



**Healthwatch:
The experience of a personal budget application & FACS assessments for people with severe
and enduring mental health issues in Hackney**

Project Name: Core Arts/ health watch grant

Department: Personalisation agenda in Hackney

Product/Process: Personal Budgets and FACS Assessments – NHS/ LBH/ CCG

Prepared By

	Project/Organization Role
Emily Cubitt	Membership Manager / Core Arts

Overview and Aims

- 1 Aimed at:
Commissioners and Local Council Strategists.
- 2 To include the following:
 - Current approach and available information
 - How informed are patients?
 - Interviews and Case studies- the experience/ barriers concluded
 - Summary of concerns and Recommendations

Background

To begin with a brief definition and overview, Personalisation is a social care approach described by the department of health as meaning “every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings”.

While it is often associated with direct payments and personal budgets under which service users can choose the services that they receive, personalisation also entails that services are tailored to the needs of every individual, responsive to service user needs and wants rather than delivered in a one-size-fits-all fashion accounting for individual differences and creating personally designed support plans. The support plan has accountability of the individual and motivation and responsibility are key factors.

The UK government's 2012 draft Care and Support Bill proposed placing a duty on councils to ensure service users can access a diverse market of providers, and the accompanying White Paper suggests they produce a market position statement, setting out how they plan to implement the duty.

As councils devolve purchasing responsibility to service users, providers may no longer rely on block contracts with local authorities. Instead, councils are setting up framework agreements, under which providers are accredited to provide services of a particular quality at an agreed price. This means that local authorities are not offering providers guaranteed business, the final choice as to whether or not to use them rest with service users. This should make providers more responsive to service users' needs and wants and should also promote a drive towards innovation and more creative ways of working.

The community care website overviews the developments and describes (www.communitycare.co.uk) “In its 2010 adult social care strategy, the UK government set an ambitious target of having all council-funded service users and carers on personal budgets, preferably as a direct payment, by April 2013. This was interpreted by council leaders as applying to on-going users of community-based services, not those in residential care or anyone receiving short-term or one-off support. The target has proved controversial with the Association of Directors of Adult Social Services warning that it has artificially driven councils to move people on to council-managed personal budgets without providing them with choice and control. Though the care and support White Paper, published in July 2012, confirmed the target – and the fact that it applied to users of on-going, community-based support, it was dropped by the government in October 2012, when care services minister Norman Lamb reduced the target to 70% by April 2013. The draft Care and Support Bill includes plans to make personal budgets a mandatory part of all care plans, meaning they would apply to all council-funded users – including those in residential care – from the bill's point of implementation. This has been pencilled in as April 2015.”

NHS England defines a personal health budget, and the things that it can be spent on, as follows.

A personal health budget is an amount of money to support the identified healthcare and wellbeing needs of an individual, which is planned and agreed between the individual, or their representative, and the local clinical commissioning group (CCG). ‘A personal health budget can be spent on any care or services that are set out in the care and support plan

that has been put together with the NHS team or voluntary organisation working with the person – and this needs to be agreed by the CCG (clinical commissioning group).

There are things that it would not be right for the government to fund such as alcohol, tobacco, gambling or debt repayment, or anything that is illegal. A personal health budget cannot be used to buy emergency care – for example, if someone in receipt of a personal health budget had an accident, they would go to A&E like everyone else – they would not use their personal health budget to arrange for it to be x-rayed, set or plastered.

A personal health budget also cannot buy primary care services such as seeing a GP or dental treatment. Other services recommended by a GP, like physiotherapy, could be included.

The budget may be:

- a notional budget (an allocated amount that is agreed with the patient but no money is given directly to the patient; the NHS arranges the agreed care and support within that budget)
- an actual budget transferred from the NHS to a third party, which then arranges the agreed care and support within the budget
- an actual budget transferred from the NHS to the patient, who then arranges the agreed care and support within the budget.

Source: Excerpted from <http://www.personalhealthbudgets.england.nhs.uk/About/faqs/>

The government has been piloting and evaluating personal health budgets and people with mental health problems have been involved in some of the 20 pilot schemes. In November 2012, the report of the 'Personal health budget evaluation' was published. The evaluation found personal health budgets generally improved people's quality of life and were cost effective. Outcomes tended to be more positive where pilot sites gave patients more choice over how budgets were spent. The government announced personal health budgets were to be made more widely available.

People who receive NHS Continuing Healthcare (care arranged and funded solely by the NHS and provided free to an individual) have had a legal 'right to ask' for a personal health budget since April 2014, and in October 2014, this will become a legal 'right to have'.

In July 2014, Simon Stevens, chief executive of NHS England, announced that from April 2015, new combined budgets to pay for both health and social care support could be offered to people who have a diagnosis of a serious mental illness, older people, people with learning disabilities and children with disabilities. However, the new combined budgets will only be available if local authorities and GP-led clinical commissioning groups choose to work together to fund them.

According to Hackney's local account of People with mental health needs 2013-14, the clinical needs provided in the borough were as follows:

- *Inpatient care to 1035 people*
- *Outpatient care to 4,400 people*

- *Coordinated health and social care to 1238 people where recovery goals were agreed and delivered*
- *We assessed 1128 people to determine their level of social care need with 867 people going on to receive funded social care.*

The remaining 261 people were offered professional support or signposted to appropriate help in the voluntary sector, primary care or psychological services.

We spent a total of £6.3 million last year on 1,342 people with mental health needs. Part of the money was spent supporting 157 carers to give them a break from caring.

One of the aims for 2013-14 is to help more people with mental health needs to control their care by using self-directed support.

Rationale:

This report is aimed at commissioners and those positioned at a strategic level in Hackney. The purpose is to provide feedback regarding the experience of accessing personal budgets in Hackney, as well as provide recommendations regarding issues and solutions to the current systems set up to provide service users in the London Borough of Hackney a personalised approach and access to personal budgets. These views are gathered directly from service users or their carers.

In this report I will be specifically looking at the barriers faced accessing funding, and a financial support plan through the community mental health team, using the outcome focussed support planning tool (appendix 1) It is important to note that Hackney Council (commissioner Christina Smith) has commissioned a pilot in which 50 service users will be assessed for a personal budget and a voluntary sector led organisation Outward (Contact: Sonia Lyng) will be delivering a Brokerage service made up from a team of various organisations that have volunteered to undertake brokerage training and deliver the service. Unfortunately, due the timing of this research (and client confidentiality) I have not been able to interview an individual who has used the brokerage service to access a personal budget. The pilot went live in July and finishes in December 2014. It would be useful to gather feedback from the persons engaging with the Brokerage and Support planning pilot and compare those to the results in this report.

Personalisation also encompasses the provision of improved information and advice on care and support for patients, service users, families, and stipulates investment in preventive services to reduce or delay people's need for care and the promotion of independence and self-reliance among individuals and communities. I will be reflecting on the current information available to patients including a Personalisation Event that was held by Hackney Council on the 20th June 2014 at Core Arts and any feedback raised by patients in interviews and case studies.

Research Methods

This report is designed for people who already have a good familiarity with the terminology used and the current emphasis on this agenda politically as discussed throughout the report. Throughout the report I will be referring to service users as patients, as they are under psychiatric secondary care support as outpatients, one interviewee was currently an in-patient of the Homerton Centre for Mental Health. I am using this terminology in line with the current approach in Hackney that those eligible for personal budgets are critical or substantial levels of need, care coordinated and therefore subject to CPA.

Core Arts is a service that can be purchased through personal budgets or direct payments and therefore we are set up and modelled in line with the forthcoming Care Act Bill and current legislation regarding payment by activities, service user choice and service provider flexibility and responsiveness. We currently have 60 persons with severe and enduring mental health needs using personal budgets to attend the service from our out of borough contracts. In Hackney we work with various NHS mental health care teams and inpatients teams (Homerton Centre for Mental Health/ John Howard Centre) alongside persons managing their mental health using secondary care services and treatment. Therefore we were able to support service users who are currently using a limited amount of Core Arts services, but eligible for further support through a personal budget to ask their care coordinator to apply for additional services. The participants volunteered themselves after hearing about the research project through Core Council meetings (user led member meetings) and were assessed as eligible by the membership manager (would likely meet the available criteria for assessment)

The assessment (Fair Access to Care Services)

Ideally, the assessment works to enable the conversation regarding need and seeks to ascertain whether or not a personal budget could be allocated to the individual. The level of risk (support need) would be identified accordingly. The areas looked at are the following;

- Your relationships and social activities
- Involvement in work, education or training
- Emotional well being and mental health
- Safety and risk

Core Arts aims are;

- Psychological well being through creative education and meaningful activity
- Supportive learning environment, to gain education, training, volunteering, experience or qualifications providing access to mainstream opportunities
- Social inclusion and peer support- Improved communication, social skills, self confidence and motivation.
- Reduction in crisis admission and re-admission to in patient service
- Improved communication; communicate risk and provide duty of care for service user with care team (preventative)

Under the eligibility criteria for adult social care needs Core Arts can support persons with the presenting critical of substantial needs re:

- Vital/ involvement in work, education or learning cannot or will not be sustained
- Vital/ majority of social support systems and relationships cannot or will not be sustained
- There is little or no choice or control over vital aspects/ there is or there will be only partial choice or control over the immediate environment

