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

A research study commissioned by Mind

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Summary

This project was commissioned by Mind to add to its knowledge base and existing work on Personalisation so as to support individuals to have greater choice and control over their care and support needs. The project was funded by the Department of Health as part of its 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 what affects their uptake and experience of Personal Budgets. 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. Recommendations are made for future work in this area.

Introduction

The aim of personalisation is to adapt services to the needs and preferences of service users rather than those being determined by service providers. Routledge (2011) wrote:

> "personalisation in social care is part of a wider shift in our society towards the full inclusion of all people. It is not a government invention. It emerged from the struggles of disabled and older people with support from allies working in public services. Three decades ago disabled people worked out how to achieve independence and avoid services that trap them in limited lives. The crowning glories of the movement that developed were the social model of disability and the 1990's legislation on direct payments"

This history of personalisation, with its origins in the disabled people's movement, has influenced the policy and legislative context for personalisation as it applies to the provision of social care and support in the UK. The move from a disabled people's vision to personalisation becoming government policy came in 2007 when the Department of Health published "Putting People First: a shared vision and commitment to the transformation of adult social care". This set out the shared aims and values which would guide the transformation of adult social care, and recognised that the sector would have to work across agendas with users and carers to transform people's experience of local support and services. It also set out a vision of how personalisation of social care services would allow people more control over their own lives and the services that they choose.

In 2011, the Department of Health published the policy document "No Health Without Mental Health" and subsequently, in 2012, its Implementation Framework, which sought to further enhance choice and control in line with the personalisation agenda within the mental health service user context by proposing, for example, equality between physical and mental health and advocating an increase in choice of providers. There was a promise by the government that personalisation would be rolled out to all in receipt of social care, but this was revised to 70% by Norman Lamb in 2012, in light of practical difficulties (Community Care, 2012). Currently a new initiative on the personalisation of health budgets is being trialled, with a view to universal application over time (see for example, Alakeson and Perkins, 2012). In the UK then, there remains a firm policy commitment to the concept and implementation of personalisation. There is, however, some debate as to the extent of its achievement in practice.

Recent studies and reviews (see Slasberg et al, 2012, 2013; West, 2013; Series and Clements, 2013) are critical of some of the approaches taken to date to achieve personalisation, and highlight some of the theoretical and practical difficulties that have been encountered. One of these areas of concern relates to the way in which the allocation of Personal Budgets is managed. Personal Budgets are needs based budgets, assessed through a Fair Access to Care Services (FACS) process in social care. While each Local Authority decides which categories of people under FACS can receive a service, in practice they are usually available only to those people who are categorised as having substantial or critical needs. A Personal Budget should allow the service user the ability to plan and purchase their support with the allocated funds. The budget can be used in a variety of ways to meet the person's eligible needs for social care. However, substantial cuts to services following in the wake of economic policy clearly indicate a threat to the adequacy of funding which is of significant concern to service users and service providers alike (McNicoll, 2014). The first step towards having a Personal Budget requires an assessment of need to be established, through a care coordinator developing a care plan, in order to help determine eligibility for a Personal Budget. The time taken by this process, and the individual experience of it, varies significantly. There is also a growing concern about how the process of assessment and resource allocation is operationalised, with recent concerns being focused on the Resource Allocation System (RAS) used by a number of Local Authorities, which has been shown to have caused additional bureaucracy and costs for the assessment process (Slasberg et al (2013); Series and Clements (2012)).

So while there is overwhelming support for personalisation from this and previous governments, user led movements and organisations, national charities such as in-Control, and Think Local Act Personal (hosted by SCIE to provide resources for and promotion of personalised practice), there are a number of issues that are affecting its success in terms of delivery. As mentioned above, there is a growing debate about the impact of austerity and the cuts to services, and how they have undermined, and may continue to undermine, personalisation as a form of practice. Furthermore, the very question of whether personalisation as experienced by mental health service users is meeting its aim of providing more choice and control of care needs is questioned by Rose et al (2014) who, having found little evidence that this is happening, propose the need for additional research on the applicability of personalisation to the field of mental health stating that:

> "it is difficult still to identify people who are in receipt of personal or individual budgets in the mental health domain" (2014:2)

A systematic review of research looking at the effectiveness of Personal Budgets for people with mental health problems by Webber et al (2014) also suggests that further high quality studies are required to inform policy and practice for mental health service users, given this group lags behind other adult social care groups in their uptake of personal budgets.

Taking as its starting point the suggestion that only relatively low numbers of mental health service users are in receipt of Personal Budgets, and taking into account recent reports on the challenges in relation to Personal Budget delivery, this study seeks to explore the factors that affect the uptake of Personal Budgets. It does so through examining the knowledge, views and experiences of people on the front line of personalisation: the service users - particularly those who are or have been in receipt of a Personal Budget, the on-the-ground staff responsible for its administration, and the service commissioners and managers.

Through accounts of Personal Budget take-up and reported outcome, our aim in this study is to explore the barriers and enablers to personalisation and, in doing so, offer informed recommendations for effective personalisation practice in the future.

Methodology

Aims and objectives

The research project had the following aims and objectives:

- To explore the barriers and enablers relating to the uptake of personalisation (in particular Personal Budgets) by mental health service users.
- To identify the similarities and differences in the accounts of uptake provided by mental health service users, carers, personalisation experts, service providers (both voluntary and statutory services), and commissioners.
- To outline key issues affecting the uptake of personal budgets and make informed recommendations for practice in mental health.
- To explore priorities for future research to help promote the uptake of personalisation and personal budgets in mental health.

Sampling and recruitment strategies

Steering group members were asked to use their existing links with statutory and voluntary organisations, and knowledge of experts (including carers and service users), as a first point of contact and make a request to take part in the research, in one- to-one interviews or in focus groups as appropriate. Hence, in the first instance, opportunistic sampling was used to recruit individuals and organisations. Information about the research was sent to the identified individuals and service providers and this was followed up by a personal approach, involving either meeting potential participants in person (where practically possible), or via the telephone to provide further information, answer questions and arrange a date either for an individual interview or focus group discussion. From this sample, requests were made to recruit further members to the study using snowball sampling as the supplementary approach. Furthermore, as a result of the simultaneous running of a training course on "making personalisation effective in mental health" as part of the wider Voluntary Sector Improvement Partnership project, a request was made to course participants to take part or disseminate information for recruitment to the study.

Data collection

This mixed sampling approach, using both opportunistic and snowballing methods, allowed quick and easy access to a range of participants. The participant groups identified for the research project included: mental health service users either in receipt of a Personal Budget or not; personalisation experts (some of whom were also service users); carers of mental health service users and finally voluntary and statutory sector service providers and commissioners. The participants were able to take part in either one-to-one interviews or in focus group discussions as appropriate. Data collection took place in several locations ranging from Preston in the north to Norwich in the east, and London and the Isle of Wight in the south.

Table of participants:

Participant Perspective category	**1-1 Interview**	**Focus group**	**Total number of participants**
Service Users	9	2 (n=7)	14 (*2 dual perspective: counted in category personalisation expert)
Carers	2	1 (n=3)	1 (*4 dual perspective: counted in categories service user or voluntary sector service provider)
Voluntary sector providers (inc user led orgs)	3	4 (n=17)	20
Statutory sector providers	3	2 (n= 5)	8
Commissioners	3		3
Personalisation Experts	3		3
Total	**21**	**9 (n=32)**	**49**

Lines of inquiry

The lines of inquiry for the interviews enabled a detailed exploration to be made of the:

- 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.

All interviews were with permission, digitally recorded, and had notes taken to allow coding and analysis of the data.

Analysis

The interview data was analysed using a systematic thematic analysis method. The coding frame used was developed from the questions used for the interviews to enable comparison and synthesis of the interview data from service users; carers; experts working in the field; voluntary and statutory sector providers; and commissioners.

Ethical considerations

As the project involved consultation with mental health service users living in the community rather than NHS inpatients, it was not necessary to obtain NHS Ethical Committee Approval but approval was applied for and given by the University of Central Lancashire, School of Social Work Ethics Committee.

Information about the study was given or sent to all potential participants outlining:

- The aims of the study and purpose of the interview.
- The areas covered by the focus group or interview.
- Consent and the right to refuse.
- Confidentiality.
- What will happen to the information collected.

Participants were asked if they had any questions about their involvement before the interview commenced and were also asked for written consent at the beginning of the interview for the interview to be recorded.

The importance of confidentiality was stressed to participants, both in the written information circulated prior to and at the beginning of the interview. All information given during the course of the interviews was treated confidentially and the anonymity of all participants in the study was assured.

Collection of data

All of the one-to-one interviews and focus groups were digitally recorded and the analysis is based solely on the recorded conversations. A full transcription of the recorded data is not provided as part of the report, instead lengthy quotes have been presented in the results section for the reader. A small number of quotes are repeated in different sections of the report as they highlight several relevant issues.

Presentation of results

The data analysis/findings are presented in six sections: one for each theme explored. Each section includes a number of extracts from the transcribed data in order to provide the context and the basis upon which the interpretations of the accounts are made. Within each set of quotes the separate speakers are not identified but the group of respondents they represent has been given: Service Users; Carers; Voluntary or Statutory Sector Provider Organisations; Commissioners;

and Personalisation Experts. This structure has been used in order to provide for an exploration of role-based perspectives. Where a quote makes a number of different points it has been repeated in different sections, to highlight each point in context. In interpreting the findings, an indication is given as to the prevalence of the views expressed across the particular study group. Terms such as the 'majority' or 'most' are used when over seventy per cent were in agreement. The two terms, however, have been used interchangeably. The term 'some' is used when the number of participants is below the fifty per cent mark.

