A study of personalisation and the factors affecting the uptake of personal budgets by mental health service users in the UK

Executive Summary

A research study commissioned by Mind

Authors: Dr Manjit Bola, Tina Coldham, & Zoe Robinson

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1. Background

Mind has made a commitment to improving mental health service users' experiences as part of a wider agenda on Personalisation. This includes work on improving the equality and quality of services; promoting mental wellbeing; tackling stigma and discrimination; raising awareness of mental health issues; the prevention of mental health problems and promoting recovery.

This project was commissioned by Mind to add to its knowledge base and existing work on Personalisation in order to support individuals to have greater choice and control over their care and support needs. The project was funded by the Department of Health under the Strategic Development fund 'Personalisation and Choice of Care and Support (IESD1) 2011'

This report provides an overview of the main findings of this qualitative study, exploring the concept of personalisation, the factors affecting its operationalisation by voluntary and statutory sector organisations, and service users' experiences of its implementation, particularly in relation to the factors that affect their uptake and experience of Personal Budgets. Recommendations are made for future work in this area.

2. Method

This study explored the concept of personalisation from the perspectives of:

- Service Users.
- Carers.
- Voluntary and statutory sector provider organisations.
- Commissioners.
- Experts/consultants in the field of personalisation.

Using this multi-perspective approach, the study explored the perceived factors affecting the uptake of Personal Budgets by mental health service users as a means of achieving and receiving a personalised approach to their care and support. 49 participants took part in either one-to-one interviews or focus group discussions. The lines of inquiry for the interviews enabled a detailed exploration of:

- Thoughts and beliefs about personalisation as a concept and its application for mental health service users.
- Knowledge and awareness of Personal Budgets.
- Factors affecting the uptake of Personal Budgets.
- Personal experiences of how Personal Budgets are administered and their effectiveness in enabling people to manage their mental health.
- Key issues for service providers and commissioners and recommendations for practice.
- Priorities for future research on promoting and implementing personalisation and the uptake of Personal Budgets by mental health service users.

3. Summary of the research findings

The thematic analysis of the data identified six themes:

- Personalisation as a concept/ principle.
- Barriers to the uptake of Personal Budgets.
- Factors enabling/increasing the uptake of Personal Budgets.
- Partnership working.
- Links between personalisation and reduction in crisis support.
- How well the current system works.

3.1 Personalisation as a concept/principle

Respondents agreed that in principle, the concept of personalisation was something with which they agreed and that as the basis for the delivery of support and/or services, it was the right way forward. While personalisation was positively viewed by the majority of respondents as a concept and principle, there was a level of caution and doubt with regard to how effectively it was being delivered in practice.

3.2 Barriers to the uptake of Personal Budgets

The impact of personalisation and most particularly, Personal Budgets, as a means of addressing the needs of mental health service users is limited in practice by a number of user-identified barriers. These included:

- Knowledge and awareness.
- The process of application.
- The relationship with the care coordinator (sometimes referred to as a key worker) and their attitudes towards eligibility.
- How the wider welfare Benefits, and health and social care systems work and the impact of reorganisation and other changes within these systems.

Some service users had little or no knowledge of Personal Budgets, the assessment process or their rights to a care plan. One of the main reasons given for this was the lack of information about Personal Budgets. This lack of knowledge had a knock-on effect upon the ability of service users to take up the opportunity to access these budgets as policy intends. Carers' issues were similar to those of service users and they described the way in which a lack of information acted as a barrier. Service providers also acknowledged and confirmed the lack of information and awareness as a factor. A number of the experts who took part in the study were also service users, and they were very aware of the barrier posed by this lack of information. Knowledge of their rights meant that they were able to access Personal Budgets but they understood that for others, this was patchy and that take-up depended upon the knowledge imparted by care coordinators due to a lack of available materials in the community to promote them. For a number of reasons, the process of application itself was seen by many as the second barrier. Of those service users and carers who were aware of the assessment process and the care coordinators' role in

carrying out a care plan, a number discussed the relationship aspects and the attitudes of the care coordinator. Some service users had to ask the care coordinator to undertake a plan to which some care coordinators did not respond. Other care coordinators carried out the assessment and care planning process in as little as ten minutes, while others undertook this process by telephone. This raises two points: firstly the amount of time being spent and secondly the means by which the process is undertaken.

The lack of time being spent on developing a care plan was reported by service users, and carers and voluntary sector service providers alike. Care coordinators themselves suggested several reasons for why they were unable to work in a personalised way, including time constraints, heavy workloads and perceived bureaucracy within the system. Further, the process of renewing an existing Personal Budget could also give rise to barriers.