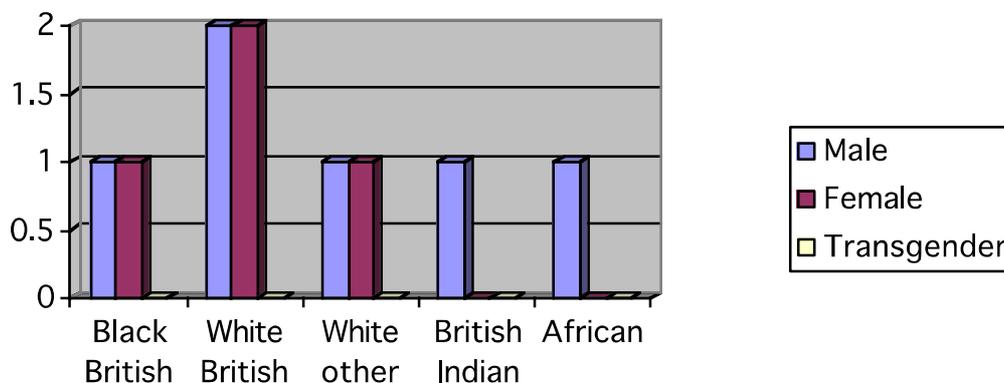
It is important to explain that the original research plan has had to change in response to the current accessibility of assessment (barriers are outlined in findings) The research was supposed to interview 8 persons from CMHT and their experience from the care coordinator and 8 people applying for FACS through the assessment and information

team, or online using Hackney icare self assessment tool. Unfortunately due to constraints of the CMHT at present (as outlined in the findings of this report), and limited RAS system and assessment protocols available, service users have found it very difficult to initiate these discussions and have an assessment. It became clear that encouraging further persons to attempt to have an assessment with the current processes in place could be considered unethical as it caused difficulties with the relationship with the care coordinator and in some instances the feedback from the local council caused confusion and undue stresses on persons with existing mental health issues.

Results are comprised of the following;

- Interviewed a total of 4 patients who tried to access personal budgets through their care team/ care coordinator.
- 1 person was interviewed regarding her application for FACS through Hackney icare (online)
- One carer came forward to share their views.
- A service user currently using a personal budget from out of borough was interviewed for comparison.
- A video that was recorded prior to the grant being given which has been included in my discussion points which depicts the views of 3 out of borough services users who have personal budgets and use them to purchase the Hackney mental health service Core Arts. It also shows extracts of feedback from 4 other service users and a carer regarding their views of personal budgets (in Hackney)
- Feedback regarding the Personalisation event held at Core Arts by Hackney Council.
- Analysis of written feedback form Care coordinators at referral stage regarding ability to assess for FACS in order to support a personal budget or direct payment (from March 14-August 14) In the form of brief case studies, 2 of which were of people supported to apply for a FACS assessment via Hackney LBH (not currently care co-ordinated)

Demographics of interviews and case studies (excluding video)



Executive summary

- Two people were successfully supported to get a personal budget or direct payments through their care team (1 PB, 1 DP)
- The two people who have managed to get self directed support in place had very different experiences, different levels of understanding and very different expectations of the involvement with the process. This may reflect the individual or it may reflect the different approaches taken by the care coordinator.
- Care co ordinators are currently the main barrier to an assessment/ application but care co ordinators are becoming more informed.
- The assessment and paperwork is too long and too complex to engage service users and care coordinators. Momentum, responsiveness to a clients motivation is key to engaging those most hard to reach, therefore the paperwork, and timeframes associated with the personal budgets may not be suitable for these clients (inpatients/ CPA discharge planning/ those with extreme fluctuations in well being)
- The array of voluntary sector opportunities in Hackney enable service users to comprise structured support and the interviewees demonstrated a high level of self management and clear understanding of own mental health and management (which may not have been agreed or directed by care co-ordinators).
- More people are being discharged from care co ordination but would still be considered to have severe and enduring mental health needs and eligible for personal budgets in other boroughs.
- A high percentage of those who initially contacted their care team to ask for a personal budget were unsuccessful, two persons interviewed highlight the barriers faced.
- Out of the 11 existing members who initially participated, 4 were happy to be interviewed about their experience. A further 57 new member referrers were asked by Core Arts to apply for on- going membership. None of which have secured an outcome focussed support plan (see referrers section/ case studies in findings)
- In many cases service users will only engage if the pro's and con's are clearly outlined to them, and how it could benefit them and applies to them (consequence of not engaging) as there appears to be apathy regarding engaging with the CMHT.
- Care coordinators are not referring into the Brokerage pilot. There is a discrepancy between those that are FACS eligible and those that are offered an outcome focussed support plan.
- A proactive approach is required by care coordinators in order to engage clients in personal budget applications and outcome focussed support plans. Further training is required to offer this and adoption of a truly personalised and responsive approach.
- Cuts to secondary services are undermining the personalisation agenda, as due to restraints services users are receiving a less personalised service than ever.
- Those who may be eligible for a personal budget need to be informed of this and supported to engage with the process, according to research a goal orientated self directed support plan has greater results and a higher service user satisfaction rate. Interviewees corroborate this theory.
- There needs to be provision for those who cannot engage with the outcome focussed support planning tool.
- Service user access to information, legal advice, local user-led organisations that can provide information, peer support and a 'problem solving' service, specific training, workshops, fact sheets and sample documents on e.g. advertising,

recruitment, making an offer, contracts etc. resources planned and available for this kind of help and support

- A person-centred culture and the use of person-centred thinking tools. If personal budgets are to be used effectively, care coordinators need to fully engage with the benefits and understand the importance of goal orientated plans and a personalised way of working to make it beneficial for the client.
- The eligibility criteria needs to be defined, and made specific to mental health care needs.
- Service users do not feel informed about the changes in line with the Care Act bill or personalisation; service users understand that political agendas change, and there are changes to funding available but they argue 'we are still the same', the experience of mental illness does not change' Patients require quality support to manage their mental health needs. Outcome focussed support plans can support persons to feel supported and clear of the support package in place for them despite changes to services funding.
- What personal budgets can be used for in Hackney is 'misleading' currently and less flexible or personalised compared to the rest of borough experience. An issue was raised regarding alternative use for funds may be stigmatised by those who do not understand managing mental health, especially in times of austerity.
- Primary care teams, psychologists/ GP's/ Housing providers are not aware of personal budgets and how to support their patients/ clients to access them.

Results from the personalisation event 20th June 2014

Core Arts was the venue for an event held by Hackney Council to promote personalisation and cascade information to stakeholders, commissioners, social workers and various practitioners working with people with mental health needs.

The second half of the day was dedicated to provide service users with information about what services are out there, what the new commissioning landscape will look like and the changes to their support through the personalisation agenda and specifically 'promoting independence' agenda at Hackney council.

There was also an opportunity for existing providers to promote services directly to service users at the market place event.

The support planning and brokerage commissioner Christina Smith hosted the day, supported by Gill Williams (NHS) Christine Knights (LBH) alongside presentations of the Hackney icare service (self assessment and support planning section) and the Brokerage Pilot service manager Sonia Lyng (Outward)

The new Mental Health Network was out to tender at the time and therefore not included (the lack of information regarding this provision did appear to give 'a gap' in provision which could equate for some of the feedback)

Feedback was gathered from service users on the day:

- What does it mean to quality for FACS? How is it measured? How does it fit with mental health symptoms?
- Where is the choice, especially if eligibility limits choice? Its actually disempowering.

- The assessment is done by the care co ordinator, but what if you feel your care coordinator doesn't understand your needs or doesn't have time to work with you?
- Would the psychiatrist be part of the assessment as they understand the role medication has played in my mental health and the severity of my experience?
- Most people are now open to duty and find it difficult to see someone in crisis let alone for paperwork or funding.
- The assessment is opposite to what you want to talk about with your care team, you want to promote how well you are doing, rather than focus on how bad your symptoms are in order to get a budget
- Service users need to know what the assessment involves, assessments by their very nature are stressful and we need to be clear about what it means.
- Brokerage is a new concept, usable information is really important, we need to be able to ask questions- is there a resource, paper or internet? Do my other workers know about this?
- Does this effect me, I'm in high support housing?
- Will we have to pay for brokers?
- Where does this personal budget money come from?
- Is this something care coordinators should be doing? Should we have plans and goals? It seems from the presentation you expect we already have this?
- It takes motivated people to understand this, and find this information out- where can we (Hackney icare was recommended as a resource)
- Lots of people are managed by GP now, as there is A&E and CHAMPHE, and less CMHT resources and staff, we are not yet able to work in most cases (and have not got the support to get back to work) will this apply to us? What will be available? (Mental health Network provision was not yet divulged)
- This relies on care coordinator, its backwards, can we do it ourselves? How is it objective and fair if this is the case?
- How does the PB deal with fluctuating mental health, you may not need services all the time, how can you predict your level of need?
- It doesn't promote recovery, if there are financial implications if you are doing better- you get less? Will services just be withdrawn if they are part of the reason you are doing so well?
- Will the plan need to restart if you are hospitalised?
- Is this a cover for cuts? I don't think they will be accessible to most people, are services going to be reduced and closed as the media suggests?
- Will it affect the quality of services if there are cuts? Salaries and training, recruitment are really important when it comes to people really making a difference!
- I've heard from Mind that those who aren't eligible with get 50hrs a year? Is this true? This is really low compared to what is available and working for me currently.
- Will we pay towards services out of our own money?
- Would we be able to spend the money on things we actually really think would help, what about holidays? (This question was answered fully by Sonia)
- Do we need a support worker to log into Hackney icare? (answered by LBH staff- icare is open to all)

Summary:

People are interested in more information, and the questions were relevant and important to be answered and clear. It was clear from the questions that it would effect each person differently and people were interested in how it would specifically apply to them, which was very difficult to answer in this forum setting.

