2. Recovery, Personalisation and Personal Budgets

Vidhya Alakeson and Rachel Perkins
There are two subjects that have the potential to shape mental health policy and practice in the UK and internationally: recovery and personalisation. Both have emerged independently and are prominent in the Government’s mental health strategy, *No Health Without Mental Health* (Department of Health, 2011). In similar ways, both challenge the current predominance of professional, clinical knowledge over the expertise of lived experience in the mental health system and require significant changes in the culture, practice and organisation of mental health services. At their core, both recovery and personalisation are rooted in self-determination and reclaiming the rights of full citizenship for people with a lived experience of mental health problems.

The purpose of this paper is to explore the links between recovery and personalisation and demonstrate how both are part of a common agenda for mental health system transformation. While personalisation in mental health services is a more recent concept, it builds on approaches that are already underway as part of recovery-oriented practice. In fact, personalisation, personal budgets (PBs) in social care and personal health budgets (PHBs) in the NHS can help embed and enhance recovery-oriented practice.

The first part of this paper describes personalisation, personal budgets and personal health budgets. The second sets out the shared philosophy and objectives of recovery and personalisation and discusses what the two approaches mean for changing the current service system. The third part focuses on personal health budgets as tools for recovery and identifies the eight core features that need to be put in place if recovery-oriented services are to maximise the potential of personal health budgets.

Introduction
Having left institutions, many disabled people found themselves living in the community but segregated from others and denied the opportunity to play a full part in family and community life. This led to a call for independence that was expressed most clearly in the desire of individuals to take control of their support in order to create a more meaningful, more integrated and more fulfilled life for themselves as active participants in the community (Brewis & Fitzgerald, 2010). The concept of personalisation was developed in part as a response to the demands raised by the ‘independent living’ movement defined as “all disabled people having the same choice, control and freedom as any other citizen - at home, at work, and as members of the community” (Disability Rights Commission, 2002).

Personalisation emphasizes greater individual control of the resources and supports needed to enable people to participate as equal citizens and pursue their own ambitions and aspirations rather than those determined for them by services and professionals (PMSU, 2005; ODI, 2008). Personal budgets in social care and personal health budgets in the NHS are, therefore, tools to support the personalisation of health and social care services.

A personal budget is an allocation of social care or NHS resources or an integrated allocation of both that is controlled by an individual and can be used to meet identified goals. PBs and PHBs give individuals and their carers greater say over how their health and social care needs are met. They do this by transferring control of public resources to individuals rather than having the state commission services on their behalf. Individuals can receive the money directly, it can be managed by an independent third party, or can be held as a virtual budget by commissioners. Whichever way individuals choose to receive the money, they should still be able make the decisions that matter most to them.

PBs and PHBs are also more than a budget; they are the basis of a different conversation between individuals, those who support them and clinical professionals in which each shares information and expertise to produce better outcomes. There are seven basic steps in the personal budget or personal health budget process, which are set out in the box overleaf.
1. The first step is for individuals to complete an assessment or self-assessment questionnaire that identifies areas where they need support.

2. The assessment generates a score which is linked to a resource allocation system (RAS) to produce a personal budget amount. The RAS ensures that resources are allocated in a fair and transparent way to individuals according to need.

3. The personal budget amount provides the starting point for developing a recovery support plan which identifies the goals a person has for his or her recovery and how those goals could be met. People can plan by themselves, with the support of friends and family, with peer support or with a professional broker. There is no set menu for support, allowing people and their supporters to develop highly personal, creative solutions.

4. The support plan is approved on the basis of being financially and clinically appropriate. Since there is no fixed menu, approval should focus on the likelihood that the support plan will contribute to a person’s recovery.

5. Individuals can exercise as much or as little direct control over the money in their personal budget as they choose. They can receive it as a direct payment which they manage, they can use a third party to manage the money on their behalf or it can be held by a provider or commissioner.

6. With decisions about the money made, the services and supports in the plan can be put in place, either by the person themselves or by the organisation that holds the budget in collaboration with them.

