



A consultation on extending legal rights to have for personal health budgets and integrated personal budgets

Prepared by the Department of Health and
Social Care, and NHS England

DHSC INFORMATION READER BOX

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Description: This consultation makes proposals, and seeks comments on, extending individual's legal rights to have for personal health budgets and/or integrated personal budgets

Action required: Views and comments are invited by **8th June 2018**

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Executive Summary

Since the 1970s, there has been an ongoing drive towards personalisation of health and social care services. Personalisation allows users of NHS and social care services to access services in a way that fits them as an individual, and enables the services to be tailored to their particular needs.

Personal health budgets are one such mechanism to achieve this. The policy fits in with a number of similar initiatives in both health and social care, as well as across government, that aim to create more personalised public services, providing people with more choice and control, and improving their experience of the public services they receive. They are simply about providing individuals with a mechanism to enable them to control and tailor their own health and care, based on their own individual needs, in a manner that abides by the constitutional values of healthcare being free at the point of delivery, based on clinical need, not on ability to pay.

The evidence for personal health budgets is strong. They have been shown to improve individual outcomes and increase satisfaction, in a cost-effective manner aligned to supporting a financially sustainable NHS. They can also help to support a move from unplanned, emergency care to planned care, in a location that people want and that is best for them.

There are also multiple areas across the country looking into how personal health budgets and personal budgets in social care, can be joined together into a single integrated personal budget wrapped around the individual's health and social care needs. A person with an integrated personal budget will have all their health and social care needs considered during one, single assessment, will have a single personalised care and support plan designed with them, not for them, and one, integrated budget that meets their needs. The overall aim of the integrated personal budget is to enable the person and their carers to exercise greater choice and control over how their needs are met and achieve better outcomes, whilst avoiding the need for multiple assessments and managing separate budgets.

Currently, the only people who have a specific 'right to have' a personal health budget, are adults in receipt of NHS continuing healthcare or children receiving continuing care. Given the clear benefits, and given the work the NHS has done to date, we believe there are now a number of other groups who could benefit from this approach. We are therefore proposing to extend this right to other groups, to ensure that for people who want a personal health budget and/or an integrated personal budget to address their needs, and if deemed clinically appropriate, the system is in place to ensure they can receive one.

Within this consultation, we have therefore identified and proposed the following groups who we believe could benefit from having a 'right to have' a personal health budget, or where appropriate, an integrated personal budget:

- **People with ongoing social care needs, who also make regular and ongoing use of relevant NHS services.**
- **People eligible for Section 117 aftercare services, and people of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services.**
- **People leaving the Armed Forces, who are eligible for ongoing NHS services.**
- **People with a learning disability, autism or both, who are eligible for ongoing NHS care.**
- **People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs.**

Within this, we have also proposed where we believe an explicit right to receiving a personal health budget or integrated personal budget via a direct payment, would benefit certain groups. This does not mean the direct payment method is the only method available; rather, we want to ensure that for those groups whom we believe direct payments will benefit, the system is in place to ensure they can receive the budget in that way if they so wish.

We would welcome your views on our proposals, specifically;

- Whether you agree that the groups we have identified should be prioritised;
- Whether you believe these groups would benefit from a personal health budget and/or an integrated personal budget or not; and
- Whether there are other groups, or areas of the system that we have not identified, who you believe a personal health budget and/or an integrated personal budget could benefit.

Across Government, there is a broader effort to think differently about the links between health, work, housing and disability - including focusing more on what the individual can do, rather than what they can't. As part of this, we are trying to find solutions to the challenges faced by people with disability and health conditions, including how we can best support employment where appropriate.

It is our belief that integrated personal budgets could be used to support people to have better lives, through providing the opportunity to incorporate additional funding streams linked to health and wellbeing into the individual's budget. The budget would then be based around a single, holistic assessment and plan, focussing purely on that individual's holistic needs. We would also welcome your views therefore on whether there are other funding streams that could be incorporated into integrated personal budgets.

Chapter 1: Introduction

Purpose of the consultation

1. Within the NHS, there is an ever-growing shift towards personalisation of health and care. It is clear that choice and personalisation matter to people. Uptake of personalised health and care plans within the NHS has increased annually since implementation, and evidence suggests that by providing individuals with more choice and control over how their individual needs are met, outcomes often improve, satisfaction often increases, and the package of care can often be delivered in a more cost-effective manner (see <https://www.phbe.org.uk/index-phbe.php> for further information on the pilots).
2. Personalisation of care also matters to the NHS. It can enable the commissioning of more appropriate services for the individual, and a better coordination of care that best meets that individuals' needs. It is clear that people with a personalised package of care value the opportunity to be involved in both the planning and implementation of their health and care.
3. In the Five Year Forward View, and based on the evidence of positive outcomes, NHS England made it clear that they would increase the direct control individuals can have over their care. Personal health budgets and integrated personal commissioning are the key mechanisms for delivering this change.
4. Currently, only individuals in receipt of NHS continuing healthcare, and in the case of children and young people, continuing care, have the right to have a personal health budget - although Clinical Commissioning Groups can offer personal health budgets to other groups if appropriate. The number of personal health budgets has been rising year on year; in the first nine months of 2017/18 nearly 23,000 people received one. Given the success of the policy thus far, we are proposing to extend individuals' 'right to have' personal health budgets to other groups that we believe could benefit.
5. There is also ongoing work across the country, through NHS England's Integrated Personal Commissioning Programme, exploring how personal health budgets and personal budgets in social care can be joined together into a single integrated personal budget, wrapped around the individual's health, social care, and in the case of children, educational needs. A person with an integrated personal budget will have all their health and social care needs considered during one, single assessment, will have a bespoke, single personalised care and support plan, and potentially one integrated budget that meets their needs. The overall aim of the integrated personal budget is to enable the

person and their carers to exercise greater choice and control over how their whole needs are met, whilst preventing them needing multiple assessments and managing separate budgets.

