

