



Department  
of Health &  
Social Care



# **Extending the legal rights to have a personal health budget - equality analysis**

October 2019

# Introduction

In considering policy changes, Ministers must comply with the equality legislation, including their duties under the public sector equality duty (PSED) set out in section 149 of the Equality Act 2010 (the 2010 Act), the Secretary of State's general duties under [the National Health Service Act 2006 \(as amended by the Health and Social Care Act 2012, the '2012 act'\), and the Family Test.](#)

Under section 149 of the 2010 Act, Ministers must have due regard to the impact of decisions on those people with the protected characteristics, which are age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation. They must have due regard to the need to:

- Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the 2010 Act;
- Advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it; and
- Foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

It is important that any policy decision made is consistent with the provisions of the 2006 and 2010 Acts, as well as the new duties as to reducing health inequalities set out in the 2012 Act

This Equality Impact Assessment considers the impact of these proposals on persons within each of the protected characteristics set out in the 2010 Act as stated above, to ensure that we have considered the impact any new policies may have on the protected characteristics stated under section 149 of the 2010 Act.

# Equality Analysis

**Title: Extending the legal rights to have a personal health budget**

## **What are the intended outcomes of this work?**

Within the NHS and across social care, there is an ever-growing shift towards personalising care, including an increasing number of people choosing to take up personal health budgets. This is an amount of money, funded by a clinical commissioning group, to support the identified healthcare and wellbeing needs of an individual, which is planned and agreed between an individual, or their representative, and the relevant clinical commissioning group. This isn't new money, but a different way of spending health funding.

Personal health budgets will always remain optional, and individuals will always be able to continue to have their care commissioned by their clinical commissioning group should they choose to do so. Those who opt to receive a personal health budget may choose how they manage a budget, which can be done in three ways:

- i) Notional budget: the clinical commissioning group manages the budget and arranges care and support on behalf of the individual.
- ii) 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 provided. The third party will work in partnership with the individual and their family to ensure the agreed outcomes can be achieved, in line with the agreed care plan.
- iii) Direct payment: the budget is paid directly into a bank account, or an equivalent account, and the budget holder takes responsibility for purchasing care and support, in line with the agreed care plan.

These three options allow people to take as much or as little direct control as they require.

It is clear that people value being involved in the planning of their care, being able to make choices and personalise their support so it best meets their needs. The evidence suggests

that the 54,000 individuals with a personal health budget (as of 2018-2019 Q4) are more satisfied with their care and can explore more innovative approaches to meet their needs.<sup>1</sup>

The NHS Long Term Plan<sup>2</sup> and Universal Personalised Care<sup>3</sup> also sets out a key ambition to increase the number of personal health budget holders to 200,000 people over the next five years. The proposals detailed below form part of this ambition.

Currently, only adults in receipt of [NHS Continuing Healthcare](#), and children and young people in receipt of [continuing care](#), have the 'right to have' a personal health budget. This means clinical commissioning groups are legally obliged to provide personal health budgets to these groups, if clinically appropriate. Individuals who feel they may benefit from a personal health budget should talk to those who help them most often with their care - for example a care manager, or a GP. They will be able to offer help and advice with personal health budgets.

However, clinical commissioning groups are already allowed and encouraged to offer personal health budgets to anyone they feel may benefit.

From April to June 2018 the Department of Health and Social Care and NHS England consulted on proposals<sup>4</sup> to extend the right to have a personal health budget to the following groups:

1. People with ongoing social care needs, who also make regular and ongoing use of relevant NHS services.
2. 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.
3. People leaving the Armed Forces, who are eligible for ongoing NHS services.
4. People with a learning disability, autism or both, who are eligible for ongoing NHS care.
5. People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs.

For 2019/20, the extension of the legal rights to a personal health budget will be for people who access wheelchair services whose posture and mobility needs impact their wider

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<sup>1</sup> An independent evaluation of the personal health budget pilot programme. Available at:

<https://www.phbe.org.uk/>

<sup>2</sup> <https://www.longtermplan.nhs.uk/>

<sup>3</sup> <https://www.england.nhs.uk/wp-content/uploads/2019/01/universal-personalised-care.pdf>

<sup>4</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/780330/Extending\\_legal\\_rights\\_to\\_health\\_budgets\\_consultation\\_response.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/780330/Extending_legal_rights_to_health_budgets_consultation_response.pdf)

health and social care needs, and Section 117 aftercare users. This means that provided it's deemed clinically appropriate, people receiving section 117 aftercare or accessing wheelchair services will be legally entitled to a personal health budget. These two groups have also been chosen due to system readiness, as personal health budget activity is already happening in many areas for both groups, so this is a scaling-up of activity rather than a brand-new initiative.

