



## Consultation response

### **Modernising support for independent living: the health and disability green paper**

**Department for Work and Pensions**

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Contact: [policy@ageuk.org.uk](mailto:policy@ageuk.org.uk)

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Age UK  
7th Floor, One America Square  
17 Crosswall  
London  
EC3N 2LB  
T 0800 169 87 87 F 020 3033 1000  
E [policy@ageuk.org.uk](mailto:policy@ageuk.org.uk)  
[www.ageuk.org.uk](http://www.ageuk.org.uk)

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## **About this consultation**

The consultation focuses on Personal Independence Payment (PIP) which it describes as ‘the primary extra costs benefit that provides support to adults of working age with the additional costs of having a disability or long-term health condition’. More broadly, the Green Paper considers whether there should be fundamental changes to the way support is provided to disabled people and people with health conditions.

## **About Age UK**

Age UK is a national charity that works with a network of partners, including Age Scotland, Age Cymru, Age NI and around 120 local Age UKs across England, to help everyone make the most of later life, whatever their circumstances. In the UK, the Charity helps millions of older people each year by providing advice and support. It also researches and campaigns on the issues that matter most to older people.

## **Key points and recommendations**

- Age UK is concerned that debate about reforming PIP is very worrying for the many people, including some over State Pension age, who currently rely on this important payment.
- We believe the focus should be on addressing the causes behind the increase in people reporting a disability or health conditions and ensuring that NHS and care services provide the support that people need and can intervene at an early stage.
- While there are problems with the current assessment, and there is a good case for reviewing it and considering at how it could be improved, we do not support the idea of replacing it with one based on medical evidence.
- The extra costs of disability are many and varied. We believe it makes sense for individuals and those administering the scheme to continue to have a system based on an assessment which acts as a proxy for the level of disability that is likely to lead to a range of additional costs, rather than try to calculate actual costs.
- Cash payments are highly valued as they enable disabled people to make their own decisions about the best way to meet their needs. They provide choice and control and help promote independence. We would be very concerned about any move to systems such as approved lists in catalogues, vouchers, or receipt-based payments as this would take away claimants’ autonomy and choice and introduce complicated claim processes.
- Changes to PIP could also affect passported support including entitlement to benefits for carers and access to the Motability scheme. In Age UK’s view there are

no obvious, or straightforward alternative ways to determine caring and disability status.

## **Introduction**

Age UK welcomes the opportunity to respond to this consultation. Although the majority of people who contact Age UK national or locally to ask about financial support are over State Pension age, we also hear from many people who are under State Pension age and may need help with disability costs, or who claimed and were awarded PIP before reaching State Pension age. We therefore know how important PIP is to many older people. In this response we focus on some of the broad themes raised by the consultation rather than attempt to respond to all the questions.

## **Impact for people already receiving PIP including those over State Pension age**

The consultation paper refers to 2.6 million people of working age being in receipt of PIP and Disability Living Allowance (DLA) and states that it 'will focus on the main non-means tested benefit paid to adults of working age with disabilities and health conditions – Personal Independence Payment.' However, PIP is not just paid to people of working age. In England and Wales there are over 500,000 people over State Pension age who are entitled to PIP<sup>i</sup> because they were entitled, and made a claim, before reaching State Pension age. It is not clear how their needs are being considered in any reforms. We are concerned that proposals to reform PIP are likely to be very concerning to people of all ages who currently rely on the payment. For example, Age UK was contacted by a man in his 70s who had heard that payments might be replaced or stopped. His 75 year old wife has received PIP for several years and is 'very worried' about how she might be affected especially as she had a very stressful experience when she had to move from DLA to PIP. He said 'I am sure many PIP recipients are as worried as us.'

We are reassured to read that people who have care needs which arise after State Pension age will be able to claim Attendance Allowance as now. Attendance Allowance is a hugely important benefit to many disabled older people, and we know that there would be strong opposition if a future government wanted to limit the support it provides or change it from a being cash entitlement.

## **The reasons for reform**

The Green Paper states that since PIP was introduced a decade ago, the nature of health and disability has changed with more people of working age reporting a disability or health condition and, in particular, a rise in the numbers receiving PIP due to mental health conditions. The consultation paper expresses concern about the increasing numbers of people receiving PIP, and the cost of this, and wants to ensure that support is focussed where it is most needed.

Age UK is concerned that the increase in disability and ill health is, in part, due to problems accessing support. We have been looking at health and access to services through regular polling and surveys. Our most recent report shows that across the age range from 50 to over 100 years, people were finding it difficult to access care and health services including primary care services such as GPs and dentists.<sup>ii</sup> It found that in some cases health problems that could have been quickly and easily resolved have worsened through long waits for appointments and treatment. Our report comments that for those of working age the problems in accessing appointments, referrals and treatment have had an impact on their ability to maintain good health, to remain in work and to care for others.

We are unsurprised that more people are claiming PIP due to mental health conditions as our polling and surveys have shown this is a major concern leading us to produce a separate report focussing specifically on this. We found that a significant proportion of people aged 50-59 are struggling in their day-to-day lives, with knock on effects on their mental health. In some areas, people in this age cohort are reporting even poorer wellbeing compared to those in older age groups. The report concludes that some of these issues could be alleviated by improved access to health and care services. Others could be improved through increased availability and easier access to social support and community-based activities.<sup>iii</sup>

In respect of the PIP reforms, Age UK is concerned that reducing costs is the primary driver. We agree that systems need to be fair for taxpayers (many of whom are also disabled people and benefit claimants) but we believe the best way to reduce the numbers needing to claim support is to tackle the root cause – that is the rise in people needing help due to increased numbers with disabilities and health conditions.