Research Findings

1. Theme One: Personalisation as a concept/principle

The majority of respondents agreed that in principle the concept of personalisation was something they agreed with, and that it was the right way forward for the way in which services should be delivered and received by recipients of services. The following quotes show how each of our category of participants expressed their agreement with a personalised approach and additionally show some of the reasons they thought this to be the case:

Service users

> *It sees the whole person. It looks at the skills a person has got. It's a sensible way to go, it's about the person. It's the humane thing to do, to enable someone to live a life.*

Carers

> *If you can get it it's great. You know what you need and having the ability to choose and have some say in that really helps.*

Voluntary or Statutory Service providers

> *People are able to feel more in control. For people with mental health problems – they are often disempowered. Personalisation can overturn that.*

Commissioners

> *Revolutionary for Adult Social Care in terms of the sense of control people have. It* (personalisation) *has changed the balance of power between councils and people.*

Personalisation Experts

> *It is an excellent idea, which is proven in practical terms. In the last 10 years there have been remarkable results from giving responsibility to people and the ability to be creative.*

The above quotes show that no one disagreed with the concept itself. The overwhelming support for personalisation as a concept is in line with previous research findings and supports the current UK policy on this issue.

There were, however, a number of concerns raised about the ability to access and manage Personal Budgets. These concerns will be addressed in the next theme on the barriers to personalisation and in particular getting a Personal Budget.

2. Theme Two: Barriers to the uptake of Personal Budgets

There were a number of barriers identified by all of the participants but especially by service users. These included knowledge and awareness; the process of application (especially completing the forms); relationship with the care coordinator (sometimes referred to as a key worker) and their attitudes towards eligibility; and finally how the wider Benefits system works and the reorganisation/changes within it. In this theme, each of these barriers is discussed in turn, followed by an exploration of the impact of these barriers on lived experience.

In the previous theme we saw that personalisation as a concept and in principle, were positively viewed by the majority of respondents. However, a level of caution and doubt was expressed, as to its effectiveness as a form of practice. Participants' views differed on both the extent of user familiarity with personalisation and the level of implementation by providers. The first sub-theme below details the first and most discussed reason given for the differences in uptake and implementation, and represents a key argument as to why the take-up of Personal Budgets by mental health service users has remained low.

2.1 Knowledge and awareness

Service Users

This sub-theme provides evidence that some service users had little or no knowledge of Personal Budgets, the assessment process or their rights even to have a care plan. One of the main reasons for this was seen as the lack of information about Personal Budgets. This lack of information has a knock-on effect in terms of service users not being able to take up the opportunity to access Personal Budgets as intended by policy:

> *There's not enough information up.*

> *There needs to be a massive increase in the take up of personal budgets but the reason it isn't is because of lack of knowledge ……We need a lot more knowledge of what they are and it needs to be a priority. We need to know what services are available and they need to be listed. I've even struggled to find phone numbers. The only organised one is the Samaritans.*

> *Personal budgets were never mentioned to me and I never came across them. I've been going from pillar to post.*

> *There's not enough sign posting for own needs. So many things are hidden out there and finding them is a minefield.*

> *There's no choice and control, to the point where it is difficult to understand the question! No information is given as to what you can spend it on.*

Carers

For carers, the issues were similar to those of service users and they described the lack of information as a barrier in a similar way:

> *If no one tells you there are personal budgets how are you going to find out. The only reason I found out was through a friend who is a social worker.*

> *There's no posters about SDS (Self Directed Support) so it's when and where you do that. Posters should be put on the ward. It's not offered to people. If people have been discharged and care not arranged it might give them something, a way to find out about personal budgets and how they should be done.*

Voluntary or Statutory Service providers

> *Marketing can be an issue, as how do individuals get to know about what provision is out there?*

> *First barrier is how do people find out what we do. People should be given a choice. They need to know that care coordinators can do plans or that other organisations can do them. Or they can be done with friends or family but they are not always told.*

Commissioners

The commissioners did not discuss lack of information, knowledge and awareness as a barrier. However, as they were not prompted to do so, we are unable to comment on the extent of their awareness in this regard. One commissioner did though say:

> *We need to get the systems right as they are not necessarily advertised or communicated regards eligibility.*

Personalisation Experts

A number of our experts were also service users and they were well aware of the way in which a lack of information posed a significant initial barrier. For them, knowledge of their rights meant they were able to access services in response to them while knowing that for others, uptake was likely to be patchy and because of the lack of available materials in the community, dependent upon care coordinators imparting their knowledge:

> *I was in the interesting position of being aware of direct payments for personal budgets as a health and social care research professional, but in my dealings with services as a user I was never offered the option of a direct payment or personal budget.*

Across a range of our participants, the majority agree that there is a lack of information available about how care planning links to Personal Budgets and that this impacts on the scope for access to self-directed support.

2.2 Process of application

In this sub-section on the barriers relating to the uptake of Personal Budgets, accounts are provided from those service users who knew about them, and had asked for or received an assessment and care plan. The following quotes show that for those who are aware of Personal Budgets and the right for Personal Budget assessment to be considered as part of assessment and care planning, the process itself posed difficulties. These were variously described:

Service Users

> *The initial application form was daunting. It was a bit like a DLA form.*

> *So all the time there are constant assessments and I'm drained from repeating my life story. It's really an effort to speak for an hour and getting no results.*

> *I always felt frustrated and more depressed. My GP approached [service organisation] and I had two assessments and never received information from them since. They never got back in touch. When I contacted them they just said go back to your GP. The manager said we don't know what is going on. Places are short of staff, there are cuts and people don't know what is going on. I don't know why I needed a second assessment and why they didn't get back to me. I have another appointment again this week but I have lost confidence in that. I've had more taken away from me than given to me.*

> *I've had two assessments and now 12 months later I'm having another meeting with [service organisation]. I've been put down by all the services I have received. I've been criticised by CPN's. I saw a CPN 3 months ago. My GP has been very supportive but CPNs I'm terrified of them. I'm terrified of taking small steps back.*

> *Still not resolved 12 months later.*

Following from initial application, renewal of an existing Personal Budget could also be fraught with barriers. The following is an extract from health and social care NHS Foundation Trust regarding written concerns raised by a service user who had not had a Personal Budget renewed after expiry of the old one.

> *The investigation concluded that there is no doubt that this process has taken too long and I would like to offer my sincere apologies for this and the distress this has caused you. The investigation has also concluded that the delay you have experienced is entirely the fault of professionals failing to make adequate decisions when given every opportunity to do so by you.*

The quotes above suggest that the process is causing a level of failure for the individual, which may imply the need to see the individual in a more holistic way than is currently the case. If having gone through the application process, individuals are required to endure long delays between application and judgement or if, as in some cases, they receive no response at all to the application, this in itself causes more distress to the individual. Even where appeals are put in place and individuals manage to overturn unfair and incorrect judgements, the process and the time taken to enact it are causing serious harm and hardship to those individuals.

While cuts to services and staff were seen as one of the reasons for staff failure in responding to service users as applications became stuck in the processing system, others, who did get a response, did not always find the response adequate or the process satisfactory. The lack of a personalised approach was evident for a small number of our service user participants:

> *There was a phone line available to me, but they never answered or called you back.*

> *Once the assessment was done, I never saw it afterwards to sign it off, I should as it should be good practice. Never had a copy of any of my paperwork.*

> *I had a telephone assessment, then sent proof of my personal budget eligibility, but I have never received any other paperwork with regard to the assessment.*

Furthermore, as a result of having moved areas or knowledge of how the process works in different geographic regions, others described the information, access and ease of availability to an assessment as a 'postcode lottery':

> *Changing the system has really messed it up, national to local, means that there is too much variation.*

> *It is a shame that if you turn right up the road, you know about it, but if you go left down the road, you know nothing about personal budgets It is a shame that people's experiences can be so different.*

Carers

> *I had to complain about my brother's assessment and it took me a long time. I sent hundreds of emails and I was made to feel like a scrounger.*

Voluntary and statutory sector organisations

> *The financial assessment required regards the personal contribution is very complex and difficult to get a clear picture when the person is in critical and substantial need. There is support available but it is difficult for people to successfully access when in a crisis.*

> *Personal budgets set at levels which are not capturing previous clients, so those who were supported by the service now are not, but still have support needs.*

> *You are repeatedly told 2 weeks, but for some people it has been 8 months or more. People then try to access drop in centres but those services have been cut.*

> *Process is complicated – 168 pages of guidance, an additional 32 pages of the form and only looking at 3 service providers – doesn't feel like people are being empowered.*

> *A barrier to access can be the inability to self-refer, only through a statutory process and you rely on them to promote the service. We do undertake our own marketing with leaflets and ward visits (the latter funded by health funding not personal budgets).*

Commissioners

Commissioners acknowledged that there was variation across the country and that partnership working was essential.

Social care packages are subject to financial assessment so that people's benefits are considered as income in relation to their care package. People are fearful that if they apply for Personal Budgets the process of financial assessment will be used as a benefits checker and as a possible opportunity for the Local Authority to reduce rather than increase their level of income. Linked to this can be the distinctive mental health issue of anxiety and/or paranoia in relation to disclosure of financial information; this represents a specific barrier to Personal Budgets for people with mental health problems.

