onset or recovery) decreased with the number of prior observations in that state. Predicting which individuals will recover is, clearly, a challenging and uncertain task and perhaps not the most fruitful in terms of providing services that support recovery. Nonetheless, research does provide clues as to the issues that service provision needs to address. The more important questions concern the possibility of intervening to promote a recovery mindset and to support people in leading what they themselves regard as 'a good life'. It is these questions, and particularly the last, that are the subject of the rest of this review.

## **5. Freedom from abuse, stigma and discrimination**

A recent book by Graham Thornicroft exploring the subject of discrimination (Thornicroft, 2006) both reviews the literature and presents the results of original research exploring the experiences of people with all kinds of mental health problems. Thornicroft makes a convincing case that discrimination pervades the lives and experiences of people who acquire a psychiatric diagnosis and he supports the views of many service users that this is *the* major barrier to living well.

The popular press is often cited as the major culprit in determining public attitudes, but Thornicroft shows that direct and indirect discrimination operate at every level, from family relationships to human and civil rights. Given that much of this discrimination is unintentional, he goes on to draw an analogy with the term 'institutional racism' from the MacPherson Report (MacPherson, 1999). Other studies have shown that people from African and Caribbean communities often experience forms of double discrimination (SCMH, 2002). Combating discrimination calls, in Thornicroft's view, for concerted and sustained action by service users and their families, and at local and national level. It is a sobering but realistic thought that the evidence on interventions in various domains that follows cannot be applied effectively unless this massive and difficult agenda is addressed at the same time.

## **6. Access to resources**

Severe mental illness is distributed right across the population, but its social consequences are exacerbated by widespread association with poverty, debt and financial insecurity. People with mental health problems are nearly three times more likely than the population at large to be in debt. One in four tenants with mental health problems has serious rent arrears and is at risk of losing their home (SEU, 2004a).

People with mental health problems also have difficulty accessing insurance and other financial services. A MIND survey (Reid and Baker, 1996) found that 25% of those interviewed had been turned down by a finance or insurance company. This figure would have been much higher, but many people said that they did not bother to apply because they expected to be turned down. This financial insecurity is not helped by largely unintended disincentives within the interactions of different welfare benefits, which make people feel very insecure about changes to their circumstances (Seebohm and Scott, 2004).

When it comes to basic healthcare – both mental and physical – there is substantial evidence of inequalities of treatment and outcomes (DRC, 2006), with many people reporting unacceptable delays, neglect and misdiagnosis. Thornicroft links this directly to stereotyping and discrimination by health care staff (pp 87-99). Supporting people to enable them to get the advice and resources they need is usually left to voluntary organisations such as Citizens Advice, Welfare Rights Services and specialist mental health advocacy organisations such as MIND. In the past few years, service user-led organisations have also entered the field, such as the Bi-Polar Organisation (formerly the Manic Depression Fellowship) which established the first travel insurance scheme for people with mental health problems, and Loonscape, set up by Fresh Finance UK, which provides access to financial services, including insurance, for people with mental health problems.

## **7. Work and employment**

The poor labour market position of people with mental health problems is well known. They constitute the highest proportion of those on disability benefits; they have amongst the lowest employment rates; and have difficulty in retaining jobs when mental health problems occur. In an economic downturn they have a lower re-entry rate into the labour market.

The scale of the issues surrounding mental health and employment were outlined in the Social Exclusion Unit Report (SEU, 2004b). Poor labour market outcomes have been a rising trend, especially for those classed as experiencing 'common' mental health problems. The average employment rate for the UK working age population is 74%, compared to 47% for all people with a disability, but only 21% for people with long-term mental illness (ONS, *Labour Force Survey*, 2006). There is some evidence that the rates for people with severe mental illness are much lower, at 8% or less for people with a diagnosis of schizophrenia (Perkins and Rinaldi, 2002).

These figures are of concern for more than economic reasons. There is strong evidence that health outcomes are heavily influenced by unemployment – work being generally good for health and wellbeing and unemployment being positively dangerous (Waddell and Burton, 2006). There is also evidence that the great majority of people who use secondary mental health services aspire to paid employment (Seebohm and Secker, 2005). The barriers to achieving their ambitions are, however, significant. Active symptoms, cognitive impairment and episodic illness all present hard, but not insuperable, challenges for the individual and the clinician (Waghorn and Lloyd, 2005). Clinical outcomes are very important (Leff and Warner, 2006 ch 5), but perhaps even more difficult are the social barriers: low expectations by clinicians and family, the effects of treatment, stigma and discrimination and disincentives in the welfare system that put basic income at risk (Seebohm and Scott, 2004).

However, each of these (and many other factors) operate differently for each individual such that the evidence strongly favours approaches that have an individual focus and are sufficiently adaptable to accommodate to setbacks, changing circumstances and changing needs. The strongest evidence base supports a service methodology known as Individual Placement and Support (Crowther et al., 2001) which has developed and tested a fidelity scale (Bond et al., 1998).

