

Money and Mental Health submission to the Department of Health & Social Care consultation on extending legal rights to have personal health budgets and integrated personal budgets

The Money and Mental Health Policy Institute is a research charity, established by Martin Lewis to break the link between financial difficulty and mental health problems. This is our response to the Department of Health and Social Care consultation on extending the legal rights to have, for personal health and integrated personal budgets.

We are pleased that the Department is taking these steps in the direction of parity of esteem between mental and physical health services. Here, we set out evidence from our research and policy work on how personal health and integrated personal budgets may be able to support people with acute mental health needs. Money and Mental Health's research is informed by our Research Community, a group of 5,000 people with lived experience of mental health problems. As part of this consultation response, we carried out a survey between 1 - 4 June 2018 of 95 members of our Research Community, about the use of personal budgets and their experience of care under Community Mental Health Services. All quotes are from members of the Community who have participated in our research.

Our response covers questions 3a, 3b and 3c of the Departments call for evidence. In addition to this response, we recommend that the Department reviews our reports *Seeing through the fog*,¹ which explores how mental health problems can affect a person's financial capability, and *Fintech for good*,² which looks at how financial technology can support people experiencing mental health problems. Both reports are attached to this submission.

Q3a. Do you agree that a person of any age under the care of community-based mental health services for a significant period of time should have a legal right to a personal health budget and/or integrated health budget?

Responses to our survey found that nine out of ten participants (90%) felt that they would have benefited from more choice and control over what services they were able to access to support their recovery.³

Services people felt they would have benefited from included:

- personal assistants and peer support workers to access voluntary work;
- gym membership to improve health, wellbeing and self esteem;
- IT equipment to support socialisation and organisational skills;
- creative art classes to develop skills, confidence and positive coping strategies;

¹ Holkar M. Seeing through the fog: How mental health problems affect financial capability. Money and Mental Health Policy Institute. 2017.

² Evans K and Acton R. Fintech for good: How financial technology can support people experiencing mental health problems. Money and Mental Health Policy Institute. 2017

³ Money and Mental Health Survey of people with experience of receiving care under their local Community Mental Health Service or after-care service following discharge from a psychiatric facility under s117 of the MHA. Base for this question: 95.



- support workers to assist with personal financial management;
- and access to a wide range of talking therapies which varied in theoretical model and duration.

“A tablet via the health budget would be a good idea to reduce the feeling of isolation that often comes with depression.”

“I want to do voluntary work, as the next step in my recovery. To do this, I need some support in getting a voluntary role and during the settling in period.” Research Community member

“Gym membership to help reduce huge weight gain due mostly to prescribed medications and enforced long periods of inactivity.”

“The funds would have helped cover travel and support to take on volunteer interests and to attend skills workshops or a educational course to help me recover faster.”

The breadth of responses we received demonstrated the wide variety of services people would like the choice to access to support their recovery, and that the flexibility and personalisation of personal health and integrated health budgets is well suited to meet this variety of need and service provision.

“I think I would have used it to access support in building skills to manage my mental health in the context of my working life. I oscillate between functioning well and holding down a decent job to unemployment and extremely poor function. Mental health services offer things like art or beauty groups whereas I need help in addressing sorting out my bills, finances and employability.”

Several people noted that their experience of the current model of service provision was led by available services rather than their personal needs. They found this restrictive, inflexible and difficult to access in a timely way in accordance with their need.

“I am still on the waiting list for PTSD therapy after more than 6 months. I would have liked to have used the money to access a private therapist, who could have seen me already. As it is, I have another 8-10 months to wait to even see them. It took 6 months to get the initial assessment and formulation.”

“I have now been told I need more one to one support (I knew this from the start but was offered CBT which helped with understanding but not deep counselling). My local NHS does not provide this. I can't afford it... funding would mean I could pay for one to one.”

“A more prolonged period of counselling would definitely have helped as I was only just starting to really reap the rewards of it when it was stopped.”



Introducing a legal right to a personal health budget and/or integrated health budget for people under the care of CMHS and those eligible for section 117 aftercare, would allow people to work with clinicians to personalise their recovery plan to their specific needs. As is demonstrated by our Research Community, people have clear ideas about what services they believe would support their recovery. Personal budgets is one way of respecting people as experts in themselves, and empowering them to identify and purchase precisely what services would support their recovery.

Our research *Money on your mind*, found that where people were unable to access the right treatment for their mental health via the NHS, in some instances people were paying for treatment themselves. This places greater financial pressure on people, and in some cases exacerbated their mental health problems.

"I'm also in private counselling as the NHS have abandoned me so I'm paying £35 a week for this. I'm really worried about money and am almost constantly anxious about this."