The other identified groups need further development work with system leaders to build the offer. It should be emphasised that the other groups identified in this consultation will still be able to access a personal health budget if they meet the eligibility criteria set by their clinical commissioning group. We do not believe that any protected characteristic would be negatively impacted by these proposals. We demonstrate our consideration of impact on protected characteristics in detail in subsequent sections of this analysis.

### **Who will be affected?**

The most significant positive impact of this proposal will be on people who become eligible for a personal health budget, either through Section 117 funding or a personal wheelchair budget, this includes some of the most disadvantaged people in society. This policy will increase the take-up of personal health budgets, as clinical commissioning groups will be obligated to provide them to a larger population. This will result in greater personalisation of care and increased choice and control over a recipient's health care.

All people who are included within the protected characteristics of the Equality Act and are eligible for the legal right to a personal health budget for either Section 117 or a wheelchair budget, will be positively impacted by this proposal. This will also include carers who will benefit from more integrated services, allowing for more choice and a move away from a 'one size fits all' model.

We do not envisage any significant impact on the workforce. This is because all clinical commissioning groups are already implementing personal health budgets, so these proposals form an expansion of current activity rather than brand new initiatives.

The new legal rights will be applicable across all clinical commissioning groups and will eliminate the 'postcode lottery' for access to personal health budgets for those accessing wheelchair services or receiving section 117 aftercare. Furthermore, NHS England and NHS Improvement's Personalised Care Group is already supporting many clinical commissioning groups to implement personal health budgets. Learning, advice and guidance will continue to be delivered to local sites and NHS England and NHS Improvement will publish revised and updated guidance for clinical commissioning groups

later this year, encouraging a similar approach to personal health budget implementation/delivery across the country.

The legislation this equality analysis is attached to extends the legal rights to have a personal health budget to the following two groups:

- i) People eligible for Section 117 aftercare services
- ii) People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs.

## Evidence

### What evidence have you considered?

The consultation ran from 6th April 2018 until 8th June 2018. During the consultation, views were sought by:

- a) giving people the opportunity to respond to an online questionnaire;
- b) providing people with an email address and a postal address so that people could respond in different ways;
- c) publishing an easy read document which explained the proposed changes in a more accessible way;
- d) utilising social media to promote the consultation; and
- e) commissioning the Equality and Human Rights Commission to run focus groups to access overlooked groups.

There were 402 responses to the consultation, of which the clear majority (83.5% on average) agreed with each proposal.

We also used evidence from the independent evaluation of the Personal Health Budget pilot programme<sup>5</sup>.

National surveys<sup>6</sup> tell us that over 40% of people want to be more involved in decisions about their care. Personalisation, and personal health budgets/integrated personal

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<sup>5</sup> [www.phbe.org.uk](http://www.phbe.org.uk)

<sup>6</sup> CQC Patient Survey 2015

[https://www.cqc.org.uk/sites/default/files/20150822\\_ip15\\_statistical\\_release\\_corrected.pdf](https://www.cqc.org.uk/sites/default/files/20150822_ip15_statistical_release_corrected.pdf)

budgets provide an opportunity for that to occur if the individual chooses to do so. For example, in 2018, NHS England commissioned Quality Health to run an independent survey of people with a personal health budget. The findings<sup>7</sup> highlighted that:

89% said that their personalised care and support plan reflected what mattered to them, to some extent or completely.

86% said that they had achieved what they wanted as a result of their plan, to some extent or completely.

77% said they were likely or extremely likely to recommend a personal health budget/integrated personal budget to someone else.

Personal Health Budgets were independently evaluated by the Personal Social Research Unit at the University of Kent<sup>8</sup>. Personal health budgets also continue to be analysed by individual clinical commissioning groups and their commissioning support units.