> *Processes required during assessment can be lengthy and formal. The financial assessment is difficult for those not wanting to disclose personal information – many people drop out at this stage, many of them £0 contributors.*

Personalisation Experts

The process of application was seen to be unfair by many and experts reported some of the reasons as to why this was the case. These included the notion of the 'postcode lottery', with some local authorities having clear systems in place whilst others performed poorly.

> *Every Local Authority implement differently than each other.*

> *Mixed picture, some areas work better than others. Better performers have specific individuals in post and they push for the increase in uptake.*

This last point concerning the differences in Local Authority practice and the funding that they have is addressed in the next sub-theme. While certain Local Authorities (such as Stockport Council and Lambeth Council) have structured processes and are successful in rolling out Personal Budget’s, there are many that have experienced problems with the austerity cuts, with restructuring of their own services and changes to their funding of local voluntary organisations where block funding has been phased out. In the sub-section below, we can see how this is noted by service providers, by service users and by some carers.

Looking at the similarities and differences between accounts of the length of time it takes to secure an assessment and to obtain a decision for the majority of our service user participants was considered too lengthy (up to twelve months and still waiting). This was also confirmed as an experience by some carers and voluntary and statutory sector providers. Additionally, the lack of a personalised approach for those who are eligible (as seen during the care planning process) and the postcode lottery is confirmed by the personalisation experts.

2.3 Cuts to funding and restructuring of services

As mentioned in the introduction, there have been a number of recent articles which have pointed to the problems being caused by the cuts to funding in social care and welfare benefits and to the negative impact of this on vulnerable members of society. It is interesting to note from the accounts of both service users and front line staff that people sometimes confuse welfare benefit payments made in response to their assessed unfitness to work or because of the presence of a long term impairment, with those related to Personal Budgets provided by Local Authorities for social care needs. The quotes below show the various accounts of how funding cuts and restructuring is affecting the participants:

Service users

> *The benefits system is so complicated and there's no need for constant changes.*

> *I find due to funding procedures and changes in services how can anyone with mental health problems understand where to go. One minute it's there and then it's gone due to restructuring. It's very unsettling for the individual. Funding is creating a lot of unsettlement in the system. I wish to have the old centres back; service users could approach them when they needed them. The drop in resource centres which have disappeared, they were centrally located and led to communication, social skills, confidence, you could choose to do activities and facilities were provided.*

Carers

> *They don't want to let you know what is available so they can save money. Few carers know that they can have a carer's assessment. It is important so you can get some respite.*

Voluntary and statutory sector providers

> *It is disempowering for the voluntary sector who have gone from having total control to no control. They are not given any information so then you cannot support people without this.*

> *Personal budgets set at levels which are not capturing previous clients, so those who were supported by the service now are not, but still have support needs.*

Commissioners

In contrast to seeing restructuring as a problem, commissioners discussed the merits of restructuring in terms of the future needs of organisations:

> *Greater partnership is needed between Health and Local Authorities as the Local Authorities have a lot of experience with personal budgets and people with physical health conditions, which need to translate across to mental health.*

Personalisation Experts

> *Huge tensions exist around decreasing budgets within Local Authorities, which has restricted the amount and spread of personalisation.*

> *Some Local Authorities are struggling to keep providers on board.*

In this sub-theme we can see that rather than experiencing more choice and an increase in providers, service users experience a lack of choice or a reduction in choice. The real impact of cuts to services concerns most of our participants in the study.

2.4 Relationships and attitudes of staff

Service Users

The service users who were successful and for whom the process of application worked explained this as being due to having a good care coordinator:

> *Whilst some people can wait months or even a year. I got lucky; the care-coordinator was very efficient.*
>
> *The Social Worker Care Coordinator at (name) CMHT was instrumental in getting the personal budget so quickly; I couldn't have done it on my own.*

For others, the care coordinator posed a barrier and the lack of a non-personalised approach was evident:

> *My needs assessment was not completed in front of me, I was interviewed by my social worker (name), who then later filled out the assessment forms. Physical issues were identified OCD (to which the social worker responded 'You should have a clean house, then'), I have an Eating Disorder; and a Hearing Impairment, which makes it difficult to use the phone. The social worker's preferred method of contact is by phone!*
>
> *It is a lottery regards social workers and CPNs (Community Psychiatric Nurses) undertaking the assessment and their views and knowledge of personal budgets.*
>
> *Process is unclear and confusing – can be quite traumatic.*

For some, the relationship with a key worker hasn't provided them with an opportunity:

> *I have a social worker but I've never had personal budgets mentioned to me. I've not known my rights and what's available and I'm totally isolated from main services.*

Carers

> *I had to tell the social worker that there were personal budgets and she didn't know anything about them. There was no follow up and I had to keep at it to get one.*

Voluntary and statutory sector providers

To avoid the barriers, one of the user led organisations described how they operated differently in a way that was enabling to individuals:

> *Our support plans are person centred. We take longer to get to know people; it's not just the money. They look at plans as a book of life, it's their words and starts new conversations around wellbeing.*

> *Our support plan is an aid to recovery not dependency we make that clear to the service user. We say its meeting your outcomes. We offer so much more and the money is incidental. We can say what they can access free from the community.*

What these statements show is that whilst some user- led organisations are receiving referrals from Local Authorities and (as for a number of care coordinators employed by statutory services), are completing care plans in a sensitive way, some statutory service front line staff are either ignoring the need to carry out a care plan or their attitudes are perceived as negative and a poor relationship exists between them and the service user which causes an additional barrier.

Commissioners

The commissioners in social care were more concerned about Personal Budgets and personalisation within health, and linked this to an observation that since health organisations, in contrast, were more likely to do things to or for people, reflecting expert clinical or medical model precepts, personalisation would represent a more challenging concept for those organisations. The relationship between the worker and person came out as a strong enabler for Personal Budgets, both in supporting the person through the process and in developing creative responses to support needs. The quotes below show the contrast and the belief that social care is better able to deliver:

> *There is risk aversion in health teams.*
>
> *The social workers' relationship with the person is very important – the way planning is undertaken with personalisation – requires a conversation.*
>
> *In social care, personal budgets are close to the original training framework of choice and control so the process has been easier to adopt.*

However they felt that these barriers could be addressed by training front line staff:

> *Training is needed for practitioners – needs to be embedded within teams and easier to access, and include risk issues.*

Personalisation Experts

> *If staff don't understand the process, they end up trying to manage it their own way, which should not happen. The job is to support how people can best benefit themselves, not the staff or the service.*
>
> *CPNs were making applications but with the attitude of 'if you think we are letting them spend our money, you have another thing coming'. This is an enduring difficulty, that trusts and Local Authorities are guarding the money.*

> *Individuals supporting people, or managers with a particular interest in developing services to give people choice and control, need to move through assumptions of what people can or can't cope with. Often people are presented with 'this is what is best for you' rather than an open discussion.*
>
> *It is important to work in a personalised way as it does not cost anything, more training staff to think about how personal budgets and personalisation can be used.*
>
> *The difficulty comes – not with what is trying to be achieved, but rather the systems and culture within services.*

The above sub-section illustrates that the relationships and attitudes of staff have a direct impact on practice, and highlights the potential here for a negative outcome for service users. The statements from the personalisation experts particularly highlight why the attitudes of some staff members are not conducive to promoting Personal Budgets. A range of reasons for the unacceptable attitudes and behaviour by some front line staff are provided above. These include a lack of training, a self-perception of their role being as custodian of the funds and the nature of the systems within which they operate.

2.5 Impact of barriers on the lived experience of individuals

Service Users

The following quotes show how the different barriers to personalisation impact upon daily life and the personal consequences of being failed by the process:

> *I'm totally lost in the system. I can't get back the 10 years of the bad memories and the poverty living, no friends, no money and knowing the thoughts of suicide and living in a card box. What life do I have not knowing who to approach and when I find someone they're not interested. I'm criticised, put down and treated unfairly and this is the 21st century. It's*

> *totally wrong. If the right support was in place you would have lived a better life. It would cut the trauma, conflict, the upsets and aggravation.*

The effects of having a lack of information can be seen in the next quote:

> *I've not had a personal budget for the last 2 years and I had a lack of knowledge of what personal budgets are. I've just been living off my Disability Living Allowance. I've never had a structured care plan and I have a social worker but I've never had personal budgets mentioned to me. I've not known my rights and what's available and I'm totally isolated from main services. I have battled to find out what I can access over the years. I've had key workers and support workers who never said anything even in 2012.*

For other service users, the time delays and reassessment process have caused additional stress. Whilst a person's needs might not change, the process may not acknowledge this and can lead to outcomes that *do* change and which leaves the individual uncertain as to what will happen each time they are assessed:

> *It is confusing, I originally had been assessed as eligible for a personal budget, but then (name of voluntary organisation) closed in March and reopened later. I reapplied then and did not hear anything back until December. Now waiting to meet with my social worker, and have gone through a tough financial needs assessment. Just received another letter from personal budget people, to say that they have reviewed the situation, and I have nothing to pay (personal contribution) which was thought to be good news, but now I have been told I have to go for another review – now don't know what is going on. Have accessed (name of organisation) to chase progress and have found the process very stressful.*

The stress caused by a lack of response, the fear of having all or part of one's money taken away at reassessment and having to repeatedly make requests for information evidences the potentially damaging character of the process itself;

leaving aside the additional complication of the RAS and the way in which it is sometimes used, rather than providing individuals with a fair assessment in eligible cases, the allocation of funds, the application process appears, for mental health users to be failing to deliver an acceptable form of personalisation service.