6. This consultation therefore seeks views on proposals to extend specific groups rights to a personal health budget and/or integrated personal budget. There are five specific groups that we are proposing, but would also welcome your views on any other cohorts that you believe would benefit from having a 'right to have'. The specific groups we are consulting on are:
 - **People with ongoing social care needs, who also make regular and ongoing use of relevant NHS services.**
 - **People eligible for Section 117 aftercare services, and people of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services.**
 - **People leaving the Armed Forces, who are eligible for ongoing NHS services.**
 - **People with a learning disability, autism or both, who are eligible for ongoing NHS care.**
 - **People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs.**
7. We would also welcome your views on whether the right to have a personal health budget for NHS continuing healthcare funded home-care should be expanded to have a right to a direct payment. Currently, the 'right to have' for this group does not extend to the right to receive the personal health budget in a specific way. However, there is clear evidence that the greatest benefit to this cohort comes when the personal health budget is managed via a direct payment. We therefore want to ensure that for anybody who wishes to receive a personal health budget via a direct payment, they can.
8. Within this consultation, we have also proposed where we believe an explicit right to receiving a personal health budget or integrated personal budget via a direct payment, would benefit some of the groups outlined above. This does not mean the direct payment method is the only method available; rather, we want to ensure that for those groups who we believe direct payments will benefit, the system is in place to ensure they can receive it in that way if they so wish. We would welcome your views on these proposals.
9. Finally, we believe it may be possible to go even further with integrated personal budgets, and explore whether we could also integrate other funding streams into the integrated personal budget. We would also welcome your views, therefore, on whether there are other funding streams that you think could be incorporated into integrated personal budgets.
10. It is important to note that the extension of the 'right to have' a personal health budgets and/or an integrated personal budget to other groups does not replace traditional routes of receiving care. Personal health budgets and integrated personal budgets are optional; the intention is to provide individuals with greater choice, flexibility and control over the health and care support they receive, if they so wish. It is also important to note that personal health budgets and integrated personal budgets will not alter the fact that healthcare is free at the point of delivery, and is based on clinical need, not ability to pay. Personal health budgets and integrated personal budgets therefore will not place any additional cost on individuals; it is simply a different way of commissioning that enables

the individual to have more control.

11. Subject to the outcome of this consultation, the Government plans to outline next steps and set the direction of travel within the forthcoming green paper on social care. We also intend to reflect the extension of the right to have in a variety of guidance, including within the *Handbook to the NHS Constitution*, which is due to be updated by July 2018. At an appropriate time in the future, we will then legislate to reflect the consultation outcome, and consolidate the extended 'rights to have' in law. As part of any legislation, the Government will be conducting, and publishing, a Impact Assessment as is the statutory responsibility.

Background

What is a personal health budget?

12. A personal health budget is an amount of money and a plan to use it, agreed between an individual and their health care professional(s). It is a way of enabling disabled people and those with long-term health needs to have greater choice, flexibility and control over the health and care support they receive.
13. Personalised care and support planning is at the heart of making personal health budgets work well. A personalised care and support plan helps people to identify their health and wellbeing goals, together with their local NHS team, and sets out how the budget will be spent to enable them to reach their goals and keep healthy and safe. The plan should set out the individual's needs, the amount of money available and how the money will be spent to meet those needs.
14. A personal health budget can be spent on anything that is likely to meet the individual's health and wellbeing needs, with all items or services purchased being signed off by the relevant health care professional. Personal health budgets should take a holistic view of the individual's life to best address their health needs; however, there are certain areas of NHS care that it does not cover, such as GP services, unplanned hospital admission, medication or operations. There is a small list of things that are excluded completely; for example, alcohol, tobacco, gambling, debt repayment and anything that is illegal. A full set of the exclusions can be found in the regulations here; http://www.legislation.gov.uk/ukxi/2013/1617/pdfs/ukxi_20131617_en.pdf.

How does a personal health budget work?

15. Personal health budgets are optional. They are intended to help people who may not always get the best out of the NHS, to get a better service. Nobody would be required to receive their healthcare in this way if they do not want to. We believe that individuals should have as much control over decisions as they want.
16. If an individual does choose to receive a personal health budget, and if their clinician believes it is clinically appropriate, the individual will firstly discuss a personalised care and support plan with their local health team. This plan helps people to identify their health and wellbeing goals, and sets out how the budget will be spent to enable them to

reach their goals and keep healthy and safe.

17. Following the agreement of the plan, the next step is for the individual (as part of the local health team) to determine how they wish to receive the personal health budget. There are three money management options available for personal health budgets or integrated personal budgets:
 - **Notional budget** – the council or the NHS manages the budget and arranges care and support on behalf of the individual.
 - **Third party budget** – an organisation independent of the person, the council and the NHS commissioner- for example, a charity, manages the budget and is responsible for ensuring the right care is put in place. The third party will work in partnership with the individual and their family to ensure the agreed outcomes can be achieved.
 - **Direct payment** - the budget holder has the money in a bank account or an equivalent account, and takes responsibility for purchasing care and support.
18. The local health team will then work with the individual to ensure that their plan remains right for them, that the budget is being used appropriately, and that the amount provided within the budget meets the agreed needs of the individual.
19. Where an individual lacks capacity (as defined by the Mental Capacity Act 2005, which can be found at <http://www.legislation.gov.uk/ukpga/2005/9/contents>), or if the individual is a child, the personal health budget will be held by an Authorised Representative; for example, a parent.
20. For additional information on how money provided through a personal health budget is managed, the governance and regulation of personal health budgets, and structure, please see <https://www.england.nhs.uk/personal-health-budgets/what-are-personal-health-budgets-phbs/frequently-asked-questions-about-phbs/>.