Our survey of 95 people who had been under the care of Community Mental Health Services within the last five years, found that only two respondents had been in receipt of a personal health budget for their mental health needs, This low number was to be expected given that the roll-out of such budgets still in the pilot stages and in its infancy.

Q3b. In making provision for people who have been under the care of community-based mental health services for a specific period of time to have a legal right to a Personal Health Budget / Integrated Personal Budget - what do you feel would constitute a reasonable definition of 'a significant period of time'?

In considering what should constitute a 'significant period of time' under the care of CMHS to give a person a legal right to a personal health or integrated personal budget, we are mindful of the experiences of our Research Community, who have shared details of the fluctuating and recurring nature of their mental health problems. In many cases people's mental health problems have been of such severity that they require repeated periods of care under their local CMHS.

In the past five years, 44% of survey respondents had three or more periods of care under their local CMHS, with a quarter (26%) having been under the care of CMHS five or more times in the last five years. ⁴

Therefore we recommend that recurrent episodes of poor mental health in close succession - typically two or more episodes of care within a one year period - that necessitate care under

⁴ Money and Mental Health Survey of (base 90) people with experience of receiving care under their local Community Mental Health Service or after-care service following discharge from a psychiatric facility under s117 of the MHA.

CMHS should be considered as a continuous period for the purpose of meeting thresholds for access to personal budgets.

Q3c. Do you agree that any right to have a Personal Health Budget for Mental Health, should include the right to have a direct payment, if appropriate?

Personal Health Budgets are the current mechanism for driving personalisation. Direct payments are simultaneously the most autonomous and empowering method of payment, but also that which come with the greatest degree of responsibility to purchase care and support services appropriately. Under direct payment, a person may be responsible for ensuring the budget is spent in line with the agreed care plan. People may also take on additional responsibilities as an employer or enter into contracts with people to provide services.

Some people may find the responsibilities of direct payment and personal health budgets too much to contend with. This may be because they are too unwell, or have managed within a much more paternalistic system for many years, and find such changes overwhelming. In introducing a legal right to have a personal health and/or integrated personal budget and direct payment, this should always be led by the choices and preferences of the person concerned.

“I was too overwhelmed to make any choices like these... I don't want the headache of a personal budget. I have enough on my plate.”

Given the links between experiencing financial difficulties and mental health problems, and the associated cognitive and behavioural impact of many mental health problems, it is understandable that increasing the financial responsibilities for people who may already be experiencing difficulties is approached with a degree of caution. Practitioners in mental health services, when working alongside people to undertake assessments and compiling recovery focused mental health care plans rooted in principles of empowerment, may be hesitant about increasing a person's responsibilities in the form of direct payments for personal budgets. However, given the strong evidence base that direct payment is most effective,⁵ and the obvious positives of empowerment, choice and control that accompany direct payment, there is a compelling case to support and promote the use of direct payments where a person wishes and clinical evidence support this.

Supporting service users to manage direct payments effectively

The existing guidance makes provision for decisions about direct payments based on need, and not condition or severity of that condition.⁶ There is also a responsibility on clinicians to consider what kind of support a person might need to manage a direct payment, and what

⁵ Forder J. et al. Evaluation of the personal health budget programme. Department of Health. 2012. https://www.phbe.org.uk/about_the_evaluation.php (Accessed 08/06/18)

⁶ Guidance on Direct Payment for Healthcare: Understanding the Regulations. NHS England. 2014. <https://www.england.nhs.uk/wp-content/uploads/2017/06/guid-direct-paymnt.pdf> (Accessed 08/06/18)

arrangements the CCG could make to obtain the necessary support.⁷ Guidance also stipulates that CCG's may decide not to issue a direct payment to a person if they consider the person would not be able to manage it - here consideration needs to be given to precisely what would prevent a person from managing a direct payment, and if there are technical tools which can be relied upon to assist the person to do so.

Many people with mental health problems tell us that they understand the principles of budgeting, but face barriers to both putting together a budget and sticking to it. Things like keeping track of spending while experiencing short term memory problems, or controlling spending during periods of heightened impulsivity, can make the challenge of budgeting all the more difficult. Guided support in managing a budget through the Care Plan, and the investment the person has in their own care, can foster a sense of autonomy, trust and empowerment, evidentially leading to wider personal development gains, including self belief, confidence and budgeting.⁸

Choosing the right bank account for direct payments to be paid into is crucial. Ensuring bank accounts do not have overdraft facilities and, where possible, offer additional budgeting support tools, may make the difference between a person being able to successfully manage a direct payment or not.