7. A person’s support plan is reviewed on a regular basis and its effectiveness is judged on the basis of whether the goals identified in the plan are being met and the person is progressing in their recovery. If a person’s needs change significantly, they will complete a new self-assessment and will be allocated a new personal budget amount.
Recovery and personalisation see people who use services as “whole people in their whole context” (Brewis & Fitzgerald, 2010). This means recognizing that alongside the diagnoses, deficits and dysfunctions individuals may have, they also have strengths, skills and assets to contribute. They have likes and dislikes, preferences, tastes and values. Everyone is more than a ‘mental patient’ and occupies multiple roles as, for example, parent, sibling, child, employee and carer. An individual’s social context also brings with it strengths and possibilities for enhanced recovery. The support of family members, social networks or having a valued role in the community can all provide the hope that drives individual recovery.

Recognising individuals as whole people and harnessing their strengths, preferences and motivations will strengthen the possibility of recovery. In the context of personalisation, the ‘real wealth’ framework (see box on the right) has been developed to define the factors that underpin the quality of people’s lives (Duffy, 2010). The challenge for the mental health system is to enhance not deplete the ‘real wealth’ that provides the basis for individual recovery and a fairer society.

For example, the common failure to take psychiatric medication often stems from the negative effects of prescribed medicines on facets of life that individuals consider important, such as their role as a parent or employee – their real wealth. These activities have also been described as ‘personal medicine’ – the everyday activities that can be a source of motivation and have significant therapeutic value (Deegan, 2005). A conflict between professionally recommended treatment and ‘personal medicine’ arises when medical professionals fail to consider the individuals when making treatment decisions (Deegan & Drake, 2006).

### The five dimensions of real wealth

1. **Strengths**
   Each person is endowed with a particular set of strengths and weaknesses. These strengths go far beyond the physical and include skills, interests and even needs.

2. **Relationships**
   One of the most important guarantees of good physical and mental health is to have friends, family and other supporters. In times of difficulty, friends and family are usually the most important source of support.

3. **Community**
   Most individual achievements are only possible to the extent that people are able to access appropriate opportunities from within a community. Work, education, contribution and personal expression all rely on community opportunities.

4. **Control**
   A person’s ability to access the community, build relationships and use their individual strengths all depend on having control over the future. Some elements of control are dependent on access to financial resources. A lack of control makes it impossible for a person to fully realise their goals.

5. **Resilience**
   Perhaps the most important factor that determines the ability of a person to achieve good outcomes is their own sense of resilience, their ability to see and value positive opportunities and not to be overwhelmed by difficulties and problems. This can also be thought of as hope.

Source: www.centreforwelfarereform.org.uk
What recovery and personalisation mean for current systems and services

Today’s mental health services are organized around the three Cs: cure, care and containment. The primary focus 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, they are ‘contained’ (Perkins, 2012; Perkins & Slade, 2012). This focus does not recognize the basic goals that most individuals have for their lives: to have meaningful activity; to have meaningful relationships; and to have a place to call home (Nerney, 2011). Recovery and personalisation challenge the mental health system to support individuals to achieve these goals. They call into question the current ‘gift model’ in mental health services in which professionals are in control and individuals are recipients of the care and treatment decided by these ‘experts’ (Duffy, 2010).

The scale of the challenge to the current system was well documented in a series of papers by the NHS Confederation that reported the views of Chief Executives, mental health clinicians and service users about personal health budgets. Demand for PHBs among service users was strong as all wanted to change something about their current care package but few were optimistic about gaining greater control (NMHDU and Mental Health Network, 2009, 2011a, 2011b). Each group saw significant barriers to the implementation of PHBs in the NHS, many of which were linked to current culture and practice. As one psychiatrist remarked:

“I’m a highly trained, highly expert specialist in a field which has involved many years of training, many years of clinical experience, and my job is to know the best evidence and best practice. It would be completely against my code of practice to say to a young person, yes go ahead and spend money on something that has no evidence base.” (NMHDU & Mental Health Network, 2011a).

The three most important challenges posed by recovery and personalization for the mental health system are:

- shifting the established balance of power between individuals and professionals,
- ending the dominance of clinical treatment, and
- reorienting the system towards wider social outcomes.