## **Disability**

The legal definition of 'disabled' under the 2010 act is somebody who has a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities. As such, most people who will benefit from these proposals are considered disabled. Whilst only those eligible for wheelchairs or section 117 aftercare are going to become legally entitled to a personal health budget within this legislation, the Department and NHS England and NHS Improvement will continue to monitor groups we think may benefit from a personal health budget and consult on these in due course.

We do not consider there to be any negative impact on this protected characteristic, as a result of these proposals.

### *Section 117*

Personal health budgets fit well with the recovery-focused 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

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<sup>7</sup> Quality Health PHB Survey 2018:  
<https://www.quality-health.co.uk/surveys/phb>

<sup>8</sup> <https://www.phbe.org.uk/index-phbe.php>

means looking beyond medical treatment to consider wider issues such as housing, employment and relationships.

Many clinical commissioning groups across the country have already successfully implemented personal health budgets in mental health. In 2017-18, there were 1380 personal health budgets for adults with a primary mental health care need, and evidence<sup>9</sup> demonstrates a range of benefits, including providing the individual with a sense of empowerment, a better care related quality of life, and better psychological wellbeing.

We believe that personal health budgets could be beneficial to people eligible for 117 after-care. Section 117 after-care services include healthcare, social care, employment services, supported accommodation, and services to meet people's social, cultural and spiritual needs – if the needs arise from, or are related to, the person's mental health condition, and help reduce the risk of this deterioration. A personal health budget would provide individuals receiving after-care with a personalised approach, will empower them, and provide them with a supportive mechanism that can help them to re-establish meaningful lives in the community.

Offering Section 117 aftercare as a personal health budget will allow greater flexibility and control to people living with mental health conditions.

### **People who use Wheelchairs**

We are also building on the work to replace wheelchair vouchers with personal health budgets as the default. 50% of clinical commissioning groups are already working to replace the wheelchair voucher scheme with personal health budgets. Thus, by making personal wheelchair budgets the default model there will be full parity across all English regions, reducing the current postcode lottery.

This will allow greater choice and control for people who use wheelchairs. There is a wider programme of scoping work to link this to Disabled Facilities Grant (administered by local authorities to make home adaptations) to enable people to access a joint budget, resulting in more adaptable wheelchairs, thus negating the need for extensive house renovations.

### **Other Groups of Disabled People**

While these proposals focus primarily on extending the legal right to have a personal health budget to people who use wheelchairs and people eligible for Section 117 Aftercare, people with other impairments can still be offered a personal health budget if deemed clinically appropriate. Further work is required to progress the personal health

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<sup>9</sup> <https://www.phbe.org.uk/>



budget offer included in the consultation. This includes working with stakeholders to define the cohorts and impact assess the policy proposals.

Further work is required to test our proposals for the legal right to have a personal budget with the remaining groups in the consultation. Those who will not benefit from the explicit legal right to a personal health budget could be negatively impacted by this proposal, as they will not benefit the same legal right to a personal health budget as those receiving NHS Continuing Health Care, section 117 aftercare, or those who make use of wheelchairs. However, the Department and NHS England and NHS Improvement will continue to encourage clinical commissioning groups to expand their personal health budget offer to other groups who may benefit, provided it is clinically appropriate. We will continue to monitor groups which we believe will benefit from the legal right to a personal health budget and will consult on these in due course.

## **Sex**

### **Section 117**

Section 117 is only applicable to people who have been formally detained under Section 3 of the Mental Health Act. Analysis of detention rates by sex shows that rates were higher for males (88.9 per 100,000 population) than females (80.9 per 100,000 population) during 2017-18.<sup>10</sup> Caveats apply as these figures do not distinguish between detentions under Sections 2 and 3 of the Mental Health Act, so making definite judgements on the impact on women and men is difficult. However, as Section 117 also applies to people subject to the forensic sections of the Mental Health Act (s37, 45a, 47 and 48) It is likely that more men will experience a legal right to Section 117 than women.

This policy proposal will reduce health inequalities experienced by men as a result of their disproportionate detention rate. However, we do not envisage that men will be placed at a greater advantage in accessing a personal health budget over women as both men and women will have an equal right for a personal health budget for Section 117 aftercare.

### **People who use wheelchairs**

No data is available to suggest that either sex is disproportionately represented among wheelchair users, as such, we believe there to be a neutral impact on sex. Both men and

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<sup>10</sup> MHA statistics annual figs,2017/18 – NHS digital:  
<https://files.digital.nhs.uk/34/B224B3/ment-heal-act-stat-eng-2017-18-summ-rep.pdf>

women will be equally eligible for a personal health budget for a wheelchair under these proposals.