Even where appeals are in place and unfair and/or incorrect judgements are overturned, the process and time taken to do so were reported as causing serious harm and hardship to individuals. The length of time that the process takes is known (by carers and voluntary and statutory sector providers as well as service users) also to vary, in a way that service users described as a 'postcode lottery'; while some experienced the process as fairly rapid, others were required to wait many months for a decision. While certain Local Authorities have structured processes and are successful in rolling out Personal Budgets, there are many that have experienced problems due to the impact of austerity cuts and/or the restructuring of their own services and changes to their funding of local voluntary organisations, following the phasing out of block grants. This has caused particular problems in some areas of the country. While statutory service providers continually have to cope with the impact on resources of these funding conditions, service recipients may continue to find that assessments take a prolonged time to complete. Cuts may also affect eligibility, with the transparency of the outcome of the assessment process being patchy or limited. It is perceived that the cuts impact on the judgement of eligibility and on the account of service providers, service users, carers and experts, can be associated with a reduced transparency of outcome.

3.3 Factors enabling/increasing the uptake of personal budgets

While many experienced the barriers to receiving a personalised approach and receipt of a Personal Budget outlined above, there were some who reported the process and receipt of Personal Budgets to be relatively straightforward and successful. They reported a number of enabling factors. These included:

- Direct Payment support services;
- availability of advocates;
- support from organisations such as Mind, Rethink and Voicability (an organisation offering advocacy services) and:
- having a good care coordinator.

There were also a number of suggestions as to how mental health service users could be better enabled, many of which reflect the ways in which the barriers described above should also be tackled. These included:

- increasing knowledge and awareness by making use of stories and having many and varied links to sources of information;
- paying attention to the importance of the relationship between care coordinator and client and:
- acknowledging the impact of the care coordinator's attitudes, knowledge and training.

The last of these was of particular concern. It was felt that since care coordinators are the individuals who are usually required to undertake assessments to inform the support plan, as part of the care planning process (involving the user), their attitudes, knowledge and ability were of critical importance. Indeed, participants felt that the uptake of Personal Budgets would remain low unless key contact workers including care coordinators were fully trained and equipped to support the individual in a personalised way. Addressing this issue was seen as critical to Personal Budget uptake and hence enablement.

The role of GP services was discussed by a number of the service users revealing the extent to which people see their GP as a first point of contact or first line of service, rather than Social Services or indeed 'mental health' (NHS) services, whom it is argued may not have a 'front door' in some areas. Mental health service users often do not know that they

are entitled to access social care support through direct access. If Social Services are to become more accessible, then knowledge and awareness needs to be raised in the community about how they can be accessed, both directly and via mental health (NHS) services (depending on local arrangements).

Critical to a successful care or support plan was the time that the care coordinator has available. A number of organisations pointed out that the time pressures that workers were under and the lack of time that they could devote to a support plan meant that only 'lip service' was paid to a personalised approach. To enable effective uptake, the time spent on the process needs to be commensurate with the necessary requirements of the process, where in reality, a number of service providers felt under a great deal of pressure, with high case loads and little time to do the assessments required. Accordingly, reports of delay in the process were commonly reported and the potential for cuts was reported as having negative effects on staff morale and the ability of staff to deliver a good service. An acknowledgement by senior statutory sector leaders of the impact of these conditions on progress towards the uptake of Personal Budgets and a commitment to addressing these is seen as imperative. A majority of participants in each of the study's respondent categories identified training as a key issue, citing the need for training and development to be repeated in order to change the culture of statutory services and to enable personalisation to be effectively delivered evenly across the country. In addition, our interviews with the voluntary sector providers and experts suggest that training of itself is insufficient and that it is also necessary to address the requirement for staff supervision, and leadership development as components in changing culture and practice towards personalisation.

3.4 Partnership working

While partnership working was seen by all to be important, a range of views were provided about the level of existing and need for improved partnership working. For the recipients of services, the variability in service provision was felt to reflect a lack of coordination, something which individuals who had moved between areas particularly noted.

Voluntary sector providers felt that the advances that had been made in recent years to work together and to connect with other service providers could now be reversed in light of the requirement for providers to pursue at micro scale the same funding pots. Experts agreed that partnership working varied across the country. They suggested that good

partnership working was not necessarily a function of resource availability but due rather to the commitment to achieving it, as evidenced by the existence many good collaborative relationships in existence. A suggestion was made by one service user that one way to achieve greater partnership working and increase uptake, was to have a database of information so that those areas in which there was a lack of evidence of integration and partnership working could be publicly exposed.

Carer groups suggested that they should be better consulted and more user-led organisations be given a prominent role in relation to shaping service provision. For these groups, co-producing services was essential.