What is the evidence that a personal health budget can be beneficial?

21. Evidence from the evaluation of the personal health budget pilot programme, showed that personal health budgets can support a move from unplanned, emergency care to planned care, and that they are cost effective in comparison to conventional services. It also found that people with the highest levels of need experienced similar or improved outcomes when using a personal health budget.
22. The use of personal health budgets was also associated with a significant improvement in the care-related quality of life and psychological wellbeing of individual's. Additional information can be found at; <https://www.phbe.org.uk/index-phbe.php>.
23. More recent evidence gathered as part of the NHS continuing healthcare strategic improvement programme, shows that personal health budgets have reduced costs of NHS continuing healthcare home care packages by an average of 17%.
24. Following the success of the pilots, adults eligible for NHS continuing healthcare and children in receipt of continuing care, a 'right to have' a personal health budget was established in October 2014.
25. Given the positive outcomes shown to date, we are now proposing to extend the 'right to have' a personal health budget to other groups.

How has a personal health budget helped Louise?

Louise, 90, has a personal health budget which pays for personal assistants, and supports her wish to be cared for at home with family rather than in a nursing home. Louise has chronic physical health problems, has trouble communicating and also has Alzheimer's disease. A local user-led organisation provides support to Louise's family to help them recruit staff. Her budget includes money for osteopathy and has paid for a laptop for the personal assistants to input information about Louise's food and fluid intake, blood pressure and temperature. The budget also covers respite for Louise's daughter and husband. Louise has not had any emergency admissions to a nursing home or hospital since taking up the personal health budget

Movement towards integrated personal commissioning and integrated personal budgets

26. There is a broader push across Government to integrate the way health and social care services are provided; one way this is being done is through integrated personal commissioning. Integrated personal commissioning is a nationally led, locally delivered programme delivered in partnership by NHS England and the Local Government Association, that is supporting healthcare empowerment and the better integration of services across health, social care and the voluntary and community sector.
27. The programme aims to ensure that services are tailored to people's individual needs, building on learning from personal budgets in social care and the progress made with personal health budgets. Through integrated personal commissioning, people, carers and families with a range of long-term conditions and disabilities are supported to take a more active role in their health and wellbeing, with better information and access to support in their local community, and greater choice and control over their care.
28. Integrated personal budgets are one way that people can experience a streamlined service. In essence, an integrated personal budget joins funding from health and social care. A person with an integrated personal budget has all their health and social care needs considered during one, single assessment, has a single personalised care and support plan designed with them, and one, integrated budget that meets their needs. The overall aim of the integrated personal budget is to enable the person and their carers to exercise greater choice and control over how their needs are met and achieve better outcomes, whilst preventing them needing multiple assessments and managing separate budgets.
29. The integrated personal commissioning programme will help to drive the expansion of personalisation by creating the wider model of personalised care for people with ongoing, high support needs in England. Further information on the integrated personal commissioning programme can be found at <https://www.england.nhs.uk/ipc/>

How has an integrated personal budget supported Denise?

Rushcliffe Clinical Commissioning Group, in conjunction with the local council, are providing people with integrated personal budgets combining health and social care funding. This enabled **Denise**, 46, a lung cancer sufferer, to move from a care home to her own home with an integrated package of care, with 30% of the funding coming from NHS. Since Denise has been at home, she says her life has improved greatly. Denise is able to get more exercise, has more opportunities to take trips out, and feels part of the family again. Denise has also employed a personal assistant to work with her to meet her health and wellbeing needs. Additionally, Denise's budget saves the system £147.35 per week on the cost of the previous care home placement.

Incorporating additional funding streams

30. When disabled people, and those living with long term conditions, have discussions with their health professionals about their ongoing health, we want to see them receive work-related advice and supportive engagement as part of making work a health outcome. This is based on the understanding that good work is good for health. This is part of a broader effort to think differently about disability and health - including focussing more on what the individual can do rather than what they can't, as well as trying to find solutions to the challenges the health condition presents to the person's life, including work.
31. *Improving Lives: the Future of Work, Health and Disability* (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/663399/improving-lives-the-future-of-work-health-and-disability.PDF) outlined the Government's commitment to explore the use of personal health budgets and personal budgets for employment support, and "...to further join up support and services through NHS England's established integrated personal commissioning programme/personal health budgets programmes, including in areas such as mental health, support for disabled people and those with long-term health conditions, and wheelchair services" (*Improving Lives: the Future of Work, Health and Disability*, 2017, p.37).
32. Similarly, there is much evidence on the positive correlation between the quality of the individual's home, and their health and wellbeing (for example, *Housing and Health*, Parliament UK, *The Impact of Bad Housing*, Shelter). *Housing and Health* suggests that poor housing is associated with an increased risk of cardiovascular diseases, respiratory diseases and depression and anxiety; with poor housing costing the NHS an estimated £1.4 billion per year through negative effects on health (*Quantifying the cost of poor housing*, BRE press, 2010). Incorporating additional funding streams relating to home adaptations, thereby providing the individual with a single, holistic plan that meets both health and wellbeing needs, could, in some cases, improve individual outcomes and the individual's quality of life; whilst being in line with the Government's focus on prevention, and reducing admission to hospitals and care homes.
33. We therefore intend to explore this, and ask individuals whether they think there are other funding streams that could be incorporated into integrated personal budgets.