The anxiety from the room was that they were not being told everything, and that they were getting a version of how it should be and not the reality with insight to

some of the barriers they might face in getting their care set up in this way (regarding CMHT engagement). Some audience members commented that they were the ones able to get to the event and participate and able to engage in this way and what about those others that couldn't, how will they get the information?

The solution is a proactive social worker or staff team that promotes and actively engages clients in an outcome focussed support plan (whether or not it has finances attached) and that the social worker/ broker should look for the best plan and services to suit that individual, not the easiest, cheapest or risk adverse way.

Stakeholder review/ referrers case studies (Example of log can be found in Appendix 2):

Summaries concluded from the case examples of referrals received / existing member reviews, the following questions were asked:

- Is the need Critical or substantial?
 - Is the client on CPA?
 - Can you assess for FACS? Or support the client to be?
 - Can you support or assess for SDS/PB?
-
- 54 Referrals in sample used.
 - 32 referred people stated as having critical and substantial FACS eligibility - 59%.
 - 41 referred people on CPA - 76%.
 - Out of all referred people 20 were identified as being eligible for personal budgets and that the referrer would ensure it was applied for within 3 months - 37%.
 - None of the referred people out of those 20 have received a personal budget which represents a completion rate of 0%. Compared to 80% of those who are currently using an MSU Mental Health Hackney (ELFT) service John Howard Centre but have duty of care from other boroughs such as Newham/ Waltham Forest or Enfield.

(Should be noted some referred people included in these figures have not surpassed the 3 month period yet, but no indication has been made that their PBs will be in place within the 3 month time frame)

- 15 people referred were inpatients on hospital mental health wards or medium secure units. None of these people have accessed a personal budget to ensure ongoing membership.

The issues explored:

41 people were referred as being on CPAs yet only 20 were assessed by their referrer as being able to apply for a personal budget - that is 52.5%. Referrers often do not understand what FACS eligibility means. This can be seen by often not answering the question about their clients FACS Eligibility in the referral form.

32 people were stated as having critical and substantial needs in line with FACS eligibility yet 41 people were stated as being on CPAs. This indicates a discrepancy of 22%. Many referrers stated that their clients didn't meet FACS eligibility but were on CPAs.

Care coordinators state that Core Arts should instigate the application; i.e. when and how it should be made/ goals/ access/ when block funding expires. These plans are reactive and do not lend themselves to proactive planning around peoples recovery or choice as part of wider recovery plan.

- A larger percentage of referrers answered that they are aware of FACS and are able to apply for an application for personal budgets to fund core arts membership, compared to those who were asked pre- June.
- Throughout the result a lack of communication can be observed between different clinical disciplines- it is a social workers, (care co-ordinator)role to do the assessment and apply for any social care means (including self directed support) It confirms the experiences given by the interviewees that there is not enough communication or information regarding the assessment form other professionals or clinicians. Psychiatrists are not aware of how to instruct someone to get an assessment, staff nurses, GP's, CPN's, housing support managers are not aware of the personalisation agenda and how to support patients to have an assessment with their care co-ordinator.
- The results show that the event has had an impact on the care coordinators understanding of the assessment and the funding panel etc. (changed priority) with the majority answering yes to the assessment and the application. The duty worker is not undertaking the assessments or able to support the process even if the application is supported to have an assessment by the consultant psychiatrist.
- It should be noted that none of the above clients have had an assessment or are using self-directed support to access Core Arts. This suggests there is disconnect between what the care coordinator says they can do and it happening and becoming real for the client/ service provider.
- All of the sample persons were told about the brokerage pilot as part of this exercise, it is unknown whether the referrals were made. Although it is known that the brokerage pilot is not meet its referral target at this point from mental health referrals.

Recommendations;

-Alternative funding for persons who are inpatients to access services/ resources as part of their treatment plan and immediate, uncomplicated access.

-Many referrers in hospital settings such as OTs/ Staff nurses state that they don't know about personal budgets or that it is not part of their remit and state that community services will pick it up. Training required in advice and guidance so they can give accurate advice to patients regarding personal budgets and support planning in the community.

- Clarity of FACS eligibility- for services provider as well as NHS/ LBH practitioners- to support clients to understand the adult social care requirements and how it affects them.

- Clear process/ named person- better promotion of the brokerage service; not widely available at present, strict referral procedure (i.e. voluntary sector managers cannot refer on behalf of care coordinator/ consultant psychiatrist)

-Development of existing information pages:

<http://www.hackney.gov.uk/Assets/Documents/your-care-your-way-information-booklet.pdf>

This is available of ELFT website and referrers are signposting to this

<http://www.eastlondon.nhs.uk/Services/Personalisation/London-Borough-of-Hackney-Personalisation.aspx/> <http://www.hackney.gov.uk/personal-budgets.htm#.VCU7wWddWnk>) to be specific to mental health service users.

-Care coordinators state that Core Arts should let them know when an application should be made/ when block funding expires. These plans are reactive and do not lend themselves to proactive planning around peoples recovery or choice.

-Joint training of service providers and care coordinators in order for us to support the process, provide guidance and information, support in managing expectations and support with the application and client engagement.

Themes from the interviews.

Understanding of personalisation;

- Who should be eligible?
- What will be approved in a support plan?

Barriers faced by those applying;

- Dependency on the social worker (care co-coordinator) and the varied response
- Confusion and care coordinators not being informed/ lack of information and encouragement
- Barriers faced when unable to articulate or advocate
- Lack of empowerment; clients do not feel in part of decision making process and aren't able to get feedback ask questions

PB's being an improvement to the way their care is currently managed

- Promote knowledge about what is available when very vulnerable and how PB's and brokerage can assist this
- Useful at the time of discharge vs. Capacity for long term decision making at this time
- May be as appropriate for those who are stable, motivated and would benefit greatly from further opportunities
- Self directed being crucial to engagement and sense of achievement

Understanding of personalisation:

"They said that's the way they do it now, because they want to make us feel more responsible for our own decisions or something yeah." Interview 2 pg 1

"In a way it's a good thing because I think that to be able to know a little bit about what is going on will help as well, because sometimes when everything is so covered up because you don't know what it happening it doesn't look good. It doesn't look good in the sense that you don't know what is going on, I know a little bit about what is going on now." Interview 2 pg 3

"What she said it that they are making changes, a change has been introduced and that's just the way they are doing things now. I'm not sure whether I agree with it matters if the government has decided. It's really up to them." Interview 2 pg 3.

"Yes I think it's a good idea for me to be funded for here, because I find that this is a service that really helps, essential. It's a good thing that the funding has taken place, because if I had to pay for it myself I wouldn't be able to afford it." Interview 2 pg 2

"The government used to choose what was good for you and you didn't need to discuss funding. I mean people might make the wrong choices, they might be too ill, I don't quite understand. Nothing is free in this world, it can't be free, free, free; you have staff to pay, overheads, rent. No we wouldn't have to think about that, we step in the door and think this is where I'm at this has got me out of my depression, this has got me out of my yard today. Now it's like, oh god, it's like a burden thinking about the money, can't you deal with that for me please, let me agree, let me see what I'm signing, I mean, keep it simple. " Interview 3 pg 2

Recommendations;

- More information and enabling people to help themselves by giving them the tools and sharing what

works for people, alternative ways of managing mental health and building identity and self esteem (less dependence on statutory services)

- The interviewees describe being 'kept in the dark' about how things work by their care team, for this to be effective the communication and information regarding adult social services will need to increase. One example above shows apathy towards changes, and decisions made by the government which relate directly to their ongoing care and support experience.
- Care coordinators to explain their role and set expectations at the start of working with a client (contract of working together)
- Specialist service required to support this process, has time, advice and can facilitate support groups, peers with similar interests etc (Independent Brokerage service)
- Important to highlight the benefits of services that directly support recovery and are evidence based to clients so they can make informed decisions about what their support plan will contain.
- Important to recognise recovery is not about just about independence, it's about feeling included, competent and supported. Therefore personal budgets need to consider this and not the individual in isolation from their circumstances, health, community or cultural needs.
- Shared documents with client, clear tools to monitor support plan. This tool will work for some clients (not everyone) however the goal and risk management sections should be clear to both parties to understand why support is in place.

Who should be eligible?

"Assessed. That's the word. Who assesses what works? That's a criteria thing, do you reach a criteria, it's almost like they are trying to trick you. It's, I dunno.. It repeats itself in the assessment part; it doesn't mean I'm well or unwell being of whether I can cook? Perhaps it should be based on medication and peoples diagnosis, mines just been increased, I'm not the same person I was last week; I need to level out and be assessed. If they assess you as not balanced, or too balanced... I don't understand how each person's circumstances can be assessed. That's why it needs to be 1:1. We are all different." Interview 3 pg 3.