### **Sexual orientation** - *heterosexual, homosexual or bisexual*

There is no data available which suggests that any sexuality is disproportionately represented among the groups affected by this policy, and so the overall impact is neutral.

### **Race** - *ethnic groups, nationalities, Roma gypsies, Irish travellers, language barriers*

White people have the lowest detention rate of any broad ethnic group (73.4 per 100,000) under the Mental Health Act, followed by Asian or Asian British (84.3 per 100,000), Mixed (105.8 per 100,000), other ethnic groups (163.1) and Black or Black British (260.2)<sup>11</sup>. We can therefore assume that black and minority ethnic (BAME) people make up a disproportionate amount of those receiving section 117 aftercare, and so BAME people will disproportionately benefit from this proposal. However, all races and ethnic groups will be equally eligible for the legal right to personal health budgets.

### **Section 117**

People from BAME communities continue to experience poorer access to health and social care services than white British people<sup>12</sup>. The interim report of the Independent Review of the Mental Health Act 2018<sup>13</sup> highlights that people from black Caribbean, black African and mixed black ethnicity have a higher risk of being involuntarily detained, are more likely to encounter mental health services via the police and are more likely to be readmitted to a secure hospital. As Section 117 aftercare is designed for people with the most complex needs to support them post-discharge, we therefore expect this proposal to have a positive impact on black and minority ethnic people, offering greater choice, control and culturally appropriate services.

### **People accessing wheelchair services**

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<sup>11</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-act-statistics-annual-figures/2017-18-annual-figures>

<sup>12</sup> <https://bmjopen.bmj.com/content/6/11/e012337>

<sup>13</sup> <https://www.gov.uk/government/publications/modernising-the-mental-health-act-final-report-from-the-independent-review>

While there is a lack of data regarding wheelchair users by race, we do not envisage any impact from these proposals on people from black and minority ethnic communities.

However, the extension of the right to have a personal health budget will need to explicitly reference inclusion and accessibility for black and minority ethnic people and to tackle health inequalities. This will also include ensuring that information is available in accessible formats, language barriers are addressed (in line with NHS England and NHS Improvement's Accessible Information Standard) and the socio-economic factors that contribute to inequality are included in system planning. The Department and NHS England and NHS Improvement will ensure appropriate guidance and support is provided to clinical commissioning groups regarding these issues to help them develop their personal health budget offer locally to these groups.

### **Age - age ranges, old and young**

We consider there to be a neutral impact on this protected characteristic, as a result of these proposals.

#### **Section 117**

NHS Digital's national statistics on the Mental Health Act<sup>14</sup> highlight that:

- i) Amongst adults, detention rates tend to decline with age. However, these statistics do not differentiate between Sections 2 and 3 of the Mental Health Act. While Section 117 is not applicable to people detained under Section 2, we can assume that these trends apply across people regardless of the section of the Act they are detained under.
- ii) Detention rates for the 18 to 34 age group (121.8 per 100,000 population) were around a third higher than for those aged 50 to 64 (88.2 per 100,000 population).
- iii) Detention rates rose again for the 65+ age group (99.8 per 100,000 population). This is likely to be due to capacity issues in older people and a lack of ability to give informed consent to admission
- iv) Rates for young people aged 16 to 17 (65.0 per 100,000 population) were lower than for all adult age groups (most likely due to a higher number of informal admissions for this

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<sup>14</sup>MHA statistics annual figs,2017/18 – NHS digital:

<https://files.digital.nhs.uk/34/B224B3/ment-heal-act-stat-eng-2017-18-summ-rep.pdf>

age group, which would mean lower numbers of people aged 16 to 17 would be eligible for Section 117 Aftercare.

It is therefore likely that people aged between 18 and 34 and people aged over 65 will positively benefit from these proposals in greater numbers. However, these proposals do not change eligibility criteria, so adults of other ages will still be eligible for the legal right to have a personal health budget.