Chapter 2: Extending individuals' rights to have

Introduction

- 34.** This section outlines our proposals for extending the rights to have for personal health budgets and integrated personal budgets. The specific groups we are consulting on are:
- **People with ongoing social care needs, who also make regular and ongoing use of relevant NHS services.**
 - **People eligible for Section 117 aftercare services, and people of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services.**
 - **People leaving the Armed Forces, who are eligible for ongoing NHS services.**
 - **People with a learning disability, autism or both, who are eligible for ongoing NHS care.**
 - **People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs.**
- 35.** This section also proposes establishing 'rights to have' direct payments for certain groups, to ensure that for individuals from these groups who want to receive their personal health budget or integrated personal budget via a direct payment, they have an explicit right to do so. Again, this right would simply provide individuals with the option of receiving the budget via a direct payment if they so wish - it is completely optional as to which of the payment mechanisms the individual would like to use. This section also seeks views on whether individuals would welcome the opportunity to extend their personal health budget or integrated personal budget to incorporate other funding streams.
- 36.** The following sections summarise our rationale, and ask for your views.

People with ongoing social care needs, who also make regular and ongoing use of relevant NHS services

37. There is a broader push across Government to integrate the way health and social care services are provided. Currently, individuals can hold both a personal health budget to meet their health needs, and a personal budget to meet their social care needs. This means that individuals could theoretically have two separate budgets, two separate plans, and two separate assessments. Integrated personal budgets, which bring the two together into one, is one way that we believe individuals can experience a more streamlined service that addresses both their health and social care need.
38. The integrated personal budget will pool funding from both health and social care into one, single budget centred around the individual's agreed personalised care plan that spans both health and social care. Under this model, all the individuals' health and social care needs will also be considered during one assessment, providing a more joined up and integrated approach to the individual's care.
39. There are approximately 5000 people who currently hold both a personal health budget, and a personal budget; a number that NHS England expect to substantially rise. For individuals who have these joint needs and budgets, the right to have an integrated personal budget will provide them with the opportunity to plan their entire care in a more holistic, seamless and integrated manner.

Q1a. Do you agree that people who are eligible for both a personal budget and a personal health budget should have the right to an integrated personal budget?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

Q1b. Do you agree that any right to an integrated personal budget, should include a right to have a direct payment, if appropriate?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

People eligible for Section 117 aftercare services, and people of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services

40. Personal health budgets fit well with the recovery-focussed approach to mental health services. The recovery model aims to move beyond symptom and risk management to supporting people to re-establish meaningful lives with their mental health condition. It means looking beyond medical treatment to consider wider issues such as housing, employment and relationships. It also depends on services being able to develop individually tailored approaches.
41. Many clinical commissioning groups across the country have already successfully implemented personal health budgets in mental health. In 2016-17, there were 1037 personal health budgets for adults with a primary mental health care need, with evidence demonstrating a range of benefits including providing the individual with a sense of empowerment, a better care related quality of life, and better psychological wellbeing. Local areas are now recognising the potential benefits in offering integrated personal budgets for people with mental health needs whose requirements sit across both health and social care.
42. As part of this, we also believe that personal health budgets and integrated personal budgets could be beneficial to people receiving 'after care' through section 117 of the Mental Health Act 1983. Section 117 after-care services include healthcare, social care and employment services, supported accommodation, and services to meet people's social, cultural and spiritual needs – as long as the needs arise from, or are related to, the person's mental condition, and helps reduce the risk of their mental condition getting worse. A personal health budget or integrated personal budget would provide individuals receiving after-care with a tailored approach that is right for them, which will empower them, and provide them with a supportive mechanism that can help them to re-establish meaningful lives with their mental health condition.
43. Based on this evidence, we are now proposing introducing a legal right to a personal health budget or integrated personal budget for the following groups;
 - People who are eligible for Section 117 after-care; and
 - People, of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services, in order to help them to access the right support that they need to maintain their recovery.

What is section 117 of the Mental Health Act 1983 ?

Section 117 of the Mental Health Act 1983 (“the Act”) requires clinical commissioning Groups and local authorities to jointly provide, or arrange, help and support for people who have been detained in hospital under section 3, 37, 45A, 47 or 48 of the Act when they leave hospital. This is often referred to as Section 117 after-care. People also have the right to Section 117 after-care if they have been discharged onto a community treatment (CTO), granted leave of absence under Section 117, or are a restricted patient on a conditional discharge.

Section 117 applies to people of all ages, including children and young people, and people have the right to section 117 after-care services after they leave hospital whether they leave immediately or stay on as a voluntary patient.

Section 117 after-care services include healthcare, social care and employment services, supported accommodation, and services to meet people’s social, cultural and spiritual needs – as long as the needs arise from or are related to the person’s mental condition and helps reduce the risk of their mental condition getting worse. Section 117 after-care services continue until both the clinical commissioning group and local authority are satisfied (and make a joint decision) that a person no longer requires services.

Q2. Do you agree that a person eligible for Section 117 after-care services under the Mental Health Act 1983 should have a legal right to a personal health budget and/or an integrated personal budget?

Yes **Yes I agree in principle, but...**

No, and my reasoning for this is.. **No**

Any additional comments?