In our view, rather than reducing support from benefits, the best approach is to ensure that the NHS and care services are providing the support that people need, and interventions are made at an early stage. In this way, going forward, fewer people may need to claim financial entitlements. It is also important to note that any major changes to benefits are themselves costly to develop and introduce, as well as being extremely disruptive to those affected.

## **The PIP Assessment**

The Green Paper asks questions about whether the assessment should move from one based on functional impact to one where there is more emphasis on the condition and the diagnosis of a medical evidence.

While there are problems with the current assessment, and there is a good case for reviewing it and considering at how it could be improved, we do not support the idea of replacing it with one based on medical evidence.

The same condition or diagnosis may affect people in a wide range of different ways and medical and care professionals do not necessarily have detailed knowledge about how someone's condition affects their day-to-day life and the financial impact this has. There could therefore be an increased risk that decisions would be inconsistent between people with similar needs. We would also be concerned about the extra workload this could bring for health professionals and the difficulties claimants would face trying to get the right medical evidence.

However, there could be merit in exploring whether there are some specific conditions that have a severe impact on peoples' lives where it may be possible to base entitlement on a diagnosis without a full assessment. This could be in line with the Special Rules for people who are terminally ill and apply to situations where people have conditions leading to serious impairments which are unlikely to improve, and often very likely to deteriorate, but where people would not qualify under the current Special Rules. However, we would see such an approach applying in very limited circumstances and, in general, we believe the current functional system should remain at present.

## **The support provided**

The Green Paper asks how extra costs are defined and whether support should be provided in alternative ways. As the paper sets out, disabled people face a wide variety of extra costs. These can vary from person to person and in some cases may be much higher than the maximum payments of PIP. However, we believe it would be difficult to introduce a fair and straightforward way to assess the actual costs that individuals face due to disability or poor health. People would find it very hard to calculate their additional costs - for example someone may know their energy bill is very high because they have a health condition causing limited mobility, but not how much of their bill is due to the extra heating costs they need. And importantly, people can only spend what they have on disability costs - if their finances are limited this may be less than they need to spend. Instead, we feel it makes sense to continue with the current system that uses the assessment of daily living and mobility as a proxy for a level of disability that is very likely to result in a range of extra costs.

One area highlighted in the consultation is the cost of aids and adaptations which it suggests could be met by non-cash alternatives or through provision from other services. However, while for example, it is possible to borrow some aids from the NHS, someone requiring this support will often have other costs associated with their disability or health condition. A walking aid may help someone with limited mobility move around more easily at home, but they are still likely to have other costs such as transport outside the home and the need for a warmer home.

Extra costs benefits such as PIP and Attendance Allowance are highly valued because they provide people with choice and control and help promote independence. They enable disabled people to make their own decisions about the best way to meet their needs. Costs will vary but most people with conditions severe enough to qualify for PIP are likely to face considerable additional costs. For example, the Green Paper highlights the increased number of people with mental health conditions. People receiving PIP due to anxiety or depression may not be able to use public transport so have to rely on taxis, may not have the motivation to prepare meals or look after themselves so will need to depend on others to carry out jobs, or due to isolation may be unable to access cheaper services so find day-to-day life more expensive.

We would be very concerned about any move away from cash payments to systems such as approved lists in catalogues, vouchers, or receipt-based payments. Such approaches would take away claimants' autonomy and choice, and introduce complicated claim processes.

The Green Paper also highlights the impact that replacing PIP could have on passported support. This includes help with mobility costs through the Motability and Blue Badge schemes and providing support for carers through Carer's Allowance which is linked to the person they care for receiving benefits such as the PIP daily living component. The paper asks what alternative ways could be used to determine disability status. However, in Age UK's view there are no obvious, or straight forward alternatives. For carers, even under the current system, financial support provided is very limited and can be complicated, as highlighted by the recent media reports of carers having to repay Carer's Allowance because they unwittingly earned more than the earnings level. Any system requiring a new way of assessing if someone should qualify for support as a carer is likely to add to the pressures carers are already face, risks people receiving even more limited support, and would also increase the administrative burden on those running schemes.

## Aligning Support

Chapter 4 asks whether support offered by PIP should be aligned with existing health care and local authority provision.

Age UK believes it is important that the different services and support should be coordinated and there may be a case for closer working – for example ensuring people applying for benefits are always made aware of, and signposted to, relevant services, and vice versa. However, we do not see it as a matter of people receiving either a financial benefit or services. Often these fulfil very different purposes and are complementary while in some cases financial support enables people to live independently and can limit their need to use care and other services.

Many of the extra costs people use their PIP for are ongoing costs that are unlikely to be met by other services or one-off items. These include, extra heating, higher laundry costs, the cost of charging equipment, special diets, higher insurance and help with tasks at home such as cleaning and gardening.

We also want to emphasise that currently health and care services are under great pressure. Services vary across the country and many people do not receive the services they need. In contrast, it is very reassuring for disabled people to know that PIP is an entitlement based on the criteria set out, not affected by local pressures or the budget constraints in any particular year.

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<sup>i</sup> <https://stat-xplore.dwp.gov.uk>

<sup>ii</sup> <https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/its-a-struggle-to-be-seen/struggle-to-be-seen>

<sup>iii</sup> <https://www.ageuk.org.uk/globalassets/age-uk/documents/professionals/mental-health-hub/i-just-feel-that-no-one-cares-march-2024.pdf>