"Anyone who needs it? A criteria? What would that be, it's hard. I guess at diagnosis, at major assessments or diagnosis. Clinical assessments. With the clinician you are working with. I wouldn't mind it being means tested... on what you can and cannot afford in your current situation, I mean expendable income. I mean some people on benefits are better off, and not using their money. The budget head says, it would have to be people that are diagnosed with a mental health issue. I would say when it disrupts your life and you need help. What you don't want to do is start using services and gets stuck in that mode [Edit] if someone is having psychiatrist appointments; they should have a personal budget plan. Everyone, who sees a consultant, and is made to do this, so few people have care plans because they don't have the time to do it. " Interview 4 pg 5

The out of borough personal budget user felt that;

"A good way to do that is with a personal budget or some kind of personalisation put in place to help somebody be able to overcome their problems. Some people are really needy but don't get the help because they don't know how to find the help, and those are the people who personalisation should be directed towards the most, because without some kind of help they're going to fall flat on their faces or they're going to end up in a really poor situation. I'm at a stage now where I'm independent enough and have enough savvy to be able to get by at least, and probably go on to do good things for myself. I'm using everything available to my advantage. But some people don't know about the help that they can receive to put themselves in a better situation. I do.

I would say that if you're seeing a GP for some kind of mental health issue and your GP agrees that you should be receiving some kind of help for you to progress out of your mental health issue, that person should be liable for it.

And the reason I why I say GP is because they're preventative. And if you've got a good preventative measure in place, you can save money. Thousands, millions of pounds! And that money could be spent elsewhere where it's needed, like on the roads and what-not. This country doesn't do enough around prevention."

What will be approved in a support plan?

There is a need for clear expectations of what will be approved;

"It should be down to the individual what you spend it up, so many things that are good, books, singing, art, some might want to talk, go to the spa. All these things save lives. It needs to be recognised and acknowledged and if it doesn't work that's down to the individual. They made a choice and they might not know why it works.

It would be better if it was personal support that makes more sense, help you get over whatever it is. Personal support yes, because they are supporting your personal circumstances." Interview 3 pg 3.

As one interviewee was very dissatisfied with the outcome;

"I was a bit disappointed because at the time of the meeting and when I did all the paperwork, I thought the idea was to be supported to do healthy things; things that I had chosen that would suit me. But that was refused as part of the plan of the personal budget and the only the existing organisations were agreed. Existing mental health organisations such as key changes were agreed, not things I had researched and found for myself. Actually most of the stuff was refused besides for actual organisations and I found that to be very misleading. Another example; I wanted to get funding for clarinet lessons, I have a clarinet and it is a passion of mine to play and because no one offers this within services I could not get classes as it is not a typical instrument. I thought it would be really helpful to me to be able to improve on my passion and meet people interested like I am." Interview 1 pg 1

"When I finally did get personal budget I wasn't able to get most things, don't get me wrong I am really grateful for the things I did get and I am happy that I got something! But I did feel that it was tough luck, as the things that were really important to me, like clarinet lessons were refused. I thought the personal budget was for all types of things to help you get back into the community and to give you the confidence to do things that used to do before and give you a sense of opportunity of being well I'm getting better and being back on your feet." Interview 1 pg 2

"I was told there wasn't enough funding for those items but I just don't understand because there must be some funding somewhere if not what are offering? I spent a lot of time researching and considering what it was that would help me and my ideas and were refused. It was disappointing. I wasn't given information about what I should be looking at or how much, I was asked what I think would support me." Interview 1 pg 1

One interviewee explained that different approaches work for different people;

"I have to say that mental health services aren't for everybody, everyone is individual. And actually, if you go to IRIE mind you very very much feel you are in a mental health day centre. Very much, you are not even allowed for access to tea and coffee and there are certain times when lunches are on. My idea is that the main stay of people that go there, seem to enjoy going there and seem to have more need? Or actually I think they are institutionalised, I'll be honest, and that was something I didn't want to get into. So it took me a long time to adjust from being staff so I couldn't engage with that, it was quite scary at first. It didn't do my self- esteem any good at all. I actually thought, oh god have I sunk so low? It took an adjustment for me, but if you go to mind there are also groups and some of those groups are good, if someone has a problem with assertiveness, then they should go to that group. If they don't want to do any of that or address the issue, how can driving lessons help? I don't think that's right. If your diagnosis is bringing you money, then you need to work with that and the symptoms. You should use what's available to you. The personal budget should reflect the issue. I guess it needs to reflect to choice behind it. I mean if driving lessons did link to your health or something that relates directly to you and your progression, then that's okay but it needs to be rational [and explained in the support plan]" Interview 4 pg 4.

Continued...

"Maybe stigma is the issue here, if people see than money is being spent in this way. Yeah there is a massive stigma, in the CMHT too. They wouldn't see the value maybe. I've changed my mind a little bit there, I think. I think there are people who have mental health symptoms, constantly whether its minor or major there are there and then you have others like me, where it fluctuates, and its gets really difficult with benefits and everything and getting on with life as you can have realistic plans one minute, and they are gone the next. You need to encompass all of that information in the budget and it should reflect that. If you don't need it you don't, when you do you do. They need to get away from this, all or nothing. They should be able to catch you as part of the plan. If you are in crisis, the delay in getting help can make it so much worse." Interview 4 pg 4

The out of borough interviewee suggests:

"You should put it on the impact of what they want, where that will take them, and what they want to achieve. Obviously you have to keep it to the amount of funds that are available, but they should have a right to choose what they want – and if you can't fund it completely, give them part of the money and let them find the rest of the money themselves."

Recommendations:

- Support plans that look as people want them to, rather than in a format that an organisation insists people use
- Culture and training that supports care co-ordinators and staff to feel confident about supporting people to come up with creative ways of using resources
- Senior management support for this approach and clear messages for staff
- Access to stories that show how things can be done differently and uniquely
- Focusing on what is important to the person
- Outcome-based support planning that helps people be clear about what is important to them. This helps focus on a simple test for the plan: 'Will this (whatever it is) help me recover, stay healthy and have a fulfilled life?' Focusing on outcomes will also provide essential clinical audit and monitoring information
- Resources for peer support to enable people to benefit from other people's experiences.
- Wide ranging information about what is available in someone's locality, beyond health and social care

-Being supported to look beyond health and social care services to understand positive health and social care outcomes from things like being part of a community, employment, leisure, education, faith and culture

The aim of the research was to highlight the barriers faced by those applying; the following discussion uses extracts from 3 of the interviewees about the barriers they faced;

*“Everything that could go wrong with applying for the personal budget went wrong from beginning to end. **They lost the paperwork and pretended that they had it, and then said they didn’t and that was three months later.** I was told to fill in all parts of the application form and told it may take some time, which was fine. But then I was told the person deciding it and in charge of **the panel was off sick and wouldn’t be replaced so I felt that it was just left hanging for months and months and the whole process was frustrating.**” Interview 1 pg 2*

*“I know I filled in the form and passed the criteria and they told me ‘Yes, you have got it.’ I know because I came and told the office here. **But I’ve heard nothing more, nothing, no paperwork, and no money, nothing in stone.** I think it was around a few thousand pounds, I don’t know! I feel like I’m in arrears, as the government should pay up because I’ve been coming here every day, but if I hadn’t been I wouldn’t be coming here because I’d be dead. Because this is what’s kept me sane, I’ve had two hospital admissions since I did the paperwork. And I thought I had a budget sorted but I still don’t know when I’m at.” Interview 3 pg 1*

*“**Mainly lack of communication, passing the buck from department to department person to person.** Communicate both verbally and in writing so you can see where you’re at, and more services coming into existing services like core and giving information and getting it clear. Because people aren’t clear. **Get the process right, because it’s daunting. People should do it, but they need to be encouraged and want to, not feel assessed or unworthy.** They don’t want to do; I mean I’ve been trying for 14 months.” Interview 3 pg 4*

*“Over a year ago, I had a social worker for 6 weeks and she sorted it, but as she left, my new care coordinator had to tie up the loose ends, **and it’s still not sorted!** Perhaps I should do the job for them; I mean it’s not that hard, I worked out what was needed. It is a new system with teething problems...” interview 3 pg 3*

*“I got the information, from Core about the Brokerage team and went back for my appointment and the person who I saw it was like news to him. He said he had heard of personalisation but didn’t know what he had to do with it, or the process. **He agreed and looked at my notes and thought I would be entitled to it, and he said he didn’t know what to do.** He gave me his name though so I wouldn’t have to see anyone else about it because I don’t currently have a care coordinator, but he agreed with the consultant. I felt as though it was extremely difficult. I have been around the houses and no one knew what on earth I was talking about, let alone that what their job had to do with enabling me to get one! It’s supposed to be in place for October, I don’t know. **They need some training; it’s all over the place, a whole lot of education. But what’s happening, funding is getting cut all over the place? What is gonna happen? There’s a gap between personalisation and budgets coming in and what’s available to people for support from CMHT.**” Interview 4 pg 3.*

Interviewees raised their concerns regarding why it won't work well for people;

Here are extracts from patients who have a outcome focussed support plan in place and is using it now to self direct support;

"I don't think personal budgets are going to work for people. I think they would need to be made a lot easier and for loads more information to be given around them and why they are a good idea and how they can help. I also think they are misleading as people may want to spent their funding on things that aren't services related and they won't be able to like I wasn't. People don't want to know about costs and funding, it makes it very complex"- Interview 1 pg 3.