Q3a. Do you believe 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 an integrated personal budget?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

Q3b. What do you feel would constitute a reasonable definition of ‘a significant period of time’?

Please answer in the text box below

Q3c. Do you agree that any right to a personal health budget for mental health, should include a right to have a direct payment, if appropriate?

Yes **Yes I agree in principle, but...**

No, and my reasoning for this is.. **No**

Any additional comments?

People leaving the armed forces, who are eligible for ongoing NHS services

44. Around 2500 people are medically discharged from the armed services each year (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/627223/20170713-MedicalDisBulletinFinal-O.pdf), some of whom have ongoing NHS support needs. For these individuals, personal health budgets are one way of providing them with more choice and control over how their needs are met.
45. The amount and type of NHS care needed by people leaving the armed forces will vary considerably; and there will be cases where personal health budgets may not be appropriate. If so, it would be the responsibility of the clinician to explain this to the individual, including the rationale as to why it is not appropriate.
46. However, in some cases, we believe a personal health budget would be appropriate, and would provide the individual with the opportunity to receive a more tailored, personalised package of care that meets their needs. In cases where the individual also has a social care need, an integrated personal budget could provide the individual with a more integrated, personalised package of care that meets their entire health and social care need.
47. Separately, NHS England and the Ministry of Defence are working in partnership to explore further ways to improve the co-ordination of care for severely injured and highly dependent service personnel who are in transition from the forces into civilian life.

Q4a. Do you agree that people leaving the armed forces who have a requirement for ongoing care through NHS services (with some exclusions including primary care and pharmaceuticals) should have the right to personal health budgets where appropriate?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

Q4b. Do you agree that any right to a personal health budget for this group, should include a right to have a direct payment, if appropriate?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

People with a learning disability, autism or both, who are eligible for ongoing NHS care

49. Sir Stephen Bubb's independent report (*Winterbourne View- Time for Change*, 2014) on transforming care for people who have a learning disability, autism or both, recommended that “NHS England extend the right to have a personal budget or personal health budget to more people who have a learning disability and/or autism, including all those in inpatient care and appropriate groups living in the community, but at risk of being admitted to inpatient care”.
50. People with a learning disability, autism, or both, currently have legal rights to personal health budgets if they are eligible for NHS continuing healthcare, or continuing care in the case of children or young people. They also have rights to personal budgets through social care. In 2016/17 around 4,500 people with a learning disability, autism, or both, had a personal health budget or integrated personal budget; a number NHS England anticipates will rise to around 10,000 people by March 2021. In addition to this, there are a further 91,000 people who receive social care via a personal budget.
51. Evidence suggests that for these individuals, a model of personalised care is beneficial to their health and care. Early learning from the personal health budget pilot sites and the implementation of personal budgets in social care showed that personalised care and support could lead to better outcomes for marginalised groups and people with complex needs, including people with learning disabilities, autism, or both.
52. The Social Care Institute for Excellence also found that for people with a learning disability, autism or both, personal budgets and personalised care and support can make a significant difference. They found that families and carers can benefit when the individual has choice and control over their care and wellbeing, and that budgets can improve life for this group, and can help prevent some individuals from going into residential care as adults (<https://www.scie.org.uk/personalisation/specific-groups/learning-disability>).
53. However if an individual receives a jointly funded package, there is currently no right to have an integrated personal budget. Existing programmes, such as the Care Programme Approach are already used to support people with learning disabilities, autism or both (and others such as people with complex mental health conditions). However the use of personal health budgets or integrated personal budgets alongside the Care Programme Approach will further increase the choice and control people have, enabling them to meet their needs in ways that work for them. It is thought there are around 20,000 people with a learning disability, autism or both, who are on the Care Programme Approach. We believe that these people could directly benefit from a personal health budget or integrated personal budget, if the right to have one was established.

Q5a. Do you agree that a person with a learning disability, autism or both who has an integrated package of care should have a legal right to an integrated personal budget?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

Q5b. Do you believe that a person of any age with a learning disability, autism or both with ongoing eligible health needs should have a legal right to a personal health budget and/or an integrated personal budget?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

Q5c. Do you agree that any right to a personal health budget and/or an integrated personal budget for this group, should be a right to have a direct payment, if appropriate?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs

54. NHS England, as part of their wheelchair improvement programme, has been introducing a range of measures to support clinical commissioning groups improve how wheelchair services are delivered. In 2016, as part of this programme, NHS England's Chief Executive, Simon Stevens, announced that personal wheelchair budgets would replace the current voucher system.
55. The existing voucher scheme for wheelchairs was introduced in 1996, with the aim of providing individuals with additional choice of wheelchairs within the NHS (<http://www.legislation.gov.uk/ukxi/1996/1503/made>). Personal wheelchair budgets build on this by introducing holistic, personalised assessments, taking into account both the individual's health and social care needs, whilst providing them with the opportunity to use integrated budgets to access their wheelchair.
56. The evidence suggests that personal wheelchair budgets increase the choice and control people have over the chair they receive, as well as provide the opportunity for the individual to access a wheelchair that meets their needs across health, social care, work and education as appropriate.
57. Given this, we now want to go further by establishing a legal right to a personal health budget or integrated personal budget for people who are eligible for wheelchair services, to help support them to access the wheelchair that meets their holistic needs across health, social care, education and work as appropriate, that will help to improve their health and wellbeing outcomes.

