Personalisation in mental health: A review of the evidence

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Personalisation in Mental Health: what do we know?

The overall vision is that the state should empower citizens to shape their own lives and the services they receive

Prime Minister's Strategy Unit, 2007

Introduction

This is a short summary of a review of academic, practitioner and policy literature about the use of direct payments (DPs) and personal budgets (PBs) by people who use mental health services.

The literature review was carried out by the Norah Fry Research Centre at the University of Bristol, between October 2008 and March 2009, for Mind's 'Putting us' first project. The project aims to ensure that more people experiencing mental distress have choice and control over their care. At the end of the project, we want more people with mental health support to be in receipt of personal budgets, and more practitioners to understand how personal budgets work in the mental health field.

This literature review summarises the extent of knowledge relating to direct payments, personalisation and personal budgets in the UK in early 2009. We have paid special attention to the issues for people who use mental health services, so that those who want to make changes can use this document to find evidence and information. The full literature review will be updated at regular intervals, and the latest version of the full review will be available at: www.bristol.ac.uk/norahfry and www.mind.org.uk

The personalisation agenda in England has much to offer the field of mental health, since it helps to challenge some of the ways in which mental health is perceived. In particular, it supports a social model understanding of mental health, which recognises the importance of social factors in contributing to mental wellbeing (Beresford and Wallcraft, 1997; Brewis, 2007). It also supports a user-centred concept of 'recovery' in which recovery is a personal journey of learning to live well, despite the continuing or long-term presence of mental health support needs. In this sense personalisation fits neatly with the independent living philosophy, as explained by Spandler and Vick:

The flexibility of being able to organise support around one's own life rather than having to adapt one's life around support is central to the independent living philosophy.

Spandler and Vick, 2006: 112

Personalisation

Personalisation is about meeting the needs of individuals in ways that work best for them (Carr, 2008). It includes prevention, early intervention, and self-directed support where service users are in control of arranging and managing their own support services. In the context of mental health services, personalisation accommodates mental health promotion and maintenance: having choice and control over one's life contributes to wellbeing. With personalisation comes:

Ensuring universal access to public and community services; prevention and early intervention; promoting coproduction of services and the growth of social capital in communities and the social care sector; improving access to information and advice for all people who use social care services regardless of how they are funded; and recognising and supporting carers.

Carr and Robbins, 2009

Direct payments

Direct payments (DPs) are cash payments paid to an individual with which they can design and manage individually tailored support to meet their social care needs. Funding for DPs comes from the local authority (Fernandez et al., 2007). Although DPs have been available since 1996, they are now just one of a range of options for people who are given a personal budget.

The number of DP users with mental health support needs has risen steadily from 50 in 2001 to 3,373 in 2008 (Care Services Improvement

Partnership, 2001-8). From 2007 to 2008 the percentage rise of people using DPs to meet their mental health needs rose by 62 per cent, the largest increase among all care groups. However, compared to other impairment groups, the proportion of DP users with mental health support needs remains low.

There are large variations between local authorities, with just 11 local authorities making over half the national total of DPs to mental health service users at the time of a national pilot of DPs in mental health (CSIP, 2005).

Research has suggested that on the whole, given sufficient support, people with mental health needs use DPs imaginatively and effectively.

It was like light on a cold, dark day
Stainton and Boyce, 2004

In a national pilot of DPs in mental health (2001 to 2003), approximately half of all DP recipients employed a personal assistant (PA) to provide social and personal support – including assisting them with daily activities (shopping, cooking, cleaning), helping them access community and leisure facilities, or providing respite and night sits. DPs were also used for transport, education, short breaks, arts activities and accessing mainstream leisure services (Spandler and Vick, 2004; 2006)

There are a number of barriers to DPs across all impairment groups, many of which also apply in the mental health field. These include a lack of awareness of DPs among care coordinators, risk aversion and protectionism and in particular the conflict between risk-taking and safeguarding with vulnerable groups, a perceived lack of overall resources, assessments led by services not by needs, and concerns over the concept of being 'willing and able' to consent to and manage a DP (Pearson, 2004; Fernandez et al., 2007; Hasler and Stewart, 2004; Spandler and Vick, 2005).

In addition, there are some specific barriers that apply in the mental health field. These include the difficulties of deciding which are health and which are social care needs, eligibility issues for people whose condition fluctuates, the role of care coordinators as gatekeepers, and specific concerns over risks – particularly the capability of some people with mental health needs to always have the insight necessary to design and manage their own support (Carmichael and Brown, 2002; Ridley and Jones, 2002; Spandler, 2004; Spandler and Vick, 2004; Cestari et al., 2006; Taylor, 2008).

There remains the fundamental issue of the extent to which health staff are trained to assess, recognize and prioritise social care needs in their… training.
Cestari et al, 2006: 479–80

Personal and individual budgets

The cornerstone of the Government's approach to transforming social care and support through personalisation is the allocation of a personal budget (PB). Individuals are supported to assess their own needs, so that a care coordinator can determine whether they are eligible for social care funding. If eligible, they should then be told how much money they can expect to receive with which to meet their needs in ways that work for them. With their PB, individuals can design and purchase their own support from the public, private or voluntary sectors (DH. 2006a; Duffy, 2007) Direct payments are just one way of receiving a personal budget; service users can also choose to use existing services, or to ask their care coordinator or another agent to manage the money for them. They can also transfer money to an organisation that currently provides services they want to use. In fact, any combination of these options is possible.

Individual budgets (IBs) are similar to PBs, but incorporate a number of different funding streams in addition to social care funding. The funding streams that could be included include: Access to Work, Supporting People, Independent Living Fund, Integrated Community Equipment Services, and Disabled Facilities Grants.