3. Theme Three: Enabling/increasing uptake of personal budgets

A number of enabling factors were identified. These included Direct Payment support services; having advocates; organisations such as Mind, Rethink and Voicability (that have 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 these overlap with addressing the barriers mentioned in theme two. The suggestions 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 coordinators attitudes, knowledge and training.

Of particular concern was the perceived lack of knowledge and training of the care coordinators who are able to raise awareness of Personal Budgets for service users. Given that care coordinators are the individuals who are usually required to undertake support plans (hopefully involving the user but as our research shows this not to always be the case), as part of the care planning process, their attitudes, knowledge and ability were seen as critical in the process. Without key contact workers being fully trained and willing to support the individual in a personalised way, the majority of our participants felt that the uptake of Personal Budgets would remain low. Whilst this is one of a number of barriers as identified in theme two, addressing it, was seen as a critical factor to advancing enablement leading to a take-up increase. The findings are presented in three sub themes: knowledge and awareness, the relationship between care coordinator and service user; the related suggestions for how enablement and uptake can be improved.

3.1 Knowledge and awareness

Service Users

Service users who were aware of personalisation and how to get a Personal Budget reflected on its importance as an enabling factor.

> *I knew about personal budgets and my advocate helped me.*

As mentioned previously, some of the service users reflected on the lack of knowledge and awareness amongst service users and when asked how knowledge and awareness could be raised they suggested the following:

> *You need to say in GP services what is available.*

> *We need many links and different links.*

> *We need a way to capture and share stories. There's so many ways the general public could know so that if a member of their family needs support that they can help the person in need by letting them know. When you are in crisis the people around you can help so everyone needs to know. There could be news items in the local paper, radio and TV, posters at bus stops or on buses. Putting information up in GP surgeries that lots of people go to or in hospitals.*

The role of GP services was discussed by a number of the service users and shows how 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 who do not have a similar 'front door'. Mental health service users often do not think or know that they are entitled to access social 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 directly or indeed (depending on local arrangements) via mental health (NHS) services. The suggestions above show how this can be operationalised.

Carers

Similar to the level of knowledge and awareness of service users, that of carers was low. Carers who were part of a carer support group reported that the support group provided them with a source of information about Personal Budgets and carer entitlements.

> *I know about them through the group meetings we have but accessing them is very difficult.*

> *There's no posters about SDS so it's when and where you do that. Posters should be put on the ward. It's not offered to people. If people have been discharged and care not arranged it might give them something, a way to find out about personal budgets and how they should be done.*

Voluntary and statutory organisations

Voluntary organisations confirmed the service users and carers' position and acknowledged that there was little information readily available to raise people's awareness. They saw advocates and advocacy services as a means by which individuals can be enabled. They also argued for the need to have better communication methods and suggested having a single point of contact.

> *The budgets have been cut and getting Carers Allowance has become so much more difficult. There just isn't the resources. We could do more and get information up on web sites.*

> *If someone applying had access to an advocate to support them and gather evidence – that would be helpful.*

> *Local Advocacy services – Rethink, Voicability. Can enable people to apply and motivate people whilst managing expectations.*

> *Need a single point of contact to address concerns around personal budgets, where you can ring a number with a query and expect an answer within a certain time limit. Communication is poor, people don't get answers and their emails are ignored.*

3.2 Relationship between care coordinator and service user

Service users

As previously stated, a number of the service users had a good relationship with their care coordinators or the voluntary organisation supporting them to do their care plans. They saw this not only as enabling them to complete their own care plans, but also saw it as a means of aiding recovery. For one service user it was a journey and it allowed her to express her life and needs in a creative way:

> *I've taken a long time doing my care plan, I've used my skills and photography is important to me so I've used it and the photo's I have to produce this album. My care coordinator has been there for me.*

Carers

For carers involved in helping the service users, a lack of information led to frustration, whereas those who had developed a good relationship felt supported.

> *I know when I need a rest, having a good support worker gives you confidence that you can take a break. I've not had any problems with the care coordinator. She understands.*

Voluntary and statutory organisation providers

The relationship between the service user and the individual undertaking the care plan can be outsourced by statutory organisations and as the following user- led organisation that carry out support planning show, when a good relationship is established additional beneficial outcomes for the service user can be achieved:

> *Our support plans are person centred. We take longer to get to know people; it’s not just the money. They look at plans as a book of life; it’s their words and starts new conversations around wellbeing.*

> *Our support plan is an aid to recovery not dependency; we make that clear to the service user. We say its meeting your outcomes. We offer so much more and the money is incidental. We can say what they can access free from the community*

Critical to a successful care or support plan was the time the care planner can spend. A number of organisations pointed out that the time pressure workers were under meant that a personalised approach was paid only 'lip service' to. To enable uptake, the process and the time spent has to be appropriate. As one commissioner states, it does require a detailed conversation which can only happen if there is sufficient time allocated. In some instances where conversations do take place, some workers of user- led organisations said they faced the same barrier as service users, (which relate to the attitude and beliefs of the care coordinator):

> *Often we feel patronised by care coordinators, so if someone does a picture it means something. We don’t want to change it we want it for the person. We listen and do the support plan from the service users’ perspective. We are reliant on care coordinators who believe in what we are doing.*

> *Really care coordinators or CPN’s have a really important role they are the ones that let you know about them. If they think they know what’s best for the person then they go ahead with what they think is appropriate!*

> *If personal health budgets are introduced more widely, then it will be difficult without care co-ordinators who are engaged.*

Commissioners

Commissioners acknowledged that the relationship between the care coordinator and the service user was crucial and that how a Personal Budget assessment and application is done matters. Whilst it may seem like common sense, a number of service users did not experience the care plan and assessment approach to be collaborative.

> *The social workers' relationship with the person is very important – the way planning is undertaken with personalisation – requires a conversation.*

Personalisation Experts

The quote below shows how experts also acknowledged that enablement relied on key individuals in statutory services being 'pro personalisation' and that where this was the case uptake would be greater:

> *Better performers have specific individuals in post and they push for the increase in uptake.*

3.3 Improving enablement

A number of issues which relate to addressing some of the barriers in theme two were suggested as means by which uptake of personal budgets could be achieved. The critical role played by care coordinators were paramount, with reasons being provided as to why these were areas of concern.

Service users

Some service users believed that their care coordinators or other staff either didn't know about Personal Budgets and how they can be spent to meet people's needs:

> *Support workers should be trained in what personal budgets are and what benefits a person should be entitled to.*

Carers

The attitudes of staff and the process of assessment were seen as barriers by the carers and something you had to fight against:

> *You feel judged by the assessment process and feel that you have to justify yourself all the time. It's as if they think you are exaggerating and trying to get more than what you need. When it comes to a review you always fear that they will take away the little you get and you feel judged all over again.*

Voluntary or Statutory Service providers

With high case loads and little time to do the assessments required service providers feel under a great deal of pressure. Delays in the process were commonly reported and cuts or the potential for cuts were having negative effects on staff morale and their ability to deliver a good service. It was felt to be imperative that this is acknowledged and addressed by statutory sector senior leaders as a condition of progress on Personal Budget uptake. A variety of concerns are expressed as the following quotes show:

> *Personal budgets are reviewed every year and if it takes 6 months to get up and running well then people's needs may change in the prolonged period of getting it up and running.*

> *I manage the carers' side and carers budgets are virtually non-existent because you can't get the assessment done and without an assessment you can't get a budget. It's wrong to raise expectations by saying there is an assessment and then budget and then don't get it. It's a disturbing process to go through. Some care coordinators were telling people roughly what it would be and then it goes to panel and it would be half that.*

> *Care coordinators know what has to be done but when you have to write up the narrative that's difficult. For example, if you say you are going to take*

someone for a coffee who would sign that off? But if you say the person has agoraphobia then to get them out of the house it's not going for a jolly. It's changing that understanding. How do you write up taking someone for a coffee?

We need facts and figures when mental health isn't black and white. We need to justify amounts.

Local Authorities and NHS need a website so people can see what is on offer. But we also need to deal with the disarray and mess. Capacity and staff within need sorting out. Until we do that were not going to serve clients.

Effects of efficiency savings and cuts mean front line staff are taking the cut. Those who make cuts need to see the frontline. Those who make decisions need to see what goes on.

Staff need to know they are being supported but we have care coordinators phoning up who are stressed themselves. Sometimes they only have 10 minutes to do an assessment. Case loads are high and they can't cope.

Personalisation needs to be prioritised; the right support needs to be in place, as there is no point in giving someone a personal budget without a support plan in place and help.

Commissioners

As for service users, commissioners acknowledged the need to have trained staff.

Training is needed for practitioners – needs to be embedded within teams and easier to access, and include risk issues.

> *Mental health Trusts should be committed to personalisation.*

Personalisation Experts

A number of personalisation experts also reflected on what works:

> *Better performers have specific individuals in post and they push for the increase in uptake.*
>
> *Mind and Rethink have made some big strides in this area following uncertainty for 3 or 4 years. Mind are making a huge leap forward – to be part of the change rather than trying to fight it.*
>
> *Not that many studies or reports on mental health and personal budgets. However No Health without Mental Health did give a clear direction of travel to personal budget s and personal health budgets.*
>
> *It is important to work in a personalised way as it does not cost anything, more training staff to think about how personal budgets and personalisation can be used.*
>
> *The difficulty comes – not with what is trying to be achieved, but rather the systems and culture within services.*

A majority of participants in every respondent category identified training as a key issue. They felt that where the care coordinator worked in a personalised way, this made a substantial difference to the person's experience when attempting to access Personal Budgets. One of the cases for training concerned the apparent lack of confidence amongst some professionals, which it was felt, would subsequently cause barriers to arise in the system. Another cited case was that of addressing the negative attitudes of some staff and to provide a forum for them to understand the reasons for a personalised service being required, and for its representation of value for money and better potential outcome. Whilst training is important and in some cases has taken place over many years, respondents' comments show that if personalisation is to be effectively and evenly delivered across the country, there is a need for this to be repeated or be part of a continuous dialogue, to change the culture of statutory services.

