

# Consultation Response

## Age UK's response to the Personal Independence Payment Independent Review

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## About this consultation

The DWP appointed Paul Gray to undertake an independent review of how Personal Independence Payment (PIP) is working. The call for evidence is aimed at individuals and organisations with information about the PIP assessment and Disability Living Allowance (DLA) reassessment process.

## About Age UK

Age UK supports people in later life and our information and advice services reach around 5 million people a year. Nationally we provide information through written guides and web based materials, and run a telephone, email and postal advice service. There are nearly 170 local Age UK organisations in England and their information and advice services can also provide direct face to face information and support including help with benefit claims.

Although most people contacting Age UK at a local or national level want information relating to people aged 65 and over, we also receive enquiries from, and provide support to, people in their 50s and early 60s. For example in the first four months of this financial year at a national level we had 920 requests for written or web based information about PIP (compared to 6700 on Attendance Allowance) while local Age UKs dealt with 2350 enquiries about PIP in the first quarter of this year.

## Our response

This response draws on enquiries we have received at a national level and the responses from local Age UK partners who we asked to tell us about their experiences with helping people claim PIP. Local Age UKs may also choose to feed comments directly to the review. We work closely with Age Cymru and Age Scotland who support this response and have fed in comments.

Age UK is a member of the Disability Benefits Consortium which has submitted a more detailed response drawing on the experiences of a wide individuals and organisations.

## Key points and recommendations

Most of the feedback we have received relates to delays. This is causing stress and financial hardship and is having a knock on effect for entitlements to other benefits and support. As steps to improve the system we recommend:

- The first part of the PIP claim should be simplified and the main aim should be to register the start of the claim.
- People should not be referred for a face to face assessment if sufficient information is provided from other sources to decide the claim – unless the claimant chooses to have an assessment.
- Any further roll out of PIP should be delayed until the system is functioning properly.
- People should receive regular updates on the progress of their claim.
- DWP and the assessment providers must ensure they have sufficient capacity to meet demand.
- There should be a system of interim payments – for example this could cover those cases where there is hardship and entitlement appears likely.
- Delays should not result in loss of linked means-tested benefits or other support because of backdating rules.
- When a DLA claimant reports a change of circumstances that leads to PIP being paid at a higher level this should be fully backdated.
- Anyone in receipt of DLA over the age of 65 at the start of the managed reassessment period should not be required to undertake a reassessment, unless they choose to claim PIP.

## Claimant experience of the claim process

For most people the process involves an initial claim, which is usually by telephone, followed by the completion of a detailed form to explain how their disability affects them, and then a face to face consultation. This is therefore a lengthy and complicated process.

Even at the first stage (PIP1) people are required to supply a considerable amount of information and the sample clerical form on gov.uk is 18 pages long. We are concerned that some people may be deterred from taking forward a claim at this stage.

We do not have any specific information on how people with different health conditions are coping with the main form (PIP2). However where local advisers have commented on completing this on behalf of clients the feedback we have had is that this is relatively straightforward and some felt it was an improvement over DLA forms. On the other hand it can be very challenging for many disabled people to make a claim if they attempt to do this alone. One woman said she found the claim form 'very daunting' and repetitive and felt many people would give up if they did not know where to go for support. She had only been able to complete it with help from her daughter.

In conclusion we believe that the claim process should be reviewed in order to make it as straightforward as possible. A first step is to reduce the information needed when making the initial claim.

#### Recommendation

*The first part of the PIP claim should be simplified and the main aim should be to register the start of the claim.*

#### Face to face consultations

The main concern we have been told about linked to assessments is around delays in getting appointments. We have had limited feedback about the experience of face to face consultations although a couple of advisers remarked that the feedback they had received suggested it was better than the Employment and Support Allowance process.

However in general people are often worried about having a face to face assessment and travelling to a centre can be difficult. These can be some distance from where people live – for example Age UK advisers have reported that some people have to travel to another town for their appointment, while in rural areas public transport is often limited. People can be expected to travel for up to 90 minutes each way for an assessment. This can be tiring and demanding for disabled people but sometimes they are not aware that they can ask for a home visit or worry that doing so would delay the claim further.

#### Recommendation

*People should not be referred for a face to face assessment if sufficient information is provided from other sources to decide the claim – unless the claimant chooses to have an assessment.*

## Delays

The main and frequent complaint from advisers and individuals is about the long delays. The Government has recognised that there are problems and the Secretary of State has *said* 'By the autumn, no one will be waiting longer than six months, and before the end of the year, no one will be waiting for more than 16 weeks, which brings things back into line with where we were expecting them to be.'

However currently the recorded message on the PIP telephone line still says it could take '26 weeks or longer for an assessment' once the PIP2 claim form has been received. Our feedback suggests that waiting 9 months is not uncommon. Delays occur at all stages – receiving forms, getting a date for an assessment and the time taken for a decision.

In addition to the financial impact, the process of claiming a benefit, waiting for an assessment, and not knowing what will happen next, can be very stressful. People talk about making many phone calls to chase up claims and sometimes being passed between the DWP and assessment providers or told contradictory things. One woman who checked the progress of a claim made two months earlier was told the form had not been sent in time and she had to apply again. She was sent a new claim form but on checking again was told her earlier claim was already registered.