Shifting the balance of power

Central to the challenge that recovery and personalisation pose to the existing service system is the issue of who holds the power and control (see Repper & Perkins, 2003, 2012; Shepherd et al., 2008). Personalised recovery-focused practice requires recognising two sorts of expertise: professional expertise grounded in research, training and clinical experience and the expertise of having lived with a mental health condition. The challenge for services is to move from attempts to ensure compliance with ‘expert’, professional prescriptions to a process of shared decision-making that brings together these two types of expertise, shifting from a ‘gift model’ to a ‘citizenship model’ with the individual at the centre of the service system (Duffy, 2010).

“Shared decision making diverges radically from compliance because it assumes two experts – the client and the practitioner – must share respective information and determine collaboratively optimum treatment .... It helps to bridge the empirical evidence base, which is established on population averages, with the unique concerns, values and life context of the individual client. From the vantage point of the individual healthcare client, the efficacy of a particular medication is not certain ... the question of how the medication will affect the individual becomes an open experiment for two co-experimenters – the client and the practitioner.” (Deegan & Drake, 2006)

Striking a better balance between the two types of expertise is particularly important for long-term conditions such as mental health problems
where the condition and its impact on everyday life have to be managed by individuals and their families, with only intermittent intervention from professionals. Even a person receiving intensive support from an Assertive Outreach Team will see a clinician for no more than 156 hours in a year (3 hours per week). This constitutes but a small fraction of the person’s life.

A new relationship with clinical treatment

Linked to the concept of a power shift has to be a move away from the centrality of clinical treatment as the only valid route to well being. Some people find treatment – whether psychological or pharmacological – helpful, but treatment forms only a part (and probably a smaller part than most professionals would care to acknowledge) of what is often a rich tapestry of ways in which people manage the challenges they face.

"Over the years I have worked hard to become an expert in my own self-care... Sometimes I use medications, therapy, self-help and mutual support groups, friends, my relationship with God, work, exercise, spending time in nature – all of these measures help me remain whole and healthy, even though I have a disability.” (Deegan, 1993)

Professionals will remain important, they have important tools to share: the latest guidelines, knowledge of research evidence and experience from clinical practice. But in a recovery-oriented system, professional expertise should be ‘on tap’, not ‘on top’ (Repper & Perkins, 2003, 2012; Shepherd et al., 2008). It should be readily on hand and available when it is needed but it is up to individuals how they use that knowledge and the extent to which it is balanced by other approaches and priorities. The value of professional treatment and intervention lies in supporting self-care and the pursuit of individual ambitions.

From service silos to health and social outcomes

Supporting people to rebuild their lives means breaking out of existing service silos dictated largely by government funding and bureaucratic systems to pursue improvement in outcomes. It means placing greater emphasis on services such as housing, friends and social networks, education and employment alongside clinical care and treatment. This will involve greater coordination across public services as well as greater flexibility in the way NHS and social care resources can be used. A college course may help someone recover and a computer connected to the internet may keep someone safe enough to remain out of hospital, but neither would traditionally be paid for by the NHS. It will also mean greater use of universal services and community resources that promote inclusion and social connection, in contrast to community-based services that have often trapped people in segregated settings (Boardman & Friedli, 2012).
1. Small, one-off payments are being used to enhance individual recovery.
2. Resource allocations systems that match an assessment of need to an amount of money. This is the approach being taken in Croydon (see box on the right).
3. PHBs based on the cost of existing packages of care. This has been the approach taken with large, residential care packages.

In addition, attempts are being made to integrate NHS and social care resources to provide individuals with a single, integrated budget and planning process. It will be critical to ensure that allocation systems for PHBs remains simple and focused on recovery and do not become overly complicated and bureaucratic, as they have done in some Local Authorities (TLAP, 2011).

2. Effective recovery planning

For personal health budgets to be effective, planning must focus on a person's whole life – what is good, what could be better, what matters most to them and what are their goals and aspirations. The planning that the mental health system does for and with individuals should, therefore, be seen as only one contribution to self-management. For people who are subject to the Care Programme Approach (CPA), that care plan can be integrated into a single plan to support recovery that the person manages as part of their own self-management plan, Personal Recovery Plan or ‘Wellness Recovery Action Plan’.