A national pilot of IBs took place in 2007–8 across all groups of disabled and older people; 14 per cent of service users in the pilot were people with mental health support needs. This group had the most positive outcomes in terms of overall wellbeing, and a tendency towards better psychological health. IBs also offered people with mental health support needs a greater range and flexibility of support arrangements than conventional services or DPs, as well as a more holistic, person-centred service (Glendinning et al., 2008; Manthorpe et al., 2008).

The pilot study also suggested that the longer people were working to a model of self-directed

support the better the outcomes, suggesting that benefits should increase over time.

Overall, the pilot study concluded that people receiving IBs experienced higher levels of independence and were more likely to commission their support from within mainstream community facilities, rather than specialist services. Individual budgets were beginning to drive changes in traditional services, for example by encouraging them to provide more individual programmes of support in the community (Bamber and Flanagan, 2008).

Concerns and challenges in personal and individual budgets

Choice and control should not mean isolated lifestyles for people in receipt of mental health support Additionally, a focus on individually tailored support arrangements should not detract from necessary investment in improving directly provided services for those who still want or need them, or addressing social inequalities and alleviating mental distress (Lyons, 2005; Spandler and Vick, 2004).

In addition to seeking individual solutions, it is essential to address root causes that create social exclusion

Lyons, 2005: 250

Many of the general barriers to IBs and PBs also apply to the mental health field. Additionally, the split between health and social care funding is perceived as a major barrier to developing IBs in mental health (Glendinning et al., 2008).

Given that mental health services are often concerned with the management and control of 'risky behaviour', there are particular worries about the management of risk for people choosing to opt for a PB (Spandler, 2007).

Ways forward and next steps

Better targeted training and support for frontline staff is needed to encourage a higher level of take up of DPs and PBs. In particular, there is a need to raise awareness and expertise amongst service users, practitioners and leaders in relation to the use of DPs and PBs in the mental health field. (Swift and Hill, 2006; Department of Health, 2006b)

Recruitment, training and conditions of employment for PAs are important, not least because the relationships they develop with DP/PB recipients are often necessary to deliver the control and flexibility that recipients require (Lombard, 2008; Spandler, 2004; Henwood and Hudson, 2008; Manthorpe and Martineau, 2008).

Effective support schemes need to be developed for people using DPs and PBs. The support schemes need to have a sensitivity to mental health issues and an awareness of the needs of diverse groups and communities (Coldham et al., 2005; Swift and Hill, 2006; Stuart, 2006). This may involve specific outreach strategies to reach people who are less likely to receive personalised services; eg, people from black and minority ethnic communities (Newbigging and Lowe, 2005).

Support systems for those with mental health needs could include specialist advocacy support and user-led initiatives that provide support. There also needs to be increased awareness and better use of specific tools developed in the mental health field, including crisis planning, self-assessment diaries, and guidelines for PAs to follow if the DP/PB recipient becomes unwell (George, 2002; Luckhurst, 2006; Heslop, 2007).

There is a need for improved joint-working at local level, and sufficient flexibility within personalisation to meet the diverse needs of different individuals. This could include better links between health and social care, and more transparency and better communication through cross-sector working groups (Spandler and Vick, 2004).

There are a number of systems-level developments that are needed, including better streamlining of the Care Programme Approach with the personalisation approach, and clarity in the application, eligibility and assessment processes (Coldham et al., 2005; DH, 2006b).

Effective and proactive leadership from senior managers, as well as direct payment support agencies and local user groups could help raise awareness and develop expertise (Newbigging and Lowe, 2005).

Finally, skills need to be developed by professionals so that genuine person-centred assessments incorporating the person's own view of their needs can become the norm. We need to find ways to encourage people to accurately represent their

needs, particularly when those needs are fluctuating (Lunt and Sanderson, 2005; Rabiee et al., 2008). Care planning should be: "a dynamic process of discussion, negotiation, decision-making and review that takes place between the individual and the professional – who have an equal partnership" (DH, 2009: 11).

A move towards personalisation implies a move towards understanding the independent living philosophy in the context of mental health (Vick and Spandler, 2006). The 'Putting us First' project will support that move, and develop practical tools to meet some of the challenges that personalisation brings to the mental health field. In particular, we aim to develop:

- strategies to nurture 'champions' amongst service users, who can spread the word and share positive stories and approaches with processionals
- forums for discussion and networking, so that progress can be made in overcoming the challenges to personalisation in the mental health field.

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Who we are

Mind

Mind has been speaking out for better mental health for 60 years. We work in partnership with around 200 local Mind associations to directly improve the lives of people with experience of mental distress.

Mental distress affects people from every ethnic background and walk of life – one in four people experience mental distress at some time in their lives and a third of all GP visits relate to mental health.

Mind believes everyone is entitled to the care they need in order to live a full life and to play their full part in society. Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively and with respect.

Mind is an independent charity supported by your donations. We campaign to influence Government policy and legislation, work closely with the media and are the first source of unbiased, independent mental health information via our publications, website www.mind.org.uk and phone service Mind*info*Line 0845 766 0163.

Norah Fry Research Centre

Norah Fry Research Centre was established in 1988, and 2009 marks a celebration of 21 years of continuous research activity. Its principal interests are in the area of social and policy-related research. The Centre aims to make a positive difference to the lives of disabled children, young people and adults – and works with disabled people, including people with mental health support needs, to support them in taking part in research and development.

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For details of your nearest local Mind association and of local services, contact Mind's helpline, Mind*info*Line on 0845 7660 163, Monday to Friday 9.00am to 5.00pm. Speech impaired or deaf enquirers can contact us on the same number (if you are using BT Text direct, add the prefix 18001). For interpretation, Mind*info*Line has access to 100 languages via Language Line.

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