## Recommendations

*Any further roll out of PIP should be delayed until the system is functioning properly.*

*People should receive regular updates on the progress of their claim.*

*DWP and the assessment providers must ensure they have sufficient capacity to meet demand.*

## Financial impact of waiting for income from PIP and passported benefits

The delays are having a serious financial impact on many disabled people particularly if there has been a recent onset, or worsening, of health problems which has affected their ability to work or resulted in a large increase in costs. People may have to do without vital support or reluctantly ask family members or charities for help.

*One woman whose husband had a stroke emailed Age UK 5 months after he had made an application to say he was still waiting for an assessment and had received no income*

*since his stroke. They have been ringing every week for an update but the DWP were unable to suggest how much longer it would be. She asked 'How can someone be expected to go without income for so long!?'*

Without the additional income it may not be possible to cover the extra costs arising from disability. For example an Age UK adviser noted that a client with severe mobility and care needs who had been waiting for a decision for 7 months was missing out on a range of services including chiropody, help from a care assistant, a personal alarm, and transport because he could not pay for these from his current income.

*A woman who is very incapacitated by heart failure and other health problems applied in October 2013 but by the end of August 2014, despite many telephone calls, had still not received an appointment for a medical assessment. Her husband stopped work to care for her and they were receiving Pension Credit but were having difficulty meeting costs, including their outstanding mortgage and adaptations needed due to her health problems.*

PIP can act as a passport for other benefits so these may also be delayed.

*A man who was taken seriously ill and spent over two months in hospital claimed PIP and was told he needs an assessment and that it will be several weeks before he receives a decision. His partner, who is his full-time carer cannot understand why it takes so long when the situation is so clear. She is also concerned about the impact on other support such as her ability to receive Carer's Allowance and access to a blue badge. He is also waiting to hear about a claim for Employment and Support Allowance.*

*A self-employed man with multiple health problems which mean he has very limited mobility wants to continue working but requires a car to do so. He has applied for PIP but been told it will take 26 weeks to process. His car needs renewing but until he hears whether he can receive PIP mobility component he is not able to lease a car through the Motability scheme.*

PIP and Carer's Allowance can also provide entitlement to means-tested support, or higher levels of benefit, and this much needed extra support is also delayed.

## Recommendation

*There should be a system of interim payments – for example this could cover those cases where there is hardship and entitlement appears likely.*

## Backdating

If someone not currently receiving DLA is awarded PIP then it will be backdated to the date of claim. However passported support, such as means-tested benefits linked to receipt of PIP, are not necessarily backdated to the date of entitlement to PIP.

We are also very concerned that PIP is not fully backdated when a DLA claimant has a reassessment on the grounds that their condition has worsened and is subsequently awarded PIP at a higher rate. In this case entitlement to the lower level of DLA continues until the decision on PIP is made. Once this happens, PIP only starts to be paid 4 weeks after the next DLA payment is due. People can lose many months of extra benefit needed to meet higher needs as a result of this process.

*A man in his 60s receiving DLA applied for PIP because his condition had worsened. He was told by the DWP that any increased award would be fully backdated. However he has now been told that this will not be the case. His PIP, which is nearly £60 a week higher than his DLA, will only start 6 months after his application.*

Recommendations:

*Delays should not result in loss of linked means-tested benefits or other support because of backdating rules.*

*When a DLA claimant reports a change of circumstances that leads to PIP being paid at a higher level this should be fully backed.*

## Impact on advice agencies

The delays are also having a negative effect on advice services. One Age UK adviser explained that they sometimes make an appointment to help a client with the claim form only to have to cancel this and reschedule because it had taken so long for the forms to be sent out. And once the claim is made advisers spend time chasing up claims and supporting clients waiting for decisions. In some cases advisers have to approach MPs to get cases resolved. Many information and advice services are already hard pressed and any additional time following up PIP claims diverts resources from helping other clients.

## Reassessment of DLA claimants over the age of 65

We would like to raise the issue of managed reassessment of older DLA claimants. This was originally due to begin during 2013 but this has now been delayed until October 2015. We understand the need to change the timetable. However as a result, although PIP is a

benefit targeted at people of 'working age', some people who will be subject to reassessment will be considerably older than 65 because all DLA claimants under the age of 65 on 8 April 2013 are due for reassessment. Those who qualify for the DLA mobility component but are turned down for PIP due to the different criteria may subsequently find their condition deteriorates in the future but by then they will be unable to claim again because they are over 65. Others may be refused the PIP daily living component but will then be able to claim Attendance Allowance. They could go through two assessments and end up receiving an allowance paid at the same level and based on the same criteria as their previous DLA award. This would be stressful for the individual and provide unnecessary additional workload for the DWP.

Age UK has been contacted by people who are over the age of 65 and are unclear what the situation is or are concerned about the possibility of reassessment.

*A woman with Parkinson's who reached turned 65 in early 2014 contacted Age UK concerned about what would happen to her DLA. She has a car through Motability so continuing entitlement is very important to her.*

*A woman who reached 65 in July 2013 told us she had received a 13 page letter about DLA which she did not understand and wanted to know why she will have to apply for PIP in the future when she thought her DLA award was 'for life'?*

The woman in the last example will be expected to claim a new working age benefit in October 2015 or later - even though she will have reached state pension age more than 7 years before.

#### Recommendation

*Anyone in receipt of DLA over the age of 65 at the start of the managed reassessment period should not be required to undertake a reassessment, unless they choose to claim PIP.*