A recovery support plan does not have to be written for a particular length of time. It may be that a short-term plan for the next month is most appropriate, with a longer term plan to follow. It is possible to build contingencies into the plan. For example, some people find a short stay in a bed and breakfast or increased support from a personal assistant at home a particularly effective form of respite that can prevent hospitalisation. They can keep money...
**Croydon’s Resource Allocation System (RAS)**

This is the approach to resource allocation taken in the Croydon PHB pilot for substance misuse. Several of the domains in Croydon’s RAS would not attract funding in the traditional substance misuse treatment system. However, Croydon has adopted a more recovery-oriented approach and recognizes the importance of supports outside of traditional treatment. The system allocates funding against the following domains through a supported self-assessment questionnaire that individuals complete with a care navigator:

- Opiate use stabilization,
- Ongoing prescribing (opiate substitute),
- Detoxification,
- Help with symptoms of withdrawal,
- Practical barriers/obstacles to treatment,
- Risk and harm reduction,
- Helping individuals to change their behaviour/use of substances,
- Emotional and mental health,
- Key relationships/family and friends,
- Community integration and community life.

Responses to statements/descriptors under each of these domains produce a score which is then linked to an allocation of resources. Not all individuals will attract resources in all domains of the RAS. An individual’s personal health budget is the sum total of the allocations in each domain.

The domains of the RAS do not restrict how a personal health budget is used. The support planning process helps the personal health budget holder to make best use of the PHB alongside universal services and other community resources.

Clinicians can be too bound by traditional ways of thinking to be effective at recovery planning. Independent support brokers can be effective but can significantly add to costs. Friends and family members, peers with lived experience and members of the community can all provide support for recovery planning. If everyone who develops a recovery plan supports one other person to plan, the costs can be kept to minimum. (Financial sustainability is discussed further below.)

**3. New approaches to safety and opportunity**

Recovery depends on individuals having control and access to opportunities and this raises concerns about safety. However, it is important to remember that recovery-oriented and personalised services are built on shared decision-making and the co-production of outcomes between clinicians and individuals. Relationships based on a thorough understanding of a person’s perspective and values can increase safety (Scott-Moncrieff *et al.*, 2009). When individuals are involved in making choices, they are more likely to better manage any risks involved. When individuals choose who is involved in their care, they are more likely to stay safe and when they work in partnership with clinicians and can enter into an honest conversation about choices, there are fewer risks involved (Langen & Lindow, 2004; Perkins & Goddard, 2008). (There will be a paper in this series on risk, due out later in 2012 - see Boardman & Roberts, 2012.)

**4. Creating a more diverse workforce**

In order to implement personal health budgets, professionals are required to work in different ways with individuals, supporting them to make choices rather than developing care plans on their behalf. When asked about PHBs, clinicians, irrespective of their professional background, were most concerned about the tensions between individual choice and their
professional duty of care. In addition, GPs, psychiatrists and psychologists were most concerned about individual choice in the context of evidence-based care and the extent to which PHBs would result in better health outcomes. Occupational therapists, social workers and nurses who generally have more experience of PBs, were primarily concerned that PHBs would add to bureaucracy (NMHDU and Mental Health Network, 2011a). This full range of concerns will need to be addressed in adapting the workforce to work effectively with PHBs.

Some roles that are currently performed by professionals may be taken over by peer workers in a more personalized, recovery-oriented system. The involvement of peer workers and third sector organizations in the delivery of services could allow clinical professionals to become more focused on those tasks where they have unique skills and expertise. (There will be a paper in this series on peer support, due out later in 2012.)

Peer support will be critical to personalisation. Peers can provide informal support for recovery planning as discussed above. Trained peer workers are being used as recovery coaches in PHB programmes such as Texas Self-Directed Care (www.texassdc.org). Using disabled people and user-led organizations to provide support planning for PBs in social care has been shown to create a more person-centred and less bureaucratic process than support provided by Local Authorities (Campbell et al., 2011).

5. Monitoring on the basis of outcomes not spending

Recovery support plans should be regularly reviewed to ensure that their goals are being met. Individuals are held accountable for meeting the goals and not for each individual purchase they make. This is more important than closely monitoring spending. The case study opposite provides an example of the health and social objectives that Ann, a PHB holder in Northamptonshire, has chosen and the mix of clinical and non-traditional services and supports that she is using to meet those objectives.