Moreover, the accounts of the voluntary sector providers suggest that training in and of itself is not enough, and that the care planning process itself, staff supervision, on-going conversations, leadership and cultural practices must all be addressed and that a combined approach is needed if we are to change practice.

4. Theme Four: Partnership working

A range of views were offered as to the reasons for current levels of partnership working. The need for better partnership working and a number of ideas for how it could be achieved were also reported. The quotes in the sections below show the perspectives of various participants in this area and reflect the impact that they felt partnership working had on service delivery.

4.1 Perceived partnership working practices

Service users

For the recipients of services, the variability in service provision was seen to illustrate a lack of coordination. Furthermore, for those who had moved from one area to another, the changes that they experienced as a result of transferring between Local Authority jurisdiction showed that whilst in some areas there was coordination of services and partnership working in other areas it was missing:

> *Information sharing just doesn't seem to happen. It's probably because of the fear of losing you to someone else and then losing the money to stay in*

> *business yourself. That's not good for someone who needs more than what one service can offer.*

> *Services are looking at how to promote their service and not looking at the individual, they are not looking at the long term packages for the person.*

> *There's one support in one town and not in another.*

The first two quotes show the lack of partnership working as experienced by some of the service user participants and the impact that this had on them. Some of the participants felt that they had a lack of knowledge about the alternatives to the service they received and that this in itself led to a lack of choice.

Carers

For carers, partnership working was seen to be decreasing as a result of cuts to funding.

> *There's less and less cooperation now and as services are losing money and simply trying to exist. There isn't the time or the money for them to spend time to get together and look at how they can coordinate and support people in our position. Everyone knows the role carers play but there's hardly any support for us.*

Voluntary and statutory sector providers

For voluntary sector providers a number felt that the advances that had been made in recent years to work together and to connect with other service providers, would now diminish given that Personal Budgets means that providers would, at a micro scale, be chasing the same monies. Also, as providers had to cost their services per individual, perhaps at an hourly rate, this meant that some commissioners were dictating to users how much money per hour they were willing to pay for, leaving users with little choice and control over what they can afford or buy. This in itself does not assist the development of partnership working and indeed can result in additional barriers - between providers themselves and between providers and commissioners.

> *When grant funded, organisations worked together, being instinctively collaborative but this is no longer the case due to competitive tendering which is extending to Personal Budgets.*
>
> *Supposed to be a tool of power but simply increases the power of commissioners to set prices.*

Commissioners

For commissioners, the need for partnership working was seen to be essential. However, they did not discuss the barriers to this in practice.

> *There has to be and there are good partnerships that are in place. There has been increasing recognition of the important role user led organisations can play.*

Personalisation Experts

A number of the experts agreed that partnership working varied across the country and that where there was good partnership working there were not necessarily additional resources but a commitment to personalisation, with good collaborative relationships having been formed and maintained. Given that evidence of successful partnership working exists, they felt that it should be achievable elsewhere but acknowledged that in the majority of Local Authorities it was not happening.

> *It is not too hard to achieve as it already has been achieved in some areas.*

> *There are some good examples out there and great strides have been made by some organisations to work together without having any additional money. It's the culture and commitment of key individuals that makes this happen.*

4.2 Achieving better partnership working

Service Users

A suggestion was made that one way to achieve greater partnership working and increase uptake would be to have a database of information so that areas in which there was evidence of a lack of integration and partnership working this could be exposed ('naming and shaming')

> *Maybe we need a mental health intelligence network. I would like lots of information in there so you can compare one area to another.*

Carers

Carers felt that they were ignored in the process of assessment and allocation of budgets and that the potential contribution they made in their support role was undermined. They argued for carer groups to be consulted and for more user- led organisations to be given a prominent role in shaping service provision, so as to address their needs as well as those for whom they cared. Co-producing services was seen as essential but its effectiveness required the voice of the carer to be heard.

> *We have a lot of experience and know what does and doesn't work. Some of us have been carers most of our lives and some of us have ended up becoming service users ourselves.*

> *We don't get asked about what we do and what our needs are. In fact we are lucky if we get believed about the needs of the person we are caring for.*

> *I treat my son the same as my other sons but if we are going out for a meal say for a birthday I will give him a choice if he wants to come or we get a takeaway another day to celebrate at home.*

The knowledge and experience of carers in addressing the individual service user's needs was felt to be valuable and yet service providers were felt not to acknowledge either this or the role that it could play in determining what an individual's needs are and from where they arise.

Voluntary or Statutory Service providers

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 roll out of Personal Budgets in other areas and support the newer roll out of Personal Health Budgets.

> *It should be, (provider) could develop specific areas and work together with other providers to allow people to pick and choose.*

> *On the health side there is much more energy than on the social care side.*

> *Have pushed for a new information sharing protocol; so this could speed up partnership working.*

Commissioners

From the commissioner's point of view, good practice would provide escalated learning for health and the potential for linking up systems. Each step of Self-Directed Support budgets has built on the last (Direct Payments, Individual Budgets, Personal Budgets, Personal Health Budgets) and so health should accommodate the learning from social care, in order to ensure implementation that is effective and that avoids unnecessary pitfalls.

> *Greater partnership is needed between health and Local Authorities as the Local Authority have a lot of experience with personal budgets and people with physical health conditions, which need to translate across to mental health.*
>
> *Work with health colleagues to identify specific issues and high case loads, and connect the two equals less service use due to increased independence.*

One outcome of better partnership working was seen as being to free up specialist resources for these to be targeted at the needs of the most vulnerable individuals.

Personalisation Experts

A number of experts while outlining the problems that had previously occurred in relation to Personal Budgets expressed their continuing support for them and felt that partnership working was a key area to work on, if they were to deliver the intended benefits to service users of choice and control:

> *Giving the knowledge to apply for personal budgets – can reach a far greater number of people, whether then they are able to actually access personal budgets is another matter. One Local Authority published guidance stating that those under Section 117 of the Mental Health Act 1983 were not eligible, I was able to address this and so amended guidance has been published.*
>
> *By all partners wanting to achieve the same, including funders and people using services.*
>
> *If health & social care and third sector could all sign up to a shared commitment – you could move mountains.*

> *It is not too hard to achieve as it already has been achieved in some areas. Phenomenal results when partnerships are strong.*

These quotes reflect a recognition that while Personal Budgets are the right way forward, they do require service users to know what is available and from whom. Information sharing and cooperation between services with 'signposting' is needed if people are to have choice and control. However, the uncertainty of being able to deliver some existing services via Personal Budget purchase by individuals (especially with the reduction of the number of people who are now eligible) creates pressure on voluntary organisations, and also in some instances sets them up as competitors. The combined effects of moving to a business model, where purchase by service users is not guaranteed, and having to project the viability of a particular service, means that voluntary organisations are facing a major shift in purchasing practice that could run counter to the conditions for partnership working. There is a need for partnership working and a desire to achieve its recognisable benefits but there are a number of co-existing challenges to doing so.

5. Theme Five: Link between personalisation and reduction in crisis support

The majority of people agreed that if personalisation is in place and it meets people’s needs, then this would lead to a reduction in crisis support and reduce the revolving door of people going into crisis, needing intensive home support or expensive hospital admission. Participants all agreed that if a personalised approach was in place and properly funded, with crisis prevention services being able to be operationalised at the time of need, then this would not only save money but also potentially prevent crisis.

Service users

A number of service users talked about the potential to prevent crisis but saw the way funding is allocated as a barrier to this potential:

> *Well they have the potential to, but it would depend on being assessed in a way that sees the need can happen. With mental health you can go up and down and the problem is when you are well, then you don't fit the criteria and you can lose all the support. That's a fear you have, and if there was a system in place, that as soon as you know you are going downhill, that you can get the support you need there and then that would make you feel more secure and less anxious of relapse.*

> *Sometimes you just know you need to get away, everything is getting on top of you. People think you are asking for a jolly if you ask to go away but it's not. If you can spend your personal budget so that you can get away when you need to that would help.*

In the quote below, a service user reflected on her partner's role in keeping her out of crisis and felt that her partner's carer role was not recognised especially in terms of helping her to prevent reaching crisis point:

> *Carers are often ignored. But family know you. It's stating the obvious, the importance. Some carers can go to pieces. Is it 60% of carers can develop mental health problems themselves......? Care workers choose to do that for a living, but carers it's something you have to do. There is a difference between care workers and carers.*

Carers

Carers have a dual need in terms of crisis prevention. One relates to their own respite needs, the other to the need to secure more intensive care for the person for whom they care when they know this is needed. For them, accessing services at this point was not an easy process. Hospital admission could mean that their loved ones could be placed miles away from family, thereby making visiting very difficult.