Q6a. Do you agree that people who access wheelchair services whose posture and mobility needs impact their wider health and social care needs, should have the right to a personal health budget or an integrated personal budget?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

Q6b. Do you agree that any right to a personal wheelchair budget should be a right to have a direct payment, if appropriate?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

Q7. Are there any other groups that you believe would benefit from having a 'right to have' a personal health budget and/or an integrated personal budget?

Please answer in the text box below

Incorporating additional funding streams

58. People with complex health conditions are often eligible for a range of other benefits and support. This can mean that people receive money from a number of different places; with often more than one funding stream coming from the same place. This can be confusing for people, who have to deal with multiple agencies and professionals with differing processes and requirements, who often see them as passive recipients of support. This process can make it difficult for people to plan their lives more holistically.
59. The Work, Health and Disability White Paper, *Improving Lives*, outlined the Government's commitment to explore the use of personal health budgets and integrated personal budgets for employment support and "...to further join up support and services through NHS England's established integrated personal commissioning programme/personal health budgets programmes, including in areas such as mental health, support for disabled people and those with long-term health conditions, and wheelchair services."
60. Dame Carol Black's review, *Drug and alcohol addiction, and obesity: effects on employment outcomes* (<https://www.gov.uk/government/publications/drug-and-alcohol-addiction-and-obesity-effects-on-employment-outcomes>) also called for the Government to promote more integrated working across the benefit and health systems to improve employment outcomes for working-age individuals and for others with long-term health conditions.
61. Responses from previous consultations have made clear that sharing information regarding work and health between interested parties could improve the care and support provided to someone at risk of falling out of work, or on sickness absence. More aligned, joined-up and person-centred care was seen as an effective way of addressing wider social needs that can affect individuals health and wellbeing.
62. Other possible additional funding streams that could be incorporated into an integrated personal budget, include grants for home adaptations, such as the Disabled Facilities Grant. This grant supports older and disabled people on low incomes to adapt their homes to meet their needs; for example, by widening doors, installing ramps, grab rails and stair lifts, or funding telehealth, telecare, and other technology that supports independent living.
63. The quality of someone's home can have a huge impact on both their physical and mental health across their lifetime (*Housing and Health*, Parliament UK & *The Impact of Bad Housing*, Shelter). Further, *Housing and Health* suggests that poor housing is associated with an increased risk of cardiovascular diseases, respiratory diseases and depression and anxiety. Poor quality housing costs the NHS an estimated £1.4 billion per year through negative effects on health e.g. overcrowding, damp conditions, lack of insulation, unsafe stairs, and poor lighting (*Quantifying the cost of poor housing*, BRE press, 2010).
64. Housing adaptation grants such as the Disabled Facilities Grant can also help to prevent admission to hospital or care homes, whilst enabling the individual a better quality of life (*Good housing leads to good health*, BRE, CIEH London, 2010).
65. We therefore now want to ask individuals whether there are additional funding streams that they feel could be incorporated into integrated personal budgets. We will set out our

proposed approach and next steps in the Government's response to this consultation.

66. To note, there are ongoing reviews of certain funding streams and grants- for example, the Disabled Facilities Grant. The outcome of any reviews will be taken into account as this policy develops.

Q8. Are there other funding streams that you believe would be beneficial to incorporate into integrated personal budgets?

Please answer in the text box below

Establishing a right to direct payments in NHS continuing healthcare funded home-care

- 67.** NHS continuing healthcare is a package of ongoing care, arranged and funded by the NHS, to meet the needs of people aged 18 or over who have been assessed as having a primary health need. (Further information about NHS continuing healthcare is available on NHS Choices (<http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/nhs-continuing-care.aspx>) and NHS England's NHS continuing healthcare website (<https://www.england.nhs.uk/ourwork/pe/healthcare>)).
- 68.** Adults in receipt of NHS continuing healthcare have had the right to a personal health budget, subject to exceptions, since October 2014. This right enables the budget to be managed in three different ways- notionally, via a third party, or via a direct payment. Evidence suggests that the greatest benefit to this group comes when the personal health budget is managed via a direct payment.
- 69.** The majority of people in receipt of NHS continuing healthcare receive their care and support in care homes. However, a significant proportion (between 25-30% at any one time) receive care and support in their own home. Personal health budgets are already routinely offered by some clinical commissioning groups for this group, as they provide people with more choice, flexibility and control over who comes into their home, what care and support they get, and when.
- 70.** However, the current 'right to have' does not give individuals a right to any specific type of personal health budget. Given the evidence suggests that personal health budgets work best for this group when managed through a direct payment (see <https://www.gov.uk/government/consultations/changes-to-direct-payments-for-healthcare>), we want to ensure that for anybody within this group who wants to manage their budget in this way (with some exceptions), they can do so.

Q9. Do you agree that people who are managing their NHS continuing healthcare funded home care as a personal health budget should have the right to a direct payment, if appropriate?

Yes

Yes I agree in principle, but...

No, and my reasoning for this is..

No

Any additional comments?