"Yes it can be challenging, difficult, yes it can be. Because, if someone had told me I would be doing this, you know 5-6 years ago I would have said 'no way'. I wouldn't be able to handle it, as much as I did right now. Simply because of the progress I have made over the years that have actually allowed me to handle things better. But for some people who don't have the support I have it would be difficult to them, because I knew that before I had support when things were difficult I know that there is no way I could be talking to you about this it would be too stressful. So yeah, I can understand it would be too challenging, like service users that don't have a vision of where they want to be in life, so putting them through the process would be tough, because thinking about that would be too much to think about. If they are thinking too much about money it could actually cause them to have to go back in hospital, you know and get admitted again and it's really because of the stress and pressure put onto them and yes, I could see, really see that happening. "Interview 2 pg 3

"Why do they make it so complicated? Why does it have to be so complicated? Why is there not written literature or simplistic ways in how it works, so we can understand the information? You need to know your clients a bit better, you can't get an appointment for love nor money these days, they have cut back too much. They can't help me. They are leaving people in limbo and it promotes suicide." Interview 3 pg 4.

A carer gave the view that;

"Now, it would be a problem for mental patients, I'm taking my medication and I can reason and make choices. I say I would like to do that, many things I would like to do... is the government actually prepared to give that person the money? Do you think they will prepare? Do you think there is actually money there?" carer interview pg 3

In contrast the person who is using a personal budget from another London borough gave the view;

"It all happened through the CMHT. My social worker at the time brought it up and recommended that I go for it... asking was there anything I wanted to maintain my well-being. And I said, "Yes, but what are you talking about?" And then she told me about the personal budget. Come to think about it, it might not be as far back as three or four years, it might be two years"

The participants in the video also explain that their social workers told them about it, and encouraged them to use a budget as part of their recovery plan.

Recommendations

- Guidance and well informed, enthusiastic staff that understand and can identify clients potential;
Clear budgets and expectations
Clear use of funds
Clear knowledge of services/ opportunities available
- Better signposting internally and externally for those who would like to be assessed for a personal budget (Brokerage pilot)
- Planning needs to be done at a time that reflects current ability to engage and motivation/ goals
- Support plans should not be recommended provider focused; should include mainstream opportunities
- Financial plan should be explained clearly and formatted in an understandable way, so client is aware but does not dominate the conversation. Dialogue should be goal orientated.
- Support plan should be strength- focused (solution based) and recovery model orientated as well as identify issues/ risk.

Many Interviewees raised the topic of dependency on the social worker (care co coordinator) and the varied response;

"There was no information and my care coordinator was too busy to support with the application form" interview 1 pg 3

"No I don't think there is much stress involved, the reason I can say that is that the work was done by the key worker and all I had to do is go to the service centre and sign the papers. I also just have to talk to my key worker and answer questions. But if it had been stressful then I would have said yes, because that would be too stressful. I think it's something anyone can handle because it's just like going to your social worker like a regular session and you use the time to answer the questions about direct payments. That she needs to find out. It's not anymore more stressful than any other session with your key worker." Interview 2 pg 2

"Yeah I filled out forms with the key worker; she did most of the work, which did the work. We sat together and she was filling in the form. "Interview 2 pg 1

"I am still dependent on the social worker she is my key worker and I still need her support sometimes, and eventually I will be discharged and won't need to use the service again. But at the moment if she is there I will make use of the support." Interview 2 pg 3

"I mean I hear stories about people not having support, I mean I'm supposed to be lucky because I have a care coordinator but she was with me for six months and saw me once. She didn't follow it up she didn't do it, each time I went to try and sort it out or talk about it, they gave me the run around, and I did all that months ago. I did all that. And they said it was sorted. But it was lies. I was like what are you doing?" interview 3 pg 1

And offered a solution;

"It's got to be a specialist, see some of these specialists don't understand and don't know how to deal with it. It needs to be someone who can work with clients and get the best out of them. I'm meeting a person called [name] and I am going to work things out with them and balance. If people give too much information you need to balance them. It can't be that complicated really. It needs to be someone who can get through the system and make it work for that person." Interview 3 pg 3

"I think it would be very unfair to rely on care coordinator. Its essential there is a specialist team, to get it agreed if they are too busy, and the dialogue with CMHT is so hard, it's like a ping-pong ball. You need a service that can do communication. Communication is

essential. Otherwise all that will happen is that people who shout the loudest will get them. Those who don't know their rights won't get them." Interview 4 pg 5.

The out of borough personal budget user also describes using brokerage;

"[The person] was actually employed to be a brokerage service for the actual personal budget scheme. She got me the forms and helped me fill them out in a way that was realistic and could maximize the amount of money that I got.

I think they were employed within the CMHT, but I'm not sure. But what I liked about her is that she was very helpful and very approachable, so I could talk about the issues that were really affecting me, so she could help me maximize my chances to get as much money as possible.

She also let me know my limitations. She was clear about what I wanted to achieve out of it, and what was realistic.

The broker's got to know a bit about their life, their lifestyle, their likes and dislikes.

Especially if that person has got... and, everybody's got talent. Some kind of talent. I believe that anyway. So if you find out what their talent is, maybe encourage them to go out and develop that skill. If somebody does what they like rather than what they're forced to do, that will probably help their mental health."

And agreed that:

Yeah it is [more reliance on the care team to organise the budget/ plan] Definitely more so than ever. If that worker is worth anything, they will commission a service for their client. Something like a life-coach. Something that is gonna get them from the next second to the next minute to the next hour to the next day until they're in a position where they're independent and make decisions for their own future.

Even though I didn't get my personal budget the first time around, I still felt I could put a certain amount of trust in my care coordinator. She wanted to help me."

"If the care coordinator doesn't know them that well, they're not going to be able to put them in the position, because they won't be able to get past the step where they can have the conversation about the personal budget. Maybe if there's actually an organization or a building you could go to within Hackney to talk about issues around personal budgets – whatever that's within the Hackney Service Centre or a CMHT, GP Surgery or whatever, a specialist organisation – and get advice on personalisation and personal budgets...."

Recommendations;

- Well trained care coordinators (and CMHT staff) that do the paperwork effectively but offer lots of choice and information
- Specialist team to assess/ apply/ support client and care coordinator
- Ethos of individualised support planning reflecting a personalised recovery orientated approach from the care team

Confusion and care coordinators not being informed or encouraging in regards to personal budgets

"I was told that things are changing to something new that they're improving, basically just got my application form back without anyone dealing with it or processing it." Interview 1 pg 1

"I think it's a great concept if you can get it. Because the communication regards to it is total confusion for the client. A lot of people saying talk to, talk to.... lots of passing the buck, talk to your doctor. So who actually fills in the form? Talk to..."

The concept is great if you can actually nail down who is actually dealing with it and who knows what they are talking about at the end of the day." Interview 3 pg 1

"Yeah, it needs to be clearly mapped out, a,b,c, 1,2,3. I'm not saying we are stupid, we are articulate and I'm just saying, keep it clear, red tape whatever, just keep it simple. Bullet points, so people can see it, and it makes sense, a pie chart even. Simple." Interview 3 pg 2

A carer gave a perspective of trying to find out more information;

"I mean if you asked care co coordinators about personal budgets, do you know what it is? Can you tell me something about it? They don't know. Trust me I've asked them. They don't know. Whom should I contact then? They don't know. "Carer interview pg 1.

"They tell me in meetings about it (personal budget) and then when you ask questions they don't know." Pg 4

Recommendation;

- Ensure resources that are earmarked and allocated to support planning and brokerage, for example, to make sure information, advice and training is available for people in support planning and brokerage roles.

It is important to note here, that the persons interviewed volunteered for the research and apply for a personal budget. Therefore, these individuals are motivated, and able to articulate their needs, and opinions on the changes taking place. I was unfortunately not able to interview those less able as they did not come forward to volunteer.

The case studies do however reflect the barriers faced when unable to articulate or advocate;

- **Language barriers**
- **Choices were not listened to**
- **Easily swayed by care coordinator/ malleable**
- **Do not understand the adult social care system**
- **'Blind leading the blind'**
- **Do not understand their rights to care and support/ no expectations**
- **Fear regarding asking/ discussing support plan with care co coordinator (concerned it will change/ reduce current services)**
- **Limited understanding of own risks/ triggers or self management**

"Oh I mean it wouldn't work for them, I've seen them I talk to them here; if you don't have a voice you will not get heard. It won't work the depressed and suicidal. How can it? You need to be motivated, and know what is out there and what can help you and want to know about what can help you. You can't have huge anxiety or concerns about not deserving anything. It those that don't have any help! When you are depressed you feel worthless, how can you make choices? The problem is I don't think they will be noticed or offered anything; people (services) don't want to help. There are less and less people with social workers or less and less support workers? Less and less. Cutting back cutting back cutting back, what's the criteria now to get a social worker? Hello!? It's a bit of a con really. The mental health team are the access point and they actually told me I can't see them, I

can't see 'god' who has the money, and until I kicked up a stink, I only then got an appointment, but I had to really push it." Interview 3 pg 2-3

"I found it very stressful and I guess if you keep on, it would do your head it it's not a nice thing, it's not real and I've learnt not to get bothered about that. But I am worried for those people who wouldn't ask in the first place." Interview 4 pg 3.

"Who can you ask? Who? Someone need to ask her, it needs to be outreach and with people. The whole problem is the care teams don't want to do stuff actively, they are avoidant. That's why people don't expect things from social services. What will happen to those who need it most, or need more input, more finance, it's not those that will get it because they won't show up and ask for it. Go and ask social services staff they don't know." Carer interview pg 3

Recommendations;

- Capacity for support planning so that people can have a choice of who assists them
- There are a range of options available so that people can choose a way to take control that suits them, and can choose who they want help from
- User-led organisations are developed as an option to provide information, advice, guidance and support
- People are willing to learn from experience how to get the right balance between level of detail and time taken to develop a support plan
- Risk enablement as a core part of the self-directed support process with a shared adult personalisation and safeguarding framework to support this
- In thinking about how to put a support plan together, people are encouraged to do as much for themselves as possible and to take account of their existing network of support.
- There is good communication when the support plan is complete about what people should expect to happen next, and how long it will take

Lack of empowerment; clients do not feel in part of decision making process and aren't able to get feedback ask questions

"There wasn't much on application form to really explain why you need the things you said and what you would use the funding for and how it would help you. I submitted mine with a supporting statement about 44 pages typed which I don't know if the panel saw but I would like to question whether any of that was actually used. I have no idea, I feel quite removed from the process. Looking back and I spent a long time writing it and it really did give a picture of why I felt I needed things. I'm assuming that it didn't make a difference as otherwise I'm sure I would've gotten a bit more funding. I really was uncomfortable at idea of someone going to panel about me about my personal issues – and without me needing there to be there to say whether what you're saying about me is accurate or to tell the panel what was most important to me, because I think I would have changed things being given this opportunity and more information. They would see that I was genuinely planning something for me to get better and see my motivation to. I don't want to waste their money, I just want to chance to get to the point where other people are getting." Interview 1 pg 3

"Okay maybe I signed it afterwards, but erm I don't think I can say that. I can't remember what the form was all about and I can't say that I followed actually what was on the form. But I know she was asking me questions and I answered them. "Interview 2 pg 1.

"There wasn't really much for me to do actually, as most of the work was done by the key worker (social worker/ care coordinator) anyway. So all I had to do is just sign papers, so I wouldn't say it was in anyway inconvenient, it was ok, ok. [Edit] She said she would make

arrangements to make it happen. She decided to get in touch with the people who can provide funding. Then she got back to me and said it had been approved.” Interview 2 pg 1

“The doctor, does very basically state how debilitating it is, he knows exactly how it is and he can understand the impact it has on your life as do the specialist. But to an assessor who has no fucking understanding of your conditions, or any conditions, pushing their pens around, how can they make a decision on that?” interview 5 pg 1

With an example of someone not really having the choice regarding the financial responsibility;

“Yeah, yeah I’m very happy.

Yeah well personally speaking I would have preferred the money to be paid directly to (service) rather than going through my bank account, through me, you know I would have preferred that because once the money was paid I could come and use the service. It was a bit, like, an indirect way of doing things you know it’s not direct. Apart from that I really don’t, well if that the way they want to do things, that’s up to them that’s fine by me. But if I had had a choice I would have preferred the money paid directly and not to go through my account.” Interview 2 pg 1

Information and communication that makes clear:

- The different ways in which it is possible for people to take control over decisions about how money that is allocated to them is managed and spent
- That they do not have to directly manage the money themselves or employ staff/ purchase services if they do not want to and that other people can do this on their behalf
- Training and organisational culture which ensures that care coordinators and staff are well informed, supportive, positive and hopeful about what people can do and achieve in their lives
- A partnership between mental health services, the Direct Payments or Personal Budgets team and learning providers to actively promote and support the uptake of personal budgets
- Integrated health and social care personal budgets
- Training courses for people with mental health needs that helps them to understand what is on offer with personal budgets, prepare and gain confidence to use them

All interviewees identified the benefits of personal budget planning and them being an improvement to the way their care is currently managed;

The first example is from the out of borough personal budget user:

“If you’ve got a personal budget, it gives the patient or member the tools to be able to get something that really helps and maintains them and lets them flourish. My personal budget was spent on gym membership and driving lessons, and the driving lessons really helped me get to a place where I’m more independent and can look after my family more. With the gym membership, I actually lost a bit of weight. I got a bit fitter, and put in an eating regime, and lost about three quarters of a stone, and feel a lot more energetic because of that. So both areas that I spent my personal budgets on have helped me.”

And those in Hackney suggest also;

“I would feel relaxed, like I know what I’m doing, sorted, and funded, whatever. It would be a relief and be wide; I would have been able to go to college, yoga, and violin tuition. Things that I can’t afford but would help.” Interview 3 pg 2

“Yeah it’s really important to know what’s there for you, I mean I was ill in 2005 and it took till 2012 for me to know what was out there. I think my life would be different if I had known, I think I would definitely be in a different space and much quicker. I feel that I spent a lot of time going around in circles not really achieving anything. If I had got a personal budget then, I would have been able to use what was there and make changes. [Edit] If I had that package in place, for a year, I would have been like, ‘I’ve got an opportunity to get better’ I have a chance to set a goal and then work towards that goal and then I would have known. I mean I’ve been stuck by the options of too many things, so I’ve not committed myself to any of them so it has been too easy not quite to get there. If had a personal budget I would have had an advisor or support from the college I would have know my options and got some advice around what to do if you fall ill and you’re on benefits, but I know there are things to make it work.” Interview 4 pg 2

The participants in the video attached all explain the budget, outcome focussed plan being the best thing about their care and support and really noticing significant differences, and their feedback was satisfaction.

Recommendations;

- Goal orientated planning and discussions with care coordinator are vital to sense of support and sense of ‘care package’
- Personal budget would lead to greater sense of opportunities available and more advice around maintaining plan and support if difficulties arise.
- Personal budgets should be time framed, to offer a sense of opportunity however this should not be used as a punitive measure. If someone does not achieve they should be able to try again. As a practitioner I have seen multiple cases where an opportunity was arranged and the client was held accountable for their failure when the placement was not completed. The client would then not be able to ‘make the same mistake again’ or it would be described as ‘avoiding another failure’ or ‘a waste of time as it took so much time and energy to arrange.’ The new system of financial arrangements must be mindful that the client will learn from their mistakes and the client should not be burdened by the financial accountability.
- Greater role for peer representatives for give examples of how their personal budgets supported them to improved mental health and self management skills, examples of achievements and bridge the gap between service dependency and mainstream opportunities (including back to work opportunities)

Lack of knowledge about what is available when very vulnerable and how PB’s and brokerage can assist this;

“Actually there was loads of support available but I had no idea at all! I think signposting needs to happen and you can’t just put it in the CMHT reception, their workload is going up and up and they are cancelling appointments and apologising. You find that when you go in all the notices are there and it says talk to your care coordinator about this course, and the date is already gone! They are not able to communicate the opportunities available. They can’t tell you directly, this course is coming up, and then you go to the GP and they tell you, but you can do this but you can to this and this. So you don’t have anything, unless you are literally in hospital or you have a really good care coordinator. So there is a gap still.” Interview 4 pg 1.

“I was very lonely and I didn’t know of organisations that could support me. I didn’t have the help and I’m sure it delayed my recovery. I found all the services myself, and I hope that other people are given more information now so that they aren’t left like I was.” Interview 1 pg 2

"I just think GP's should know more, should be educated about it, know what exists out there for people so it's more widely known. I spent 15 years before in my pyjamas, I had no reason to wear clothes, I wore a skirt for the first time in 13 years... from the first operation [Edit] there are too many vulnerable people living in boxes, and what's the point, it's like we're already in a coffin." Interview 5 pg 1.

Useful at the time of discharge vs. Capacity for long term decision making at this time

"I had come out of hospital and really could have done with one then, I have one now, but I think I am in a much better position in terms of my mental health than I was when I was discharged. I then heard about it 10 –12 months ago again and tried again and it took 7 months to get to the point I am at with it now. Interview" 1 pg 1

"I would have had the opportunity to get better quicker as I have only been able to benefit from having services later. These services were actually crucial to my recovery and where I am at today. At that time my application was refused, and I really had a hard time working out what was out there to help me." Interview 1 pg 2

"I think you definitely need to be able to, like if you have had an acute illness, you need to have come out of that and have a few weeks to recover, its tentative steps at first, and just feeling well. You don't want to be thinking about how you would spend money or plan for the future. You need a couple weeks just for prayer. You can't make decisions for your more well self, when you can if it's your less well self. "Interview 4 pg 5.

Recommendations;

- It could be argued that the indicative budget should be decided at discharge, the assessment at this time would be appropriate to show patients needs and reflect the indicative budget for the next 6 months of support.
- There is a need for holistic assessment at discharge; housing, debts, responsibilities, medication, use of time, social networks etc are all part of CPA discharge planning. The patient need to play a larger role in this planning to identify areas of risk and support required.
- Patients should be able to have forward planning relapse plans in place; when they are able to make decisions about the care that they feel they would require and what works for them. Giving greater choice and control if symptoms increase or if the person no longer has capacity to make decisions.
- If advice and guidance is clear, and appropriate options and opportunities are given for the patient to choose at this time, it could support the occupational therapy role and reduce re-admission. A strong use of time plan, consisting of relevant services would improve risk management at this stage and promote full recovery.

Personal budgets may be as appropriate for those who are stable, motivated and would benefit greatly from further opportunities;

"About one or two years ago and I found out about the applying and I was really quite excited about it because I've a lot of stuff I needed to do and I knew I would get help and I gave it to my care coordinator and she tried to give it in but they wouldn't accept it, why I don't know." Interview 1 pg 1

"What I am doing now is a vision for me, it's something I want to do and get better at for the rest my life. I can do that here. So the idea of changing cannot be entertained. I want to achieve." Interview 2 pg 3

"I like the idea, thinking okay if you want to do something like core or college, you can take maybe part... well I think this is right what I'm saying as a client, I seem to remember certain sentences, I was confused by the meeting that happened here when they said, this

is what it is. I remember them saying you can carry it over between services, further education or I think, it's just what I think because no one can or has explained it to me. I am confused as a client. Confusion. "Interview 3 pg 1

"Yes it would not be for everyone, it's for people who are able, and for people at a point where they can make choices. Not for people whose mental health could easily deteriorate." Interview 2 pg 4

"Even if there is no personal budget or direct payment in my life I would still have to manage money anyway, so maybe it's just part of what is necessary. What I'm trying to say is that I do get paid every month and I have to manage that so it's just maybe it's just adding a little bit onto that to manage. You know because managing finances is really part of life and I know that managing things more effectively will help me grow and mature as a person you know it means that I understand what is going on and I'm not depending on others to do things for me." Interview 2 pg 2

"It's motivational! I mean I want to do these things, and I would be able to. I want to give up smoking, and I would know I was spending money on it, exactly how much I would know. That would go alongside with keeping me out of hospital, whether it be yoga, it's all to do with well being and recovery and living a balanced lifestyle. "Interview 3 pg 2

"No way I couldn't wash and I couldn't go out of the house, I couldn't get to my appointments, I was so paranoid. My GP could see there was a problem. And so, I was in debt and I was getting repossession notices and there was no way I could do myself a care plan!" interview 4 pg 2

Self directed being crucial to engagement and sense of achievement;

"I actually had to find out about the organisations available by myself, I wasn't given any information. For key changes I did everything, I thought they looked like a really good service, but I was told I couldn't work with them and Core Arts? I actually saw the services advertised on an advert in a department in the hospital, but couldn't find anyone able to give me any advice on applying and on other things; I had to research online and find it myself. I am and was really motivated to get better and change my life, moving forward from my time in hospital but I doubt others would be so motivated. I had to just find out by word of mouth and online, and I couldn't ask questions about the application and I didn't find anything to help or anyone to speak to about it." Interview" interview 1 pg 2

"It might be for some people, some people might want to know, so that they know they are not just wasting money, then people might take it more seriously, that is an advantage. But for me personally, knowing the amount that it costs and things... well it's how you look at it, anyway, knowing the fact that a lot of money has been spent helps me as well to take it more seriously, and for me to know, I'm getting the best value for money and that's important so it might work out as a good thing in the end. " Interview 2 pg 2.

"I mean, I know about the focus being (money) I don't want to waste that money, I want to do something valuable and productive with it so that information helps to know a little bit, not too much but a little bit of what's going on. " Interview 2 pg 3

"It's not a case of it's not my money, I'm not paying for it. It your budget, and if I had a budget, I would spend it wisely and take it personally. I would imagine it is encouraging and would make most people think, shit I'm gonna give it a go, I'm gonna do that and

value what I've got, I'm not messing around with that. Yeah okay, I might have a relapse or something, but I'll be back on track because I've got this commitment, this package deal if you will. While the government are willing to do it, I've got to make the most of it, you know, don't mess up. You would need to be at a certain level I guess to make the most of it, I mean if I was in depression right now I wouldn't be able to sit here and talk to you about it, I'd be at home in bed."

Interview 3 pg 2

"If it was place, if only for one year, the effect would be huge. I would have to seriously think about it properly. I would have to seriously think what would I want to do? I would think about it in the longest term, like what will do me the long term good, what can secure me? I mean to be able to better myself and look after myself. I would have to really think about it. And that would be good, cathartic. I would be really hard; I would need the proper information. I haven't a clue really what's available." Interview 4 pg 1

FACS experience

Interviewee 5 spoke passionately about the negative experience of asking for an assessment from the assessment team via the Hackney icare website;

"So anyway I filled in the filled in the form online, which wasn't easy, but of course you know, they send me a letter and they phoned me and said 'so you are obviously not answering your phone' and no I couldn't answer the phone because I can't get out of the bed. On my voicemail they left this message, as in I'm deliberately not answering? And sometimes I don't, but who are they to judge me? I mean for a start it takes me three hours to get out of my bed each day to try and get myself ready because I'm in so much pain, and also I'm so caught up with anxiety. [Edit] And it's those times I can't face talking to people and I can't answer the phone. I just can't."

[Edit]

"Then they phoned and the conversation I had was so unexpected. She was just unbelievably rude on the phone, so aggressive. I actually phoned whilst I was here, I knew it was unlikely I would get help and I know I don't fit all the boxes, so I knew the chances were slim that I would get the help. So that makes me more angry, because I know people getting all the help and people playing the system and getting help. But if only you could see my pain, if only I had blood gushing and people would be screaming and phoning the ambulance for you. Wouldn't they? But because they can't see it, that's the difference.

So she was so aggressive 'you don't need help from us', 'with what?' this is why I don't ask for help! "You don't fit the criteria", and I said well actually it hurts me to even wash myself. It was an argument, "you don't need personal care?" I mean I'm in really bad pain all the time. It hurts me. I can't even shower sitting down. It takes hours; people don't have to face that. She went on and on, aggressive, aggressive aggressive, and I just thought, I can't fight this... And I had tears streaming down my face and I just hung up the phone. I couldn't say anything back, I just felt attacked, from the minute I picked up her decision and tone was made. I didn't stand a chance. No. She had made up her mind, you don't fit nothing, you should see your doctor for that? My doctor can't help me get dressed in the morning!" Interview 5 pg 2.

A carer offers a perception of the care offered;

“We make mistakes everyone makes mistakes, there are reasons why people don’t come to appointments and a warning letter isn’t the approach to take, for gods sake, phone, find out what’s happened... that’s what the problem is. If they don’t see what’s happening, you can’t see that something is getting worse. The whole system is draconian and they really aren’t wanting to help, they are so used to the system and think its right, they don’t see a need for change. It’s the same; NHS and it should be ...” Pg 2.

SCIE describes the recovery model as:

‘A framework or guiding principle that focuses on working with the individual service user to identify their strengths and build resilience. It also focuses on working with individuals to regain control, support recovery, and to lead a life meaningful to them after experiencing a serious mental illness. It is not just about treating or managing their symptoms.’

Personalisation and the recovery approach to mental health have developed separately but they are both based on the need to build on strengths and hope for the future, self-management, the equality of relationships, social inclusion and the role of family, friends and communities as partners. Both support goals ‘to have meaningful activity; to have meaningful relationships: and to have a place to call home. Recovery and personalisation challenge the mental health system to support individuals to achieve these goals’

Examples of what needs to be in place to support this:

- A culture that systematically promotes and nurtures the right approaches and skills, with all new staff routinely inducted into person-centred and recovery approaches and person-centred thinking
- Senior management commitment and enthusiasm to get the culture right
- Clarity about resources for training in person-centred systems, approaches and person-centred thinking (including for senior managers) and for developing good information and communications
- Learning and problem solving encouraged and built in to systems
- Clear local and government support for innovation and creative use of processes, practice and resources so that staff are confident that this is a recognised and endorsed way of working

Questions & comments directly from interviewees;

Interviewee	Question or comment
Interviewee 4 (applying for PB)	<p>According to the information available on the internet, it says everyone is entitled to a care plan which I think is fundamental and will make a huge difference. This needs to be done even if there are issues getting this started and it’s a paperwork exercise, you need then to make them real. You do need these and you need to do them with people together. No cutting corners.</p> <p>People need to know what the goal is, meaningful and broken down into something achievable, not clinical. Everyone needs to have one and they can own it and it will cut down expenditure. And it will be positive,</p>

	<p>and reviews will show that. We don't need pieces of paper which mean nothing, we need to make it real.</p> <p>How can this be implemented when the CMHT is so burdened?</p>
	<p>This social work element should be separate from the psychiatrist, they should be doing good plans of care. But they need to communicate. So the psychiatrist can see what's real to you, what's your goals alongside your medication. It will help you stick to it.</p>
Interview 3 (applying for PB)	<p>Why do they make it so complicated? Why does it have to be so complicated? Why is there not written literature or simplistic ways in how it works, so we can understand the information?</p>
	<p>You need to know your clients a bit better, you can't get an appointment for love nor money these days, they have cut back too much. They can't help me. They are leaving people in limbo and it promotes suicide.</p>
Interviewee 5 (applying via Hackney icare for FACS)	<p>There is a massive lack of communication across departments, and what the care system can do.</p>
	<p>Are they trained in customer service and understand the importance of their communication? In my experience, I was a problem from the start, not someone who might need help.</p>
Carer interviewee	<p>How can we go ahead with this when nobody is really aware how it will be implemented?</p> <p>Are the staff, are they aware to give feedback to patients on how this will happen?</p>
	<p>Concerning the budget itself, if someone is asking for too much, how</p>

	will that be managed? What will be the limit? How is it decided? (Some things cost more, but would have equal or greater benefit) How are you going to draw the limit?
Out of Borough interviewee	-Why has it taken this long to get to this stage? -What's the hold up, and why did you cut the numbers of people in the pilot from one hundred to fifty? To just a few with mental health needs? -Are you liaising with other boroughs to find out how they're doing it, because some boroughs have got it set up for so long – like my borough has had brokerage set up for the past two or three years to find out how you can best offer a service.

Concluding discussion;

Wider implications and factors regarding changes to resources and cuts:

The importance of Primary Care Team in mental health; there have been an increased number of people being discharged from the Community Mental Health Teams (CMHT) to be supported in the community to manage their mental health by their GP. This is due to aims and government agenda for maximizing independence and is in conjunction with the introduction of the CHAMPHE service in Hackney for referrals back into the CMHT and responsive to the needs and accessible intervention if required. Overall, the affect is that more GP's are directly supporting persons with severe and enduring mental health issues in the community under the primary care services and CMHT's are under more pressure to discharge people to their GP for ongoing support.

Therefore, this means that all general practitioners and surgeries in the borough need to be made more aware of the services available to vulnerable adults in the community and how they can assist persons to be linked in and engaging with community services such as Core Arts. An open dialogue is required between the PCT and voluntary services, especially regarding FACS assessments and funding for services. In order to satisfy the personalisation agenda to ensure the patients have the right to choose their treatment & services.

Changes to secondary services:

As described above, recent changes in secondary care teams and CMHT service structure, reduction in staff teams and higher case loads has pushed for less people to be care managed and faster rate of discharge (especially 'non engagers'). As a response the CMHT has an available duty worker who can support individuals if required and provide additional support as and when required. This means that although there is a less personalised service in terms of seeing the same person/ professional each time attending the CMHT, clients are more likely to be able to be seen on the same day and can walk in at a time suitable to them; the change promotes independence and not dependence on

relationships (although evidence suggests relationships are vital to recovery, specifically mental health service users). Of course, those persons who require more assertive, proactive and relationship based support have allocated care coordinators, even though the care coordinator role is stretched due to caseload and impending cuts.

Overall, bureaucracy and cuts are continuing to undermine the implementation of personalisation yet it appears that the agenda could still prove beneficial to service users, promoting choice, understanding of finances and allocations of resources to them, being able to see their eligibility to service as a measure for their achievements and recovery and having a range of services to choose from.

This research aims to provide insight into the results of implementing the use of personal budgets for referrers and service users to purchase services at Core Arts. It has provided reflections from the service users and professionals working with those people and discuss why personalisation does not appear to be achieving its stated goals of greater choice and control for service users, and how clearer systems and proactive frontline professionals could help to turn things round. We have also gathered examples of good practice from other Boroughs who have managed to reduce the bureaucracy that has undermined progress in Hackney to date.

However, this is largely to do with care coordinator engagement in the process not the service user's experience. The limiting nature of personal budgets can have the positive effect that service users are focused and are more aware of their use of the service and what they get out of it personally. The 'investment' element can be motivational for service users, as they could use the money in other ways but they have chosen to use it at Core Arts. There is still the issue that the care coordinator may not be transparent and clear with the service user as to why they were allocated the funding, in order to give the service user a good understanding of how the system works and why.

Summary of main concerns:

- Weaknesses in knowledge, training and information- it is paramount that systems are in place and stakeholders and providers alike are able make service selection/ eligibility meaningful for the service user rather than arbitrary.
- Ensuring staff within all relevant services understand the practice and role design implications of moving from a 'care management' system to a 'support planning' system, including risk enablement approaches
- Clear protocols and information sheets need to be able to respond to the specific needs and deal effectively with Mental health service users. This can be achieved though ensuring that those managing self-directed support systems within local councils understand the needs of people with mental health problems and how to assess their eligibility specifically.
- Ensuring people using mental health services are fairly accounted for in the local RAS
- Wider knowledge regarding the changes in the system is required promotion via GP's/ CMHT/ housing providers/ preventative services regarding their role in assisting patients to be funded for their support plan (or eligible to access services)
- CMHT unable to facilitate the paperwork and support planning element with high caseload and difficulty with process & time management. For example, care coordinators are keen for their clients to be supported by Core Arts, and understand the service in principle, agree with the service user that it is suitable and they have the right to choose what may work for them, however do not take the outcome

focussed planning tool into consideration. A specialist brokerage team could break down this initial barrier.

- Personal budgets were not of sufficient value to help people meet their needs and resource allocation systems did not allocate resources to people in line with their needs (resource constraints are limiting choice for users, contrary to personalisation's ambitions)
- Curbing assessment paperwork/ SLA's or contracts providing a pathway with clear timescales. Better communication; Patients are unaware of assessment, they are not in the loop and neither is the support service, therefore advice and guidance is difficult to give. Suggestion that contact names are given so that individual can ring and check in on the status/ progress of application
- The introduction of a clear Resource Allocation system (RAS) in Hackney which manages applications for funding as well as managing brokerage for service users.
- Potential for all patients to be assessed for PB/ FACS as part of discharge plan and funds allocated as part of discharge CPA and on-going community, support planning.
- Ensure people using mental health services can exert appropriate and effective authority in local implementation and evaluation

Conclusion:

It is clear that there needs to be significant investment and resourcing to ensure that personalised budgets can be effectively utilised for persons that are FACS eligible (and others with mental health needs). There need to be training for professionals and stakeholders, so that there is clarity and the infrastructure that can be administered effectively and consistently; this is key for smaller organisations to provide creative and quality services without concerns that the bureaucracy involved will have an impact both on financial stability and service user experience. It is evident that there are positives in encouraging the uptake of Personal Budgets that will demonstrate the need, and are recovery focused and time limited. However the process and RAS system will need to be in place so that this is streamlined and effective ensuring a safe and efficient transition from block-purchased to choice-based commissioning of diverse providers.

It also needs to be addressed how this method of support planning can effectively achieve outcomes alongside reducing deficits in budgets and increase further cost saving. Almost double the number of trusts reported deficits for the year to 31 March 2014 than for the previous year (Dorsett 2014), and the British Medical Association has recently stated that doctors and medical students are concerned that cuts are 'destabilising a number of GP practices and could lead to their closure' (BMA 2014). At the same time, funding for social care has been reduced by £3.53 billion, or 26 per cent, since the start of the present spending round (ADASS 2014) – potentially affecting local authorities' ability to provide the types of social care that prevent avoidable- patients in control 2014.

The National Personal Budget Survey found that outcomes were better where service users were informed about the value of their personal budget, fully involved in the support planning process, alongside family carers, relatively free of constraints and bureaucracy, and where they had a direct payment rather than a council-managed personal budget. There are concerns that councils are looking to maintain control over resources by managing personal budgets themselves, rather than giving service users a direct payment, and denying service users genuine choice and control at the same time. However, at the same time, there is recognition that managed personal budgets are the most appropriate

options for many people who do not want the responsibilities of a direct payment, putting a premium on ensuring they deliver genuine choice and control.

Despite the links between less bureaucracy and positive outcomes for service users, the implementation of personal budgets has been beset by excessive bureaucracy. Eighty two per cent of social care professionals said there was more bureaucracy in their role as a result of personalisation, found Community Care's 2012 annual personalisation survey, up from 73% in the previous year's survey (not mental health practitioners specifically). Explanations put forward include long and complex assessment forms and the need for personal budget support plans to be signed off by council panels, rather than social workers themselves. The situation has sparked repeated calls for the processes involved in personal budgets to be simplified, which is one of the priorities for action of sector coalition Think Local Act Personal.

The research was both frustrating and confusing for service users due to little clarity and the heavy reliance upon the dedication of the professionals involved to pursue the application on the service user's behalf. Social workers have a critical role to play in shifting the focus of mental health services from an overly medicalised approach to care to one that supports broader recovery, care minister Norman Lamb has said. Lamb said there was a need for services to "move away" from a model of mental health care focused on medical treatment to one that focused on supporting people to return to "a good life". The minister made the comments; "Social work is critical in that. If we are to make more effective use of resources in mental health this is central to that," Good social work, and the social model of care underpinning it, considers service users' whole life rather than simply their illness. Medical models of mental distress can get in the way of recovery by focusing on illness rather than the person's potential and opportunities to change their life.

Social workers can help mental health services become "a resource and collaborator, not a controller", the according to a College of Social Work report. Lamb said the report made a clear statement on the importance of social workers in both adults' and children's mental health services. "Social workers working in statutory mental health services provide a vital counterbalancing view to clinical models of illness and disorder and where this is done well, can have a powerful impact on NHS culture and practice," he writes in its foreword. Ruth Allen, chair of The College of Social Work's mental health faculty and author of the report, said: "We believe that social workers can change the whole mental health system for the better". The issue of systemic change, communication and empowerment is to be discussed further, as this process currently does not promote this.

Finally, it is important to recognise that voluntary sector services have been working in this manner with service users, creating holistic support plans, discussing money and meaningful use of time; creating weekly timetables of support in the best interest of each individual and their strengths and goals whilst managing the risk and acknowledging the issues and needs with the client. The role of the voluntary sector thus far has been a support navigator, advocate and communication across the support. This change in social work practice will have the opportunity to integrate the sectors, and manage the sharing of information and ensure the client experience is consistent (including care plan) and service user experience.