Individuals have the strongest incentives to make good use of their personal budget and generally maximise value for money more effectively than commissioners. Nevertheless, concerns about fraud and abuse are frequently raised in the context of personalization. There is almost no evidence internationally of significant fraud and abuse and programmes can be designed to maximize accountability. For example, PHBs can be held by a third party rather than being directly paid to individuals in the form of a direct payment to increase financial control. This may be appropriate where individuals have, for example, serious addiction issues.

6. Building a new evidence-base

Recovery and personalisation call for the development of a new evidence base looking at the effectiveness of treatment, care and supports in generating ‘real wealth’ and supporting individuals to live the lives they choose.

There is currently a limited evidence base related to the contribution of clinical care and other interventions to the wider, life outcomes that people care about most. There is no evidence as to whether Clozapine is effective in helping a person with schizophrenia to get a job or whether cognitive behaviour therapy helps someone with depression to find a partner. The evaluation of the PHB pilot programme will develop this evidence base by assessing the extent of the clinical improvement and recovery that is secured through individual choice and control compared to treatment as usual.

7. Creating a more diverse market

For personalisation and recovery to succeed, there needs to be a range of alternative provision in place. Although PHBs can be used to purchase mainstream opportunities that promote wellbeing (like joining a gym to increase physical health, or driving lessons to enable a person to see their family and friends), early experience with personal health budgets shows that investment in creating new
Ann’s personal health budget:
a case study from the Northamptonshire PHB pilot

Ann is a mother and grandmother from Northamptonshire, with a large family who care for her. She has depression, anxiety and a personality disorder and has been using mental health services for ten years. She was taking approximately 36 overdoses a year but with help from her community mental health team (CMHT), other mental health services and learned self-help techniques she had managed to reduce this to three to five times a year. Last year she had 18 overnight inpatient stays, three respite stays and 49 contacts with professionals from the CMHT.

Ann was eligible for a PHB as part of Northamptonshire’s mental health pilot. Her indicative budget was calculated based on the cost of the CMHT service in the previous 12 months, a clinical assessment of her health status and from this, an estimation of the CMHT services that she was likely to use in the following 12 months. Ann’s care coordinator discussed the budget allocation with her and the final amount was agreed by Ann.

One of Ann’s central objectives from her recovery support plan is to be able to help her family rather than being a source of concern to them. Some of the other outcomes that Ann wants to achieve with her budget include:

- Reducing her demand on the CMHT, on acute mental health services and on her GP,
- Reducing the number of overdoses she takes,
- Increasing her confidence and socialisation and decreasing her self-harming behaviour,
- Reducing her reliance on medication, and
- Cutting down or stopping smoking.

With her PHB, Ann has bought regular, twice weekly psychotherapy sessions, 3 contacts with her consultant psychiatrist and a minimum of 25 contacts with her care coordinator. A short course of NHS psychotherapy in the past had started to work for Ann so she negotiated to reduce her contacts with her care coordinator and psychiatrist to free up funds to pay for a private psychotherapist, one that she chose herself.

Ann has now had a PHB for seven months and is making steady progress towards achieving her health outcomes. So far she has had no inpatient admissions or overdoses. She has not needed to use the crisis team or respite service. She has reduced her contact with her psychiatrist, from once every three months to once every four months. She has less contact with her care coordinator and there is a possibility that she will be discharged from the CMHT in 2012/13. She has reduced her medication and has lost some weight. She is especially pleased that her relationship with her family, her children and grandchildren has greatly improved. She sees a lot more of them now because she has changed so much. They are not so frightened for her any more and want to see her more often.
provision can pay off. In the PHB pilot for alcohol detoxification in Southampton, for example, work with providers has led to the creation of a range of alternatives to inpatient detoxification that did not previously exist. In social care personal budgets, Stockport has developed an online market place that allows individuals to find a broad range of providers, from providers of clinical services such as physiotherapy to music teachers and yoga instructors.

However, there is a risk of moving too quickly to give individuals a budget before there is anything available outside of statutory services. It is, therefore, important to find ways to ensure that people can access assured alternatives when contracts are changed and that changes happen on a timescale that allows investment in alternatives to occur. Some areas rapidly closed day services and individuals were given a personal budget as an alternative but found little else on offer locally. Notional budgets that designate a certain level of resources to each individual without removing the money from existing contracts can be an important intermediate step towards personalisation. Individual service funds that allocate funding for individuals to a provider who then develops a package of services and supports in collaboration with the individual can also act as a stepping stone.