Equalities

71. In developing any policy or, if necessary, amending legislation in light of the outcome of the consultation, we will undertake an analysis of equality issues, in line with Secretary of State's statutory duties, including the public sector equality duty.
72. However, in advance of undertaking that analysis, we would welcome your views on whether you believe anything set out in this document might have a beneficial or adverse impact on any equality issue; in particular, on the protected characteristics as defined in Section 149 of the Equality Act 2010.
73. The protected characteristics are;
- a) **Age-** Under the Act, individuals must not be discriminated against because they are, or aren't, a certain age, or within an age range. They must also not be discriminated against because somebody believes they are, or aren't, a certain age, and they must not be discriminated through association to somebody of a certain age or age group.
 - b) **Disability-** Under the Act a person is considered disabled if s/he has a mental or physical impairment that has a substantial and long-term negative effect on his or her ability to carry out normal daily activities.
 - c) **Gender reassignment-** Transgender people are protected when they propose to undergo, are undergoing, or have undergone a process for gender reassignment. Under the Equality Act 2010 there is no longer a requirement for medical intervention.
 - d) **Marriage and civil partnership-** The Act states that individuals must not be discriminated against in employment because they are married or in a civil partnership.
 - e) **Pregnancy and maternity-** A woman is protected against discrimination on the grounds of pregnancy and maternity during the period of her pregnancy and of any statutory maternity leave to which she is entitled. The employer cannot take into account the employee's period of absence due to pregnancy-related illness when making decisions about her employment.
 - f) **Race-** For the purposes of the Act, race includes colour, nationality, and ethnic or national origin.
 - g) **Religion or belief-** The Act protects individuals of all religions and beliefs, as well as those with none. Religion has the meaning usually given to it but belief includes religious and philosophical beliefs, including lack of belief (e.g. Atheism). Generally, a belief should relate to a substantial and weighty area of life and affect an individual's life choices or the way they live for it to be protected.
 - h) **Sex-** The Act protects both men and women.
 - i) **Sexual orientation-** The Act protects bisexual, gay, heterosexual and lesbian people.

Q10. Do you think anything set out in this document might have a beneficial or adverse impact on any equality issue- in particular, in relation to any of the groups who share a characteristic that is protected for the purpose of section 149 of the Equality Act 2010?

[The relevant protected characteristics are; age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, and sexual orientation].

Please answer in the text box below.

Chapter 3: Statement on impact and equalities

- 74.** The purpose of this consultation is to collect views on the possibility of extending individuals' rights to have for personal health budgets and integrated personal budgets, including an assessment of whether an extension of the right to the groups identified within this document is something that respondents want. The evidence collected via this consultation will contribute to that assessment.
- 75.** This consultation also explores public opinion on whether personal health budgets and integrated personal budgets could be extended to incorporate other funding streams related to health and social care. The views we collect during this consultation will contribute to the development of any policy on this proposal.
- 76.** In developing any policy or, if necessary, amending legislation in light of the outcome of the consultation, we will undertake an analysis of equality issues, in line with Secretary of State's statutory duties, including the public sector equality duty.

Chapter 4: Summary of consultation questions

The questions below seek your views on a series of proposals aimed at extending individuals rights to have a personal health budget and/or integrated personal budget. When answering each question, there are four options available to you;

- Yes
- Yes, I agree in principle but...
- No, and my reasoning for this is...
- No I disagree

If you completely agree with the proposal, please select 'Yes'. Similarly, if you completely disagree with the proposal, please select 'No'.

If you agree with the proposal in principle, but disagree about an element, please select 'Yes I agree in principle but...', and use the free text field to explain your rationale. Similarly, if you disagree with the proposal, and would like to explain the rationale behind this, please select 'No, and my reasoning for this is...'. using the free text field to explain that choice. All responses will be analysed, and used as evidence when developing any future policy.

Some questions within this consultation are not multiple choice, and instead, seek any comments you have on the question posed. For these questions, please draft your response in the text box provided.

All responses will be analysed, and will be used to inform the development of policy.

People with ongoing social care needs, who also make regular and ongoing use of relevant NHS services

Q1a. We are proposing that people who are eligible for both a personal budget and a personal health budget should have the right to an integrated personal budget. **Do you agree?**

Q1b. We are proposing that any right to an Integrated Personal Budget, should include a right to have a direct payment, if appropriate. **Do you agree?**

People eligible for S117 aftercare services, and people of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services

Q2. We are proposing that a person eligible for Section 117 after-care services under the Mental Health Act 1983 should have a legal right to a personal health budget / integrated personal budget. **Do you agree?**

Q3a. We are proposing 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 / integrated personal budget. **Do you agree?**

Q3b. What do you feel would constitute a reasonable definition of 'a significant period of time'?

Q3c. We are proposing that any right to a personal health budget for mental health, should include a right to have a direct payment, if appropriate. Do you agree?

People leaving the armed forces, who are eligible for ongoing NHS services

Q4a. We are proposing that people leaving the armed forces who have a requirement for ongoing care through NHS services, (with some exclusions including primary care and pharmaceuticals), should have the right to personal health budgets where appropriate. **Do you agree?**

Q4b. We are proposing that any right to a personal health budget for this group, should include a right to have a direct payment, if appropriate. **Do you agree?**

People with a learning disability, autism or both, who are eligible for ongoing NHS care

Q5a. We are proposing that a person with a learning disability, autism or both with integrated packages of care should have a legal right to an integrated personal budget. **Do you agree?**

Q5b. We are proposing that a person of any age with a learning disability, autism or both with ongoing eligible health needs should have a legal right to a personal health budget / integrated personal budget. **Do you agree?**

Q5c. We are proposing that any right to a personal health budget/integrated personal budget, for this group should be a right to have a direct payment, if appropriate. **Do you agree?**

People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs

Q6a. We are proposing that people who access wheelchair services whose posture and mobility needs impact their wider health and social care needs should have the right to a personal health budget or integrated personal budget. **Do you agree?**

Q6b. We are proposing that any right to a personal wheelchair budget should be a right to have a direct payment, if appropriate. **Do you agree?**

Proposals for other groups

Q7. Are there any other groups that you believe would benefit from having a 'right to have' a personal health budget and/or integrated personal budget?