> *Getting support for my parents to get away from caring for my brother is really important and respite care means they can do that.*

> *It would cost far less if the services recognised the need to keep people well. When you know you need help and can recognise the symptoms you need to be listened, and support if you can get it in time would save so much. No one wants to go to hospital if they can avoid it, and it is the most depressing place to go.*

Voluntary or Statutory Service providers

A number of voluntary sector providers also discussed the importance of respite and argued for Personal Budgets to include early intervention provision:

> *If personal budgets could be used for early intervention it would be superb, say for 3-4 months because it would allow the person to stay in the community, stay in work or decrease social isolation. At the moment you have to scratch around well-being projects as they're not around.*

> *They should do. It matters if it is a social care bed not a health bed. Respite is important for reducing crisis.*

Commissioners

In accord with the views of all other participants, commissioners also saw the potential for early intervention and Personal Budgets in reducing the need for crisis support:

> *More flexible support allows people to be closer to their own homes and people can focus on a specific issue with their personal budget.*

Commissioners felt that by addressing issues earlier and in a more targeted way, people are able to avoid hospital and achieve greater stability in employment, relationships and housing. They saw this as having a massive impact; being able to reduce negative experiences and high cost interventions.

Personalisation Experts

A number of experts again reflected on the difference in practice between areas. They also felt that the money/system is focused on crisis care and that the funding needs to be redistributed from crisis interventions to preventative interventions.

> *Personal health budgets have been used in specific areas to reduce admissions; therefore they will be the target group. Only one pilot was more broadly addressing mental health across health and social care, with one looking at repatriating people being supported OOH (out of hospital) or OATS (out of area treatments).*
>
> *Should not just be focused on crisis or acute situations.*
>
> *System already provides support for those in crisis, at admission, primary care and secondary care support. People move through the system depending upon the options within that pathway however personal budgets pathways can be inconsistent with existing pathways.*
>
> *There is guidance on how to avoid admission.*
>
> *There are a range of experiences for people whilst an inpatient – some feel it necessary, others hate it so clearly need a range of crisis options to respond to the range of experiences.*

> *An alternative could be providing more support at home to avoid admission.*
>
> *St Clements example – x amount of weeks a year to visit a guest house in Felixstowe, for a frequent revolving door client.*
>
> *There is huge potential to reduce admissions.*

Some of the experts asserted a need to move away from a crisis model and to start to provide alternative options to individuals. They felt that a reduction could be achieved and that there was existing provision in some areas and by some providers which mean they should be replicable in other localities and marketed to ensure awareness.

6. Theme Six: How well does the personalisation system work

In this section when we refer to the 'system' we mean the structure in place to support the process, where the process relates to assessment and application. A number of issues arose when it came to the system aspects and to what extent it leads to the practice of personalisation. Service users discussed the system aspects, in terms of how they found accessing the system and the process involved before receiving a Personal Budget. For service providers and commissioners, the system aspects related to how well they perceived it to be working.

Service users

The majority of service users reported experiencing the accessing of and subsequent process of assessment in negative terms:

> *I've been left very upset and now I'm on the waiting list for counselling but don't have the confidence in that as what's been done to me by services where benefits have been taken away and I've been left with no support.*

> *When you are ill there are too many barriers. You feel like a victim to the system. As I came away from residential care I had problems with housing and only Shelter has helped.*

For some it was a fight to have an assessment done and even when completed they were unaware of the care plan and the process by which they would be assessed. Whilst this lack of knowledge meant that they were unaware of how the process worked, for others, seeking to establish what had happened to their assessment led to continual chasing and the need to resort to complaints in order to pursue entitlements

One person's complaint led to a Local Authority investigation. The findings of the investigation included the statements...

> *"The investigation concluded that there is no doubt that this process has taken too long... apologies for this and the distress this has caused you. The investigation has also concluded that the delay you have experienced is entirely the fault of professionals failing to make adequate decisions when given every opportunity to do so by you". "... The investigation has concluded that you did try to resolve matters yourself but to no avail and this was as a direct result of professionals not responding to your situation. This should not have happened". "... The investigation has upheld your complaint."*

The causes for their poor experiences were partly seen to be due to the restructuring of services and changes to existing systems:

> *All the restructuring means no one knows what they are doing and it leads to more aggravation.*

> *Changing the system has really messed it up, national to local, means that there is too much variation.*

Furthermore the variation across the country was known to exist by some service users and added to what they saw as an unfair process:

> *It is a shame that if you turn right up the road, you know about it, but if you go left down the road, you know nothing about personal budgets. It is a shame that people's experiences can be so different.*

Carers

Carers also cited the experience of care planning not being offered and conveyed a sense of feeling that the question of the size of the budget to be allocated would be answerable by way of a transparent process:

> *It should be that everyone is told that they can apply to be assessed but that's not the case. Even if you raise it you rely on the care coordinator to do them. Even then you don't know what they are looking for and what they use to make a decision.*

Voluntary or Statutory Service providers

A number of service providers were also negative about the workings of the system. A range of quotes are provided below to demonstrate this:

> *The way personal budgets are arranged; with a fixed panel assessment, who make judgement on substantial levels of disability. The assessment stands for a year prior to review. This is quite a rigid approach, despite the fact that mental health can be a flexible condition and can improve. The assessment process removes lots of people with complex needs who are assessed as not eligible unless using free at the point of access services equals a tiny fragment.*

It should be noted here that if a service user has a relevant change of circumstances then the care coordinator should review the care plan and it can be amended as soon as is practicable to respond to current needs. The comment above is not uncommon when reporting the actual experience of the workings of the Care Programme Approach (CPA).

> *Locally, people with mental health problems won't get allocated personal budgets as it will be spent on physical health conditions.*
>
> *The process of applying for personal budgets has made people unwell.*
>
> *It doesn't, it is rubbish.*
>
> *You are repeatedly told 2 weeks, but for some people it has been 8 months or more. People then try to access drop in centres but those services have been cut.*
>
> *The process is complicated – 168 pages of guidance, an additional 32 pages of the form and only looking at 3 service providers – doesn't feel like people are being empowered.*
>
> *No transparency as to why people are turned down.*
>
> *It's very varied. Even within a small area and a small team it can be different. The process also takes too long.*
>
> *If more people do take them up and the money in the system is not redistributed more toward social care than medical care then cut backs and finances are the biggest threat.*
>
> *The way the system is set up there is competition that is set up amongst charities which means they are not as open as they should be to partnership work as they are in competition.*

> *Local Authority approach can be confusing as want a competitive service that works collaboratively – this can drive a wedge between providers.*

In one sense, this was ever thus, but in recent years there has been an emphasis on partnership working between the voluntary sector agencies and perhaps an expectation on the part of the statutory sector that the voluntary sector will work in partnership on particular issues. This becomes significantly more challenging when partners become viewed also as competitors. Voluntary sector providers felt that there were additional threats from the private sector:

> *Threats by the private sector as some are coming in and they don't even know the local area or people. They bid lower and get the contracts.*

This issue of private contractors not having a background in Personal Budgets, not understanding the development history or meaning of 'choice and control', and therefore missing the key point of personalisation when delivering on contracts is something that concerns service users and carers.

A number of service providers and personalisation experts stated that a complete overhaul of the current system would be needed if existing problems in this regard were to be addressed:

> *Has to be whole system re-design like in Lambeth and Stockport. Need to publish their stories so others can see how to go about it. Commissioners have to get involved and support it. Need both top down and bottom up training and support.*

As previously mentioned, additional concerns relating to the changes in funding and contracting were expressed:

> *Shift from block contracting to spot contracting has been massively bureaucratic, in terms of admin and finance. The resource required by providers and Local Authority has been large especially on admin.*

> *More generally and not just related to personalisation – emphasis on cost can be a real risk to quality.*

> *Plurality of choice and providers, but there's no plurality of cost. Providers have no say over unit costs. "This is how much we are willing to pay".*

> *They have pulled out of tenders due to price issues.*

> *Depends on the spectrum being offered and how services choose to undertake it.*

> *Personalisation appears to be a way to remove risk from the Local Authority and push it onto providers. Spot purchasing inevitably brings fluctuation in demand and so risk is carried by providers, which can be an issue for small providers – unintended consequence of personalisation.*

If, for whatever reason, an individual care package fails, then the ultimate responsibility for ensuring that a person is kept safe falls back to the Local Authority. Providers are however, finding it difficult to provide a coherent 'service' when their block contracts have ceased and as a consequence, they are reliant for commissioning a critical mass of provision with service users acting as micro-commissioners:

> *Wouldn't defend the old system of bad services being sustained, but new system can risk the levels of quality being offered.*

> *People are still thinking in terms of buying Local Authority approved services when it may be that they can purchase wider universal services.*

The variety of issues affecting how the system works, especially from service provider accounts, shows that there are indeed a number of factors that are affecting the current system and multiple areas of concern remain.

Commissioners

In the accounts provided by commissioners, there was support for the concept of recovery - and personalisation was seen to provide this. However, it was felt to be important for commissioners to take a longer term view on the investment needed in mental health, especially in view of the need to fund preventive services that will impact positively on the cost of providing treatment after crisis:

Definitely cost effective – good investment in people's recovery

Whilst this reflects the view of at least one commissioner, many service users felt that in practice, it was held to be necessary to be in, or emerging from crisis before being be eligible for a budget.

Personalisation Experts

The views of personalisation experts reflected those of service users, carers and voluntary sector providers in this area though this group also noted particularly the differences across the country in terms of provision and how well the system works:

> *Mixed picture, some areas work better than others.*

While the perceived failings within the system and the reasons for these have been outlined here, it should be noted that the personalisation experts and some local authorities pointed up the existence of good practice in some areas and argued that this needs to be highlighted, disseminated and used to influence those who are failing to deliver.

Discussion

The results of this study have been presented as six themes: personalisation as a concept/principal; 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. A summary of these findings and what they tell us about the factors affecting the uptake of personalisation will be explored in turn.