### **People accessing wheelchair services**

There are 1.2 million wheelchair users in the U.K<sup>15</sup>, 72% of which are aged 60 and over<sup>16</sup>. Personal wheelchair budgets will be available when an individual develops the need for a chair or requires a replacement to their existing chair. As already stated, 50% of clinical commissioning groups are already offering personal budgets for wheelchairs so this is an extension of an existing system. However, we can assume from the demographics that the majority will be older people, so services will need to be accessible to this group. This will therefore have a positive impact on not only all wheelchair users but older users in particular.

Some consultation responses highlighted a concern that older people and people with mental health conditions could find it harder to manage a personal health budget. However, as personal health budgets form part of the wider Personalised Care Programme people will be supported to make their own decisions. This includes how they manage their budget. The options listed on page 3 allow budget holders to take as much or as little direct control as they choose.

A national programme of workforce support and development is underway, led by NHS England and NHS Improvement, to support clinical commissioning groups to work with staff to change the nature of their conversations with people. This includes providing accessible information (written and verbal) to people in formats that best suits their needs.

### **Gender reassignment (including transgender) - transgender and transsexual people**

We do not have current data regarding the numbers of transgender people in receipt of a personal health budget, and there is no data available suggesting a correlation between

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<sup>15</sup> NHS England, Improving Wheelchair Services:  
<https://www.england.nhs.uk/wheelchair-services/>

<sup>16</sup> Disabled Living Foundation:  
<https://www.dlf.org.uk/content/key-facts>

gender reassignment and wheelchair usage or detention under the Mental Health Act 1983.

As such, we believe that the extension of the legal right to a personal health budgets to wheelchair and section 117 aftercare will have a neutral impact on this group.

**Religion or belief** - *people with different religions, beliefs or no belief*

There is no data available to suggest that any religion or faith are overrepresented in the population of people who would benefit from a personal health budget for wheelchairs or section 117. There is also no data to suggest that any religions or faiths are overrepresented in the groups which will not benefit from this proposal. The personal health budget programme forms part of the wider Personalisation strategy (included in NHS England's Long-Term Plan). This requires health and social care staff to take a 'whole life approach' when planning with someone using services, taking into their account their wishes, requirements and faith-based needs.

**Pregnancy and maternity** - *working arrangements, part time working, infant caring responsibilities*

There is a lack of data available which suggests that pregnancy and maternity are affected either way by this policy proposal.

**Other identified groups**

**Veterans**

Around 2,500 people are medically discharged from the armed services each year, some of whom have ongoing NHS support needs. For these individuals, personal health budgets could be a way of providing them with more choice and control over how their health and care needs are met. Work is ongoing with the Ministry of Defence to explore this option further and identify which groups of veterans would benefit the most.

**People on low incomes**

Some respondents to the consultation felt that the extension of the legal right to a personal health budget could result in wealthier people experiencing a greater advantage by being able to 'top-up' their budget with their own contributions. However, personal contributions are not allowed in health funding, thus removing this imbalance. The personal health budget should meet all identified health and well-being needs. The one exception to this is personal wheelchair budgets. These allow personal contributions. Therefore, this could lead to a discrepancy between people depending on their assets and incomes. However, the wheelchair voucher scheme has allowed personal contributions since 1986, and so we don't expect any additional impact on inequalities.

The proposal to extend the legal right to have a personal wheelchair budget further opens up the opportunity for more people to combine funding streams to be included in an integrated personal budget. For example, in some cases a contribution can be made via adult social care where a different specification of wheelchair can meet the identified health and social care needs of an individual; something which traditionally can be more difficult to achieve. These integrated budgets enable different and sometimes higher specification of chairs to be provided which can reduce the needs for personal carers and / or costly adaptations to a person's home. They can also reduce the need for a personal contribution, save money for services and promote greater personal independence.

**Carers** - Consider and detail (including the source of any evidence) on part-time working, shift-patterns, general caring responsibilities.

The consultation was largely in favour of the extension of personal health budgets, although some respondents felt that this could result in a greater burden being placed on carers. Specifically, the administration of the budget itself. However, the Carers Action Plan outlines that more personalised and integrated commissioning offers an opportunity to develop a more person-centred and integrated approach when identifying, assessing, and supporting the health and wellbeing needs of both the individual, and any carers involved.<sup>17</sup>

More personalised and integrated commissioning offers an opportunity to develop a more person-centred and integrated approach when identifying, assessing, and supporting the health and wellbeing needs of both the individual, and any carers involved. The outcome of this joint assessment can then be incorporated into a joined-up plan, to make sure that the needs of both the individual and carer are met. Personalised approaches can also

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<sup>17</sup>[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/713781/carers-action-plan-2018-2020.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf)

deliver transformational change by working with carers as expert care partners; fundamental in the planning, design and shaping of services.<sup>18</sup>

Further, personal health budgets can be delivered in three ways, as a notional budget, a third-party budget or direct payment. This flexibility allows carers to take as much or as little responsibility for the management of the care plan as they wish. In addition to this, personal health budgets will always remain optional, and no carer will be forced to take on more responsibility than they wish to do so.