Both voluntary and statutory sector providers who were successfully working in partnership felt that there were good practice stories and that their experiences and knowledge could be used to further the rolling out of Personal Budgets in other areas. This was especially so for the new roll out of Personal Health Budgets.

3.5 Links between personalisation and reduction in crisis support

The study also sought to explore the possible link between the uptake of Personal Budgets and the need for crisis support. The majority of participants agreed that if personalisation was to be in place in a way that met the needs of individuals, there would be a reduction in the need for crisis support which, in turn, could reduce the 'revolving door' of people going into crisis and needing intensive home support or expensive hospital admission. The participants all agreed that if properly funded, a personalised approach combined with crisis prevention services that were capable of being operationalised at the time of need, would both reduce costs and in potential, prevent crisis.

In agreement with all the participants, commissioners also saw the potential value of Personal Budgets for early intervention and for reducing crisis support. Furthermore, some of the experts suggested that there was a need to move away from a crisis model and to start to provide alternative options for individuals. They felt that a measure of crisis reduction could be achieved, and that there were existing provisions in some areas which could be promoted to achieve this.

3.6 How well the current system works

When participants were asked about how well the system itself worked, a number of problems were identified. These relate to the way in which participants interpreted what the system meant to them. For example, service users discussed the system aspects in terms of how they found accessing the system and the process involved in receiving a Personal Budget. They also discussed some of the causes for their poor experiences and saw them as being partly due to the restructuring of services, staff losing their jobs and changes to existing systems. For service providers and commissioners, the system aspects related to how well they perceived it to be working operationally. Views differed as to how effective they are, and how well quality of services was being measured.

4. Summary

Our research findings show a recognition that while Personal Budgets are regarded as the right way forward as part of a personalised approach, their take-up does require service users to know what is available, when and from whom. There is a lack of equity and transparency in relation to who receives a care plan and how they will be assessed and to the nature of any subsequent link to receipt of the Budget. For Personal Budgets to impact upon crisis prevention and response, early intervention needs to occur in a timely way and the availability of alternative community services needs to be increased. Without this a lack of choice and control for the service user will remain. Additionally, many service users receive a Personal Budget only when they have substantial and critical needs; there is evidence of a lack of provision for many who do not meet this criterion. If an increasing number of mental health service users are likely to qualify only once they are in or close to crisis, prevention and early intervention via Personal Budgets may be unachievable. In the course of our investigation into current practice and experience, we have identified a number of barriers and enablers.

Our view is that the impact of effective action to tackle the barriers will result in an improved experience of the Personal Budget process and its outcomes for carers and front line staff as well as service users. Some of the changes required include: information sharing and cooperation between services with signposting for individuals, making a care plan available to all potential recipients with an entitlement to one and putting in place a process for assessment that is: equitable across the country; advances the objectives of

choice and control; urgently acts to reduce the time taken between assessment, decision and receipt of payment. At a service level, with the removal of block funding and the intended move towards purchasing by individuals, there are new pressures on voluntary organisations and the services that they can provide. The combined effects of moving to a business model in which, in some instances, these organisations have become competitors; where service user purchasing is not guaranteed, and the consequent need to protect the viability of a particular service may have become central, amounts to a major shift in practice that could be held to work against the partnership that is widely seen as desirable.

More significantly, the cuts to block funding appear to be leading to cuts in the services that keep people well. There are thus a number of co-existent challenges. The recommendations below are concerned with meeting these challenges. They focus on how a positive impact can be made on Personal Budget uptake through improving the front-line experience of the uptake process.

5. Recommendations

1. Increase general public and mental health service users' knowledge of the existence of Personal Budgets and how to request one by making more information available in public places which are frequently visited, such as GP surgeries. This is particularly important with the advent from April 2015 of a 'right to ask' for a Personal Health Budget for people with long term conditions. This must include mental health.
2. Improve equity and transparency as to who can receive a Personal Budget and the process of application, decision and appeal.
3. Reassess the whole pathway in local areas to improve processes that reduce the waiting time between assessment, decision and, if eligible, receipt of money.
4. Increase the number and types of early intervention programmes to prevent and/or reduce crisis support demand and resource these accordingly.
5. Improve information sharing and cooperation between services and increase signposting within services.

6. Address service provider concerns about reduction in staff and workloads and their identified consequences: low morale, inadequate time to carry out care plans, long delays in relation to process and the knock-on effect of poor service for service users.
7. Make continual professional development for front line staff a requirement.
8. Conduct further research on the Personal Budget process from initial awareness raising to ultimate decision, drawing to scale on the wider experience of care coordinators and service user's in order to substantiate the evidence base for effective practice.