Theme one, in which the concept of personalisation and attitudes towards it were explored, showed all our participant groups to hold favourable attitudes towards the concept. While there were no significant differences in the responses, there were a number of service users who had never encountered the term and so could only reflect on it being a good idea having heard a description provided by the researcher. Others who knew of personalisation thought that whilst it was good in principle, the provision for making this happen in reality was insufficient for a number of reasons (these reasons are highlighted in theme two in which we looked at the barriers relating to the uptake of Personal Budgets). Returning to theme one, a small number of quotes were presented to illustrate the way in which support for personalisation was articulated. One of the possible explanations for this unanimously positive response may relate to the socio-cultural shift towards community based approaches, the social model of disability and the progress which has been made by user led movements towards equality over the last few decades. Support for the concept and ideology of personalisation has been the cornerstone of many user led organisations and groups who are still active in advocating personalised practices and are encouraging the co-production of services in order to provide for a better understanding of the needs of support service recipients.

A number of significant barriers were identified in theme two, which evidences as the multiple reasons for failures in personalisation practice, to make a reality of the promise of personalised services for all recipients of social care. The barriers were notably: a lack of knowledge and awareness; difficulties with the process of application (especially completing the forms); the service user's relationship with the care coordinator (sometimes referred to as a key worker) and their attitudes towards eligibility and how the wider benefits system and the reorganisation/changes within it work. In this theme, discussion of each barrier in turn was followed by an exploration of the impact of these barriers on lived experience. One of the reasons why uptake is low amongst mental health service users relates to the fact that for many, knowledge and awareness of personalisation and the availability of a Personal Budget option for self-directed support is not present. The lack of information is a major barrier, and measures to tackle the lack of awareness amongst both service users and carers need to be addressed if numbers are to increase. For those that did know about Personal Budgets and self-directed support, a different set of barriers relating to the process of application may be identified. Service users and carers who may potentially be eligible for a Personal Budget to meet their social care needs require a care plan to be drawn up and have an assessment made. Our findings show that, for many, there were difficulties in either getting the care coordinator to do an assessment and related care plan in order for the application process to begin or, once the process started, to have a decision made about their eligibility in a reasonable time frame. Some of our service users reported relationship problems with their care coordinator, saying either that they did not know about Personal Budgets or that having received the request for one, the care coordinator had not acted upon the request. Where care coordinators did carry out a care plan and hence start the process of assessment, further difficulties were reported by a small number of our participants. Service users experienced considerable delays between assessment and decision, with one participant who had gone through the process a number of times still awaiting a decision on eligibility twelve months later. Service users reported a number of negative experiences relating to the poor relationship between themselves and the care coordinator, ranging from never receiving a copy of a completed assessment, to being able to contact a care coordinator only by phone or even having their plan completed solely by phone. The importance of the care coordinator or key worker has been stressed by SCIE (2011 briefing 36), which reports that most of the recipients who hold Personal Budgets become aware of them through their social worker or CPN and also report that they would have liked to have become aware sooner. Our study found that those who had knowledge and awareness of Personal Budgets similarly received information about them through such key workers. Raising awareness may not be high on the agenda of some key workers, especially if they already have high workloads and are time pressured, but it seems reasonable to suppose that unless the key worker supports provision of this awareness uptake will be limited.

For those that did manage to have a Personal Budget allocated, a lack of transparency was identified in relation to how they had been assessed and needs matched to budget and outcomes. This created particular stress and difficulty when it came to re-assessment, as service users were unsure what would happen and whether they would experience cuts even if their identified needs remained the same. Despite several letters of complaint following a cut to her Personal Budget, one participant was successful only after having an upheld complaint. Of course, not all care coordinators are unaware of Personal Budgets and the need to make an assessment in relation to them, but there appear to be a significant number who, for a number of reasons, are not undertaking this duty. SCIE (2011 briefing 36) goes on to report service users' experiences of the process of assessment, and in common with our research, found that some of their participants would have liked more support with the assessment process and wanted a consistent contact person who would know them and their circumstances. In our study, we found that some service users did not have a consistent key worker and found the assessment process difficult to navigate. The brevity of time taken to carry out the assessment (with one participant reporting it took less than 15 minutes) and the lack of a personalised approach, show that the needs assessment process is not working acceptably in a number of instances. One of the reasons for a poor relationship between care coordinators and clients relates to the cuts in services and increased workloads that care coordinators are likely to have as a consequence. The lack of time to undertake adequate care planning was reported to be a problem both by the study's service providers (statutory and voluntary organisations) and by its service users, carers and personalisation experts. Providers also reported that the complexity of the financial assessment posed a further barrier. Furthermore, commissioners also reported that the assessment process is often lengthy and formal.

Another concern was raised by service providers relating to the eligibility criteria. Most Local Authorities now operate a policy of meeting only critical or substantial needs and hence where previously some clients qualified, they now no longer do so. The existence of on-going support needs is acknowledged but these were reported as remaining unmet. Access to centres had reduced with those that previously provided support services closing down or removing support services due to funding cuts.

This section on the barriers to the uptake of Personal Budgets indicates a range of existing barriers, from failure to progress past the initial assessment process because of lack of knowledge - on Personal Budget existence or personal entitlement or on who can conduct one; because of the time duration between completing the assessment process and a decision being made by the Local Authority (often compounded by there being little transparency as to how the decision has been made); because of a poor relationship with the care coordinator in which there may be inadequate continuity of contact and/or post-assessment feedback. Changes to the eligibility criteria, coupled with a reduction in services, appear to be exacerbating service user experience which in a majority of cases is reported as poor, and this is the case too for a number of individuals who, in receipt of a Personal Budget, report a reduction or complete withdrawal of the Personal Budget consequent upon a re-assessment in which no change of circumstance is identified (the Budget, in one reported case being re-instated only after an upheld formal complaint). Our findings suggest that personalisation and the allocation of Personal Budgets is failing to deliver.

In contrast to the findings reported in theme two, those reported in theme three suggest that there is the potential for personalisation to work and we have identified those factors that have enabled Personal Budget uptake. One of the principal ways in which people felt supported was via Direct Payment support services, and having a good advocate and/or support service as offered by organisations such as Mind and Rethink. Whilst a number of care coordinators are criticised for their lack of knowledge, refusal to complete assessment applications, offering poor relationships and a lack of support for clients, others reported a good relationship with their care coordinator and highlighted the central role that they play in achieving an assessment, ensuring the subsequent decision and providing effective input for administering their self-directed support. Care coordinators are seen here to have a critical role and a good care coordinator who is pro - personalisation and has the time to carry out a full care plan is seen to be key to a successful and positive outcome. Our findings confirm and reiterate the advice by SCIE (2011 briefing 36) that we need to acknowledge:

> "*the central importance of the relationship between personal budget holders and the practitioner who supports them to plan their care and support. Giving staff support, information, training and time to work properly with personal budget holders is crucial*" (pg 6).

The accounts of such positive relationships show that service users can be aided to seek and manage their own care provided that they are supported to do so. In this section, we discuss findings that relate to how barriers can be overcome. In relation to care coordinators and their role, one of the key recommendations made by the participants in this study related to the need to have more and continual training of front line staff, with such training needing to become part of continual professional development programmes as opposed to consisting in brief short course formats. For effective change to occur our findings show that this needs to be augmented by increased staff supervision, on-going conversations, improved leadership and cultural practice change. As previous research by Slasberg et al (2012, 2013) has identified, there is also a need to address issues associated with the resource allocation systems used. It is also important to recognise and address the concerns raised by service providers who feel under a great deal of pressure with high case loads and little time to do the assessments required. Delays, financial cuts or the potential for such cuts were having negative effects on staff morale and their ability to deliver a good service.

Theme four considered issues relating to what services are available and the sharing of information about them. Service users reported poor information sharing for reasons that they felt were related to the need for services to retain their customer base and hence their business viability. For others, moving location and changing Local Authority jurisdiction highlighted the differences in service provision across different parts of the country. This variability was also reported by the personalisation experts who took part in the study.

For some participants working in the voluntary sector, the introduction of Personal Budgets itself was causing problems, which in turn were impacting on how confident they felt about continuing with some of their partnership work across the sector. The move towards individual purchase compared to block funding was leading to required changes to their own business model. A small number felt that the advances that had been made in recent years to work together and to connect with other service providers would now diminish in view of the need for Personal Budgets providers to be compete for the same finite cash pot. In addition, as providers had to cost their services per individual, often on an hourly rate basis, some commissioners were in a position to be able to 'dictate' to users how much per hour they were willing to pay, leaving users with little choice and control over what they could afford or buy if the hourly rate reduced purchase power. This in itself does not assist partnership working and indeed can result in barriers between both providers and providers and commissioners.

In terms of how partnership working can be increased, a number of suggestions were made by participants. These included having an intelligence network, a database of organisations and case studies that highlighted where and how good partnership working was being achieved. Of particular importance was the need to involve service users and carers so that they could input on service delivery design and guide the partnership process. One of the personalisation experts suggested that if health, social care and third sector organisations signed up to a shared commitment, then substantial improvements could be made in this area. It was suggested in relation to this that the original ministerial concordat “Putting People First: a shared vision and commitment to the transformation of adult social care” might be revisited. Greater partnership working alongside information sharing between services with adequate signposting would provide people with more choice and control. However, with the removal of block funding and uncertainty of being able to deliver some existing services via individual Personal Budget purchase (especially with the reduction of the number of people who are now eligible) there is pressure to look after one’s own service provision as opposed to pursuing the cooperative approach regarded by most as more desirable.