### **The Family Test:**

- 1. What kind of impact might this policy have on family formation?*
- 2. What kind of impact will the policy have on families going through key transitions such as becoming parents, getting married, fostering or adopting, bereavement, redundancy, new caring responsibilities or the onset of a long-term health condition?*
- 3. What impacts will the policy have on all family members' ability to play a full role in family life, including with respect to parenting and other caring responsibilities?*
- 4. How does the policy impact families before, during and after couple separation?*
- 5. How does the policy impact those families most at risk of deterioration of relationship quality and breakdown?*

We consider this policy to have neutral impact on family formation, and on families before, during and after couple separation.

This policy will positively impact those who become eligible for a personal health budget. The greater choice and flexibility offered by personal health budgets in comparison to standard NHS commissioned care allows those going through key transitions to choose, in co-operation with their local NHS team, how they can best be supported. This policy can improve family relations at the onset of a long-term health condition, as it allows them to tailor their care, including around their family, allowing those receiving care and their families to play a full role in family life.

We received consultation responses expressing concern in relation to the perceived extra burden on both formal and informal carers resulting from the management of personal health budgets. As many informal carers are family members, this may have a negative

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<sup>18</sup> Department of Health and Social Care, Carers Action Plan 2018-20, Supporting Carers Today [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/713781/carers-action-plan-2018-2020.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf)

impact on families as the informal carer may have to deal with the administration of a personal health budget. However, personal health budgets can be delivered in 3 ways, which allow carers and those receiving care to take on as much or as little responsibility for the management of the budget as they would like. Personal health budgets will always remain optional, and local NHS teams will continue to commission care in the usual way for those who would not like a personal health budget.

People with long-term physical and mental health issues are among those at risk of deterioration of relationship quality and breakdown. This policy will positively impact those with long-term physical and mental illnesses which result in the need for a wheelchair, or section 117 aftercare.

## Engagement and involvement

### **How have you engaged stakeholders in gathering evidence or testing the evidence available?**

As referenced above, a national consultation exercise was carried out in 2018, which involved:

1. giving people the opportunity to respond to an online questionnaire;
2. providing people with an email address and a postal address so that people could respond in different ways;
3. publishing an easy read document which explained the proposed changes in a more accessible way;
4. utilising social media to promote the consultation; and
5. commissioning the Equality and Human Rights Commission to run focus groups to enable access to hard to reach groups.

The proposals also build on the long-term work to develop and roll-out personal health budgets over recent years, which have been independently evaluated.<sup>19</sup>

Our stakeholders are constantly engaging with the Department and NHS England and NHS Improvement, and are heavily involved with the development of personalisation

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<sup>19</sup> An independent evaluation of the personal health budget pilot programme. Available at: <https://www.phbe.org.uk/>



policy. This engagement will continue as and when we legislate for the extension of the legal rights to a personal health budgets to other groups.

### **How have you engaged stakeholders in testing the policy or programme proposals?**

The consultation received 402 responses. The majority were submitted by individuals, including those who use health and care services, both formal and informal carers, NHS staff and the wider health and care workforce. A range of organisations also formally responded. All responses received were analysed jointly by the Department of Health and Social Care, and NHS England.

Analysis of the consultation demonstrated broad support for our proposals with an average of 83.5% agreeing with each proposal. On average 12.2% of people did not agree with the proposals we made, while on average 4.3% of people chose not to respond to individual questions. When removing those who did not answer each question, the average rate of 'agreement' to extending legal rights to have personal health budgets and integrated budgets for each group identified, was 87%.

## **Summary of analysis**

### **Considering the evidence and engagement activity you listed above, please summarise the impact of your work.**

Overall these proposals will provide a positive benefit to all the protected characteristics who receive the legal right to a personal health budget. We will also continue to encourage clinical commissioning groups to expand their personal health budget offer to those who will benefit from personalised care and support plans, regardless of legislative rights.