More recently, there have been studies assessing the strength of the evidence on different service features within the IPS fidelity scale (Schneider et al., 2002) and more work on issues such as: preparation using cognitive educational methods (McGurk et al., 2005) and cognitive remediation (Wyke et al., 2007); readiness and selection (Roberts and Pratt, 2007); and the influence of job-seeking styles (Alverson et al., 2006). Even so, the basic principles of IPS remain unchallenged. They are now incorporated in commissioning guidance recently issued by the Department of Health (DH, 2006).

There remain, however, some outstanding questions. Much of the research has been carried out in the United States. Although there is a developing evidence basis in the UK and Europe (Burns et al., 2007) which is pointing to similar levels of efficacy, there remain considerable differences in the context in which programmes operate. So it may be necessary to make local adaptations to achieve maximum effect (Waghorn and Lloyd, 2005).

The best programmes in the US in randomised controlled trials report success rates of 47-78% (average 61%) in achieving some form of competitive employment (Bond et al., 2008). Firstly, these figures still leave a lot of people who do not get work (Roberts and Pratt, 2007). Secondly, although this is a vast improvement on what went before, the work people do obtain is often part time and short-term. The paucity, as yet, of published studies of longer term outcomes and career pathways means that we do not know if the effects of these programmes are maintained across people's working lives. However, we do know that the longer people are in supported employment the longer they stay in jobs and the more hours they work (Becker et al., 2007; Salyers et al., 2004). Until supported employment becomes established and available on a sustainable basis across much more of the UK, this research cannot be done. So, the best that we can say is that the evidence is pointing in a clear direction, but much more work remains. Employment is, of course, not the only form of work. Many people find benefit in volunteering and in pursuing further education – sometimes as a stepping stone to employment and sometimes as ends in themselves. The scientific evidence on effective ways of supporting volunteering and education is not extensive, but there are descriptions of such services which also review such evidence as exists (Mowbray et al., 2005) and provide guidance on good practice (Bates, 2005). The principles applied in each case are similar to those for supported employment.

## 8. Housing and housing support

In the UK, health authorities and local authorities are expected to provide a range of care and support services for people with severe mental disorders. Local housing authorities are responsible for assessing and meeting the needs of vulnerable people, but only in unitary authorities will the housing and social care authority be the same body. Both housing and care and support services are often achieved in collaboration with healthcare trusts, and with third sector organisations, including housing associations. However, for such an important topic, the research literature on housing and housing support is disappointingly thin.

The National Institute for Mental Health in England published a study of mental health issues arising in social housing (NSIP, 2007). This looks at the joint working between housing and other agencies. Following the Social Exclusion Unit's report (SEU, 2004a) the report cites strong evidence that people with mental health problems are at a disadvantage in the housing market, namely:

- People with mental health problems are significantly under-represented in owner occupation;
- Mental health issues are highly identified in tenancy breakdowns;
- There are high rates of mental ill-health amongst homeless people and higher concentrations of individuals with mental health problems in inner cities where poor housing predominates.

Some studies cited suggest that medical priority re-housing can have a particularly beneficial effect for people with mental health problems (Blackman et al., 2003), although area-based neighbourhood renewal initiatives provide a more mixed picture of success (Kai et al., 2000; Ellaway and MacIntyre, 2004), perhaps because building work itself can exacerbate stress. Their overall conclusion is that mental health services need to change and appreciate that housing and the right kind of support is their business.

A Cochrane review (Chilvers et al., 2006) looked at studies in which people with 'severe mental disorders' were allocated to supported housing compared with outreach support and standard care. The review deals with two types of housing: dedicated supported schemes and tenancies with outreach support. 136 studies were found but none reached the initial criteria set by the authors. These are set out in the review, but reasons for their exclusion may be summarised as failing to compare supported housing with 'ordinary' care. It found that choice of one or other of the two types of scheme is based on a combination of personal preference, professional judgment and on the availability of services. The review suggests that the topic would benefit from rigorous research.

An unpublished paper accompanying a conference presentation (O'Mally and Croucher, 2003) provides a review of the policy environment from the community care reforms of the late 1980s and through the 1990s. The authors refer to evidence of psychiatric beds 'blocked' by those unable to leave for want of suitable accommodation. They also review a number of studies looking at accommodation with low levels of staff and support, finding some evidence that this works well for some people but is insufficient for all. The evidence is weak in terms of design but does suggest that clients using these services are relatively satisfied. For accommodation with high levels of support there is a paucity of evaluation of schemes aside from hospital hostels. There is also tension between whether this type of support is permanent for 'long stay patients' or whether it can be seen as transitional – preparing people for more independent lives. Overall, the authors found that the literature was not able to provide any clear models of good practice. Some reports on the situation in London (Boyle and Jenkins, 2003; SCMH, 2003) showed serious inadequacies in the capital's provision of housing for people with severe mental illness, including unavailability of move-on accommodation, weakness in planning, and poor inter-agency working. This tends to emphasise the point that types of housing and support are determined to a great extent by what is available at local level.