Theme five explored issues concerning the potential to reduce crisis support, by using Personal Budgets as a means of meeting one’s own needs. The majority of study participants agreed that if personalisation is in place and is meeting people’s needs, a reduction in crisis support need and the crisis 'revolving door' might be expected to follow. However in reality, service providers felt that the way in which funding is allocated actually acted as a barrier to this potential, since for prevention to be effective, a service user would need to be assessed in a way that sees relapse and crisis as a possible outcome and plan for measures to prevent it. Whilst some service users and providers discussed this as part of their care planning process, it was not a widespread activity. All our participants recognised that there is inevitable variability in the conditions of people with mental health issues ('you can go up and down') and so to reduce the incidence of crisis, adequate recognition and support measures had to be in place. One of the problems faced by the mental health service user is that when well, they do not fit the threshold criteria for Personal Budgets and they often find that they lose all the support they need for prevention to be effective. With the cuts to funding and the changes to eligibility, precluding from entitlement all but those with critical and substantial needs, many do not have a care plan in place through which to provide measures to prevent or reduce the impact of crisis. A number of experts reflected additionally on the differences in practice between different areas, feeling that the money and/or the system is focused on crisis care rather than being distributed in such a way as to achieve effective balance between crisis and prevention. Some of the experts noted a need to move away from a crisis model; to begin to provide alternative options to individuals. In a few places there are schemes which try to address prevention and provide pre-crisis support but as yet few such options are available. For the majority it appears that personalisation is failing to deliver adequate prevention planning and services prior to the point of crisis.

Finally in theme six, a number of issues were identified related to how and why the system itself was failing to work and showed the ways in which the process and systems in place for many were impeding the development of personalisation practice. Service users discussed this in terms of how they found accessing the system and the process involved before receiving a Personal Budget, while service providers and personalisation experts discussed the system aspects from beginning to end. There were a significantly greater number of accounts about the whole approach that were negative than there were positive. In contrast, commissioner's accounts related to how well they perceived the process to be working.

The service users pointed out how difficult it could be to get an assessment done, and also commented on the problem of not knowing what would happen following the assessment. They were unaware of how allocations for a Budget were made and experienced long delays between assessment and notification. Even once they had an assessment and were awaiting allocation they feared that systemic cuts would lead, in turn, to cuts in their Personal Budgets when they were next assessed. Indeed one of the service users lost all her Personal Budget despite having had no change in her circumstances since the previous assessment. This lack of transparency as to how needs are identified and how funding is allocated can be said to represent a means by which equity and equality are impacted.

Some service providers acknowledged the existence of long delays in the process and commented also on its complexity. They also commented on the lack of transparency in the system and the variability in who does and does not get a Personal Budget. Series and Clements (2102) in their study looking at the Resource Allocation System (RAS) assess the validity of the arguments concerning the simplicity, transparency and equitability of RASs. They state that this comes at a time:

> "when some of the leading proponents of the early personalisation programme are severely critical of their obscurity, stating (for example) that: Complexity has grown; but there is no empirical evidence to suggest that any of these systems is leading to fair and sustainable allocations for all. Frequently, local leaders inform you that their system is currently 'broken' and

> that they need more time to make further amendments" (Duffy & Etherington, 2012 p.8) (pg 209)

Our evidence on reported lack of transparency can be held to endorse the evidence of this literature.

Separate and additional concerns were raised by voluntary and statutory sector providers on the need for collaborative working between providers and the ways in which this was being compromised by the ways in which funding was now being allocated to support provider competition and the establishment of providers who, in some cases, have little knowledge of local people or of the agenda for “choice and control” but who nonetheless are positioned to undercut the costs of voluntary organisations who may have these local links and concern for the agenda. The problems of spot purchasing were also discussed. While the extent of negative experience appears somewhat overwhelming, as noted in Disability Now (2014), it is important to distinguish the problems associated with Personal Budgets from the wider principles and values of personalisation:

> “personal budgets are equated with personalisation. We know that the two are far from synonymous: the present system of personal budgets is a technique. Personalisation is a goal. So far the former seems to be very far from delivering on the latter”

The reports of some of our participants serve to echo this and the argument of Slasberg (2012) that the:

> “notion of self-directed support seems to have failed in its ambitions. However, the concepts of personalisation and personal budgets associated with it may retain value if interpreted in an appropriate way, delivered through an appropriate strategy. Then even so long as resources fall short of needs, they are likely to ensure the best possible outcomes for service users are secured. If and when adequate levels of funding are also provided, there may be the real prospect of enabling all to live their lives on the same terms as others who do not need social care support.” (pg 161)

The results of our research also bear out a conviction in the value of personalisation and Personal Budget when guided by appropriate strategy to be effectively interpreted in practice. It is important to note that our study is a small sample study and presents people’s own narratives, and as such the research findings do not claim to be generalizable or fully representative of all personal budget holders’ experiences. It does however lend weight to the growing body of literature which details the failings of the implementation of personal budgets and asks for them to be revisited (Slasberg et al 2012a; Slasberg et al 2012b). If Personal Budgets are to continue then, in the interest of advancing this goal and addressing the entitlement of mental health service users to authentic choice and control through equitable access to Personal Budgets, in conclusion our study offers a number of recommendations in the key areas that we have investigated. These recommendations are set out below.

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.

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Useful Links

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In Control

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Mental Health Network NHS Confederation

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TLAP

http://www.thinklocalactpersonal.org.uk/

Appendix: Semi Structured Questionnaire:

Mind project: Personalising the future - research questions:

These research questions are for use in one to one interviews and focus groups. They are a guide to the relevant questions which will be asked, however additional specific questions may also be asked at the time. The approach to be taken is semi structured allowing additional questions and reordering of questions when appropriate.

There are 3 groups of questions – People who use services (one to one interviews and focus groups); Voluntary sector service providers (one to one interviews); and Statutory sector providers (one to one interviews).

Research Questions

People who use services:

- Do you know about Personal Budgets (otherwise referred to as self-directed support; direct payments; individualised budgets; independent living; personalised services)?
- Have you ever received a personal budget?

If yes:

- If yes– How did you find out about them?
- How did you find the process of application?
    - What went well/helped you? and/or
    - Were there any particular barriers/problems?
- How long did the process from applying for the personal budget to getting it take?
- Were you satisfied with the process?
- What were your reasons for the level of satisfaction experienced?
- Did you feel you had choice and control in determining your personal budget and on what you could spend it on?
- What support or help were you looking for and did you get it?
    - If yes where from and what was it?
- What difference do you think PB's have made to the management of your mental health and recovery?
- Do you think having a PB (Self-directed support) has led to an improvement in your Mental Health and recovery?
- Has getting a personal budget helped you get anything else? (e.g. managing your condition; personal freedom; more engaged in the community; social networks; education)
- What do you use your personal budget for?
- How satisfied were/are you with having a PB?
- Would you recommend PB's to other MH service users? –Why?
- How can they best be informed of PB's?
- What changes would you like to see in the system and why?

If No:

- Were you aware of PB's?
- Did you apply for one?
    - If yes what happened?
    - If no – why not?
- Did you/do you know where to go to help you with the process?
- How do you think a PB could help you with your Mental Health and Recovery?
- What changes would you like to see in the system and why?

To all service users:

- Is there anything else you would like to tell us about your experience of PB's?
- Do you think there needs to be an Increase in uptake of Personal budgets (for those eligible)? If so how this could be achieved?

Voluntary Sector Service providers:

- What do you think about personal budgets as a concept/meeting people's needs?
- What do you think about PB's for Mental Health service users?
- Do you help individuals in applying for PB's?
- How well do you think the process works?
- Are there any barriers that prevent access and uptake?
- Are there any specific enablers to access and uptake?
- What services do you provide for those in receipt of PB's?
- Have you brokered support to access for something you don't provide (e.g. buying a car; support role; advocacy; education; leisure)?
- How do you measure the quality of your service?
- How do you measure the outcomes/impact of your service?
- Do you think there are particular barriers and challenges to your service with respect to PB's?
- What do you think can benefit MH service users and their use of PB's?

- Do you think PB’s can reduce the need for acute and Crisis Care support?
- Do you think Greater partnership working (and supportive working) between the sectors could be achieved?
    - If so how this could be done;
    - If not what are the barriers?
- What role do you think the local authority and NHS could play in developing the market for PBs
- Do you think there needs to be an Increase in uptake of Personal budgets (for those eligible)?
    - If so how this could be achieved?
- What could you as an individual or as an organisation do to enable this?
- Is there anything else you would like to tell us?

Statutory Sector providers (including commissioners):

- What do you think about personal budgets as a concept/meeting people’s needs?
- Do you/How do you enable take up of personal budgets?
- How well do you think the process works?
- Are there any barriers that prevent access and uptake?
- Are there any specific enablers to access and uptake?
- How do you measure the quality of your service?
- How do you measure the outcomes/impact of your service?
- Do you think there are particular barriers and challenges to your service with respect to PB’s?
- What do you think can benefit MH service users and their use of PB’s?
- Do you think PB’s can reduce the need for repeat acute and Crisis Care support?
- Do you think Greater partnership working (and supportive working) between the sectors could be achieved?
    - If so how could this be done;
    - If not what are the barriers?

- What role do you think the local authority and NHS could play in developing the market for PBs?
- Do you think there needs to be an Increase in uptake of Personal budgets (for those eligible)?
    - If so how this could be achieved?
- What could you as an individual or as an organisation do to enable this?
- Is there anything else you would like to tell us?