Incorporating relevant disability benefits

Q8. Are there other funding streams that you believe would be beneficial to incorporate into integrated personal budgets?

Establishing a right to direct payment in NHS continuing healthcare funded home-care

Q9. We are proposing that people who are managing their NHS continuing healthcare funded home care as a personal health budget should have the right to a direct payment, if appropriate. **Do you agree?**

Equalities

Q10. Do you think any of the proposals set out in this document might have a beneficial or adverse impact on any equality issue- in particular, in relation to any of the groups who share a characteristic that is protected for the purpose of section 149 of the Equality Act 2010?

Chapter 5: The consultation process

77. This consultation will run from 6th April to 8th June.

78. You can find out more and respond to this consultation at:

<https://consultations.dh.gov.uk/commissioning-integration-and-transformation/extending-rights-to-personalised-budgets>

79. You can contact us via: phbrightstohave@dh.gsi.gov.uk

80. The consultation principles can be found on the Cabinet Office's website at:

<https://www.gov.uk/government/publications/consultation-principles-guidance>

81. The principles inform Government departments of the considerations that should be made during consultation. These include consideration of the subjects of consultation, the timing of consultation, making information useful and accessible, and transparency and feedback.

Comments on the consultation process itself

82. If you have concerns or comments which you would like to make relating specifically to the consultation process itself please contact: Consultations Coordinator, Department of Health and Social Care, 3E48, Quarry House, Leeds, LS2 7UE e-mail: consultations.coordinator@dh.gsi.gov.uk

83. Please do not send consultation responses to this address.

Confidentiality of information

84. We manage the information you provide in response to this consultation in accordance with the Department of Health And Social Care's Information Charter.

85. Information we receive, including personal information, may be published or disclosed in accordance with the access to information regimes (primarily the Freedom of Information

Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

- 86.** If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.
- 87.** The Department will process your personal data in accordance with the DPA and, in most circumstances, this will mean that your personal data will not be disclosed to third parties.

Summary of the consultation

- 88.** A summary of the response to this consultation will be made available before or alongside any further action, such as laying legislation before Parliament, and will be placed on the Consultations website.

Annex 1: Glossary

- **Children's Continuing Care-** A package of continuing care needed over an extended period of time for children or young people with continuing care needs that arise because of disability, accident or illness, which cannot be met by universal or specialist services alone. Children and young people's continuing care is likely to require services from health and local authority children's and young people's services.
- **Continuing Healthcare-** NHS continuing healthcare is the name given to a package of care that is arranged and funded solely by the NHS where the individual has a 'primary health need'.
- **Direct Payments-** One way of managing a personal health budget is a direct payment where money is given directly to an individual or their representative for the management of their NHS care. This option became legal on 1 August 2013 and is in addition to the pre-existing legal options for managing a personal health budget – by the NHS, or through a third party. Direct Payments for social care needs via local authorities have been available since 1997.
- **Integrated Care-** An organising principle for the care delivery with the aim of achieving improved patient care through better co-ordination of services.
- **Integrated Package of Care-** A combination of resources, planning, co-ordination and support designed to meet an individual's combined health and social care needs.
- **Integrated Personal Budgets-** where the budget includes funding from both the local authority and the NHS at a minimum, commonly with a single assessment, and single, integrated plan based on the individuals holistic needs.
- **Patient Experience-** A term used for individual and collective feedback. (1) Individual patient's feedback about their experiences of care or a service e.g. whether they understood the information they were given, their views on the cleanliness of the hospital where they were treated. (2) A combination of all the intelligence held about what patients experience in services, drawing on a range of sources including complaints, compliments, and reporting of incidents and serious incidents.
- **Personal Budgets-** Sums of money allocated by a local authority to service users to be spent on services to meet their care needs. They can be managed on behalf of users by the authority, or a third party, or given to users as direct payments: money to spend

themselves. They enable users to have more choice and control over the services they receive, tailoring their care to their personal circumstances and the outcomes they want to achieve.

- **Personalisation-** Personalisation means recognising people as individuals who have strengths and preferences and putting them at the centre of their own care and support. The traditional service-led approach has often meant that people have not been able to shape the kind of support they need, or receive the right kind of help. Personalised approaches involve enabling people to identify their own needs and make choices about how and when they are supported to live their lives.
- **Person- Centred Care-** Person-centred care takes patients and their families as the starting point of all decisions. Patients are equal partners with health professionals in planning, developing and assessing care to ensure it is most appropriate to their needs. It involves putting patients and their families at the heart of all decisions and requires a different kind of interaction between patients and healthcare professionals.
- **Personal Health Budgets-** A personal health budget is an amount of money to support an individual's identified healthcare and wellbeing needs, planned and agreed between them, or their representative, and their local NHS team. At the centre of a personal health budget is a care plan. The plan sets out the individual's health and wellbeing needs, the health outcomes they want to achieve, the amount of money in the budget and how they are going to spend it. Personal health budgets can be used to pay for a wide range of items and services, including therapies, personal care and equipment. This allows individuals to have more choice and control over the health services and care they receive. For more information please visit the [NHS England website](#).
- **Personalised Care Planning-** A personalised care plan is an agreement between a patient and their health and care professional(s) which links support for self-management and clinical care to help the person manage their health day-to-day. The process of care planning is based on a collaborative discussion about the goals the patient wants to work towards; the support services the patient wants and needs; who is in charge of providing these services; what the support services have agreed to do and when they will do it. It may also include plans for medication, diet and exercise. These discussions are recorded in a written document and should be regularly reviewed.