Since 2003, housing support for vulnerable people in England has been based on the Supporting People programme (DETR 1999; SCMH, 2004). The programme is locally devolved, though there is now a national outcome framework launched in May 2007 which records how successful the housing support services have been in meeting clients' needs (including mental health clients). Outcomes are based on DfES's five high-level outcomes:

- Economic Wellbeing;
- Enjoy and Achieve;
- Be Healthy;
- Stay Safe;
- Make a Positive Contribution.

As yet there has been no published evaluation of the outcome framework in relation to outcomes for people with mental health problems, though the data is available on a public website ([www.spkweb.org.uk/Subjects/Client\\_groups/Mental+Health](http://www.spkweb.org.uk/Subjects/Client_groups/Mental+Health)). In addition, there has been a report on the financial benefits of the programme (Department for Communities and Local Government, 2008).

US studies have tended to concentrate most on the problems of low-income people with psychiatric disabilities, many of whom are homeless including street homeless. One study (Seigal et al., 2006) compares two different housing and support arrangements. Tenants in supported housing reported greater housing satisfaction in terms of autonomy and economic viability but, over time, reported feelings of isolation. The latter problem was particularly associated with those suffering depression. Another study (Martinez and Burt, 2006) from California examined the impact of supportive housing offering high levels of support to homeless people with mental health and substance abuse disorders. This was a very disabled population receiving high levels of support in whom it was found that the use of psychiatric emergency and in-patient facilities was reduced.

A further recent study (SAMSA, 2006) looked specifically at the US board and care system. Recommendations of relevance in the UK include:

- Increase consumers' self direction, with money management training and peer support;
- Improve methods of outcome measures for health status and quality of life;
- Strengthen peer support;
- Enhance access to both physical and mental health care with wellness recovery plans.

In conclusion, then, there is evidence that housing and housing support are key issues for people with mental health problems and that poor housing is associated with increased levels of mental ill-health, unemployment and criminality. There is, however, a lack of evidence about how the differing housing needs of people with mental health problems can best be met, coupled with little firm evidence about their housing and support preferences. Placement seems more often driven by the range of available provision rather than individuals' needs or choices.

## **9. Social participation**

Chapter 7 of the SEU Report (SEU, 2004a) sets out evidence on the association between mental ill-health, impoverished social networks and low participation in sports, arts, leisure and community activities. Consultation with service users showed that as many as 84% felt socially isolated (as against 29% of the

general population) and that young people, ethnic minorities and people in rural communities were the most likely to be affected.

The consultation also showed that people valued highly the activities they were able to participate in and that they contributed positively to feelings of wellness. We could find no large-scale, controlled studies on the efficacy of specific interventions to promote social participation, although there is a literature on the positive association between physical activity and mental health (Crone, 2003), and also some commissioning guidance from Government with examples of intervention programmes (DH, 2006).

However, the grey literature on social participation has a great many descriptive pieces – with the journal *A life in the day* (published by Pavilion, Brighton, UK) being largely devoted to such topics. Activities described include creative arts, physical exercise/sports, time banks, and faith and religious groups. The last of these, of course, provide much more than social participation. Spirituality can give meaning to life which transcends pain and suffering. An editorial in a recent edition of the *Psychiatric Rehabilitation Journal* devoted to spirituality and recovery proposes the concept of ‘supported spirituality’ (Rusinova and Blanch, 2007), but this has yet to be developed in any practical way.

## **10. Personal relationships**

Family, friends and intimate sexual relationships are at the heart of every human being’s sense of worth and wellbeing. The SEU Report (2004a) documents the negative effects that mental ill-health can have on these crucial relationships, and there are many forms of therapy that attempt to help people maintain and repair close relationships that have become damaged, including family interventions for which a Cochrane Review found some evidence on prevention of relapse and improved compliance with medication, but weak evidence on short- and long-term outcomes (Pharoah et al., 1995). There are, however, very few accounts in the mental health literature of interventions specifically designed to help people make and sustain new friendships. One such is so unusual that it appeared in the national press (James, 2005). *Tapestry* is described as a ‘Social Relationship Agency’ which holds courses in flirting, the (sexual) side-effects of medication, and how to use internet dating agencies (Proudlock and Halle, 2006).

## **11. Conclusion**

Interventions to support people with severe and enduring mental ill-health to recover their lives and live well in ordinary settings are a relatively new phenomenon.

It is inevitable at this stage that the most researched programmes are those dealing with the issues that are most obviously costly to the public purse such as unemployment. But, even here, the science is largely yet to be done in the UK, while the other major area of cost – housing support – has yet to develop a substantial evidence base in relation to user outcomes.

The literature on interventions in other life domains is largely descriptive and based on the activities of inspirational pioneers – increasing numbers of whom are ‘experts by experience’.

The linking of scientific research, especially controlled trials and longitudinal outcome studies, with the increasing participation, creativity and empowerment of people who use mental health services is, arguably, the next big challenge in the mental health research field.

So far as support programmes are concerned, the most important challenge here is to find ways of redesigning and recommissioning existing services to meet to outcomes that users want and need.

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