8. Sustainable funding

While the personal health budget pilot programme did attract additional funding from the Department of Health, the long term sustainability of PHBs will depend on the extent to which they can be implemented on a cost neutral basis, at least over time. Experience from the pilot sites indicates that the upfront costs of implementation were on average £150,000 over two years, with the expectation that ongoing costs will be less as PHBs become embedded into existing NHS delivery structures. This figure represents investment in developing local systems and procedures, including support for individual planning (Jones et al., 2011). The final report of the national evaluation will assess the extent to which upfront investment improves outcomes for PHB holders by creating a more effective process and, therefore, improves value for money in the long run.

Local areas will need to find some initial investment for implementation. However, the bigger challenge is to free up money to provide personal health budgets themselves and to fund ongoing support for recovery planning thus avoiding double running costs (NMHDU and Mental Health Network, 2009). Much of the money in the mental health system is currently tied up in block-purchased contracts with NHS provider organisations in secondary care. Unless some of this money can be released to invest in personal health budgets, it is difficult to see how they can be taken to scale. Until then, individuals’ choices will be restricted to commissioned services.

There is emerging evidence that PHBs can reduce use of emergency and secondary mental health services. However, these savings will need to be released by decommissioning some services if the funding is to be redirected into personalization. Taking money out of secondary care to invest in community services is a long standing challenge in the NHS and one which personalisation only makes more acute (Davidson et al., 2012).

In this context, the development of mental health Payment by Results (PbR) may be helpful. Although there are serious doubts about the consistency between the cash value attributed to care clusters through PbR and the resources allocated to individuals with similar levels of need through PHBs, Payment by Results could provide a catalyst to break up block contracts. By allowing money to move more freely around the system, PbR may benefit Personal Health Budgets. However, the relationship between the two will need to be carefully managed if Payment by Results is not to limit the flexibility of PHBs given the clinical definition of care clusters within PbR (Clarke, 2011).
Many people in mental health services have lost hope for the future. They have been told not to expect to work or find a partner, not to expect the things that other people take for granted. The system has focused on problems and disorders and has often eroded aspirations. This lack of hope for the future creates a culture of low expectations that affects those who use services as much as those who provide them. In the end, low expectations become a self-fulfilling prophecy as life is reduced to being defined as a user of mental health services. ‘Real wealth’ is eroded and replaced by isolation, dependence on services and the failure to participate in society as a full citizen.

Recovery-oriented services demand a new attitude. Professionals and providers must challenge themselves and the individuals they work with to have high expectations of what is possible. The culture of services must offer people opportunities to rebuild their lives through an individual journey that accepts what has happened and moves beyond it. The success of the recovery approach should be judged according to the changes it achieves in people’s lives and the extent to which it enables people to achieve the goals they set for themselves, not solely how well their symptoms are managed.

Personal health budgets provide a tool to enable this individual journey, recognizing and nurturing individuals in their many different roles, with aspirations for the future and talents to contribute. Services that embed the principles of recovery and personalisation must offer hope and challenge, not limiting people to the confines of their disorders, but supporting them to define and realise a life that they choose and value.

Conclusion:
Recovery and personalisation: raising expectations
References


Deegan, P. (1993) Recovering our sense of value after having been labelled mentally ill. *Journal of Psychosocial Nursing and Mental Health Services, 31*, 7-11


Think Local Act Personal (2011) *Response to the Department of Health’s Caring for our Future Engagement Programme.* London: Think Local Act Personal Partnership
Recovery, Personalisation and Personal Budgets

This briefing paper is one of a series for the Implementing Recovery through Organisational Change project, managed by the NHS Confederation Mental Health Network and Centre for Mental Health and supported and funded by the Department of Health. For more information about the project and other resources about Recovery-oriented practice visit: www.centreformentalhealth.org.uk/recovery.

Published September 2012
© Centre for Mental Health, 2012
Photograph: iStockPhoto

Recipients (journals excepted) are free to copy or use the material from this paper, provided that the source is appropriately acknowledged.

Register for our monthly email bulletins at www.centreformentalhealth.org.uk.