Fintech tools

Money and Mental Health's report, *Fintech for good*⁹, looks at how financial technology can support people experiencing mental health problems. A number of these fintech solutions can be used to support a person to manage a direct payment. Below is a list of tools and interventions which could be utilised to support a person to manage a direct payment:

- 1) **Accounts that offer timely reminders and tools** - Allowing people experiencing mental health problems to visualise both their spending data and financial obligations could help people to remain aware, and feel more in control, of managing their direct payment.
- 2) **Double confirmation or cooling off periods** - In the case of paying large invoices for personal assistant care for example, these payments are routinely likely to be of a large sum. Offering a person the safety net of double confirmation or a cooling off period before payments are completed gives a person more control and reassurance in managing their budget.

⁷ NHS England. Guidance on Direct Payments for Healthcare: Understanding the Regulations. 2014. <https://www.england.nhs.uk/wp-content/uploads/2017/06/guid-direct-paymnt.pdf> (Accessed 06/06/18)

⁸ Alakeson V. Personal health budgets for mental health: The experience in Northamptonshire. Nene Clinical Commissioning Group. NHS England. 2014. <http://www.neneccg.nhs.uk/resources/uploads/files/Northants%20MH%20report%20July%202014.pdf> (Accessed 06/06/18)

⁹ Evans K and Acton R. *Fintech for good: How financial technology can support people experiencing mental health problems*. Money and Mental Health Policy Institute. 2017.



Additionally, some people may make large impulsive purchases when they are unwell, which can cause serious distress. A simple pause prior to processing would give a person time to reflect, and could prevent more difficult problems from arising.

- 3) **‘Jam-jarring’ Ring-fencing money** - Tools that allow a person to ring fence money for each aspect of their personal health budget, eg: funds for weekly counselling could be separated out from the funds needed for exercise or art therapy classes. This would help people who tend to spend impulsively when unwell to ensure they can always pay for the services identified in the care plan.
- 5) **Ability to temporarily stop (‘freeze’) a payment card** - The ability to block a card for a set period of time could be incorporated into personal health budget care plans, to make provision and safeguard budgets during fluctuation in mental health and/or mental health crises.
- 1) **Support of a trusted friend** - A person should be entitled to request notifications of specific activities on their account(s) to be sent to a care-coordinator carer or trusted friend, alerting them to the fact that support might be needed. This would allow for effective and early intervention to prevent a situation from escalating, although care would need to be taken to ensure this did not facilitate financial abuse or fraud.

Careful planning and attention to the management of a direct payment at the outset is crucial, as is identifying a person's specific support needs in managing a direct payment, and choosing a provider that has the tools required to meet a person's specific needs. Our *Fintech for good* report provides a useful summary of the stages financial services are at in providing each of these tools.¹⁰ Regulating bodies, healthcare providers and financial services can work together to ensure that such tools are available to maximise independence, personal choice and control.

Planning for fluctuations in mental health problems

For people with fluctuating mental health problems, a caveat could be built into their care plan, making provision for direct payments and purchasing during periods of acute poor health. This could incorporate identifying markers of deteriorating mental health, and an agreed plan for taking over payment of services, managing accounts etc. Guidance already makes provision for direct payments for people with fluctuating capacity, stipulating that where fluctuations in capacity occur, CCG's may allow a representative to temporarily receive a direct payment on another person's behalf.¹¹ Routinely planning for such eventualities, and incorporating this into care plans, adds another level of safety to ensure that a person can be supported to have as much choice and control over their personal health budgets as possible, and reassurance that a backup plan is in place in times of acute poor mental health.

¹⁰ Evans K and Acton R. *Fintech for good: How financial technology can support people experiencing mental health problems*. Money and Mental Health Policy Institute. 2017.

¹¹ *Guidance on Direct Payment for Healthcare: Understanding the Regulations*. NHS England. 2014. <https://www.england.nhs.uk/wp-content/uploads/2017/06/guid-dirct-paymnt.pdf> (Accessed 08/06/18)



Implementation - avoiding exacerbating difficulties

Direct payments are integral to promoting independence, autonomy and facilitating choice and control. However, any roll-out needs to ensure that the infrastructure is in place in the first instance, to support such a payment method. Delays in assessment, difficulties in agreeing on budgets or issuing payments will invariably have a knock on impact for people in terms of stress and anxiety.

"[I] fought through the CCG and others to get the care I needed. It was so hard, but after a lot of heartache I got them to give me a personal budget... They can never get it right first time... it never comes on time. I asked them last year to come two months before it was due, as the year before they had messed it up, they didn't and it was late and wrong again. This causes extra stress as you don't have money and have to pay for your care up front.. It seems a good idea, and it is, but they have to get it right."