The vast majority will be disabled people or people living with one or more long-term conditions. These proposals will offer greater flexibility, choice and control for recipients. However, we are aware there are key groups who experience substantial disadvantage, in particular, people from black and minority ethnic communities and people with severe and enduring mental health conditions. We also acknowledge that there is a current lack of detailed evidence about the experiences of transgender, gay, lesbian and bisexual people.

Where there is a lack of evidence, we will continue to explore options with our partners and stakeholders to address these.

### **Eliminate discrimination, harassment and victimisation**

The aim of this programme is to extend the legal right to a personal health budget to wider groups of people who would benefit. The groups identified include some of those which experience the greatest disadvantage and health inequalities. To eliminate discrimination, harassment and victimisation ongoing partnership working will take place with key stakeholders to ensure that direct or indirect discrimination is prevented, and that service provision is equal and inclusive.

The programme will directly benefit disabled people and those living with long-term conditions. We are aware that many of these people will also fall under other protected characteristics, so services will need to be supported to provide fair and accessible services.

### **Advance equality of opportunity**

These proposals are designed to support people who would benefit from a personal health budget to lead more independent lives and to exercise choice and control over their support. Similarly, they also require a system change in how services and staff with engage with people who use services. This is supported by the wider work of DHSC's and NHS England's Personalised Care Programmes, which aim to develop shared decision making between clinicians and services users and shift the conversations to focus on what matters to people, rather than focusing on just their clinical needs. Both programmes also aim to build community capacity and increase the opportunities for universal services – thus allowing people who have a personal health budget to live more inclusive lives in their local areas.

### **Promote good relations between groups**

Primarily, these proposals will support disabled people (regardless of impairment) to live more independently and be more visible in society. Visibility is essential to promote

equality and good relations between groups. Further, disabled people will also be able to exercise greater choice and control over the support they receive.

### **What is the overall impact?**

The overall impact of these proposals is positive. They allow greater numbers of people to have the legal right to exercise choice and control over their support requirements. personal health budgets are designed to be flexible and person-centred.

However, ongoing work is required to promote and embed these principles within services and support staff to work as equal partners with people who use services. We will build upon the success to date of rolling out personal health budgets to over 54,000 people as well as working with key stakeholders to monitor the programme and identify and resolve barriers and issues.

### **Addressing the impact on equalities** - *Give an outline of what broad action you or any other bodies are taking to address any inequalities identified through the evidence*

Provision is already in place for personal health budgets to be delivered in 3 different ways, which allow as much or as little involvement as the budget holder chooses. Personal health budgets will always remain optional.

## **Action planning for improvements**

### **Give an outline of your next steps based on the challenges and opportunities you have identified.**

NHS England and NHS Improvement will continue to work with clinical commissioning groups to support them to have appropriate data collections in place to identify the groups either most benefitting from personal health budgets, and those who are not. NHS England is also reviewing the existing national data collection and considering the level of demographic data that can be collected at a national level.

From July 2018, clinical commissioning groups in England have been required to report the mandatory personal health budget data collection to NHS England, through NHS Digital, quarterly. This allows us to see the take-up of personal health budgets across the following groups, by clinical commissioning group:

1. Cumulative children
2. Children receiving continuing health care
3. Children and young people with education, health and care plans
4. Children whose primary need is learning disabilities and/or autism
5. Other children
6. Total number of adults
7. Adults receiving continuing health care
8. Adults receiving joint-funded packages
9. Adults whose primary need is a learning disability and/or autism
10. Adults who have a primary mental health care need
11. Adults not included in the above 4 sub categories

The mandatory data collection also splits the above groups further, showing the method by which the personal budget is delivered. This data will allow the Department and NHS England to monitor the take up of personal health budgets across the country and monitor other groups which we believe may benefit from the extension of the legal right to a personal health budget.

## For the record

**Name of person who carried out this assessment:** Sam Chidlow (Department of Health and Social Care), Gareth Owen (Department of Health and Social Care) and Tom Raines (NHS England and NHS Improvement)

**Date assessment completed:** 11/10/2019

**Name of responsible Director:** Rosamond Roughton

**Date assessment was signed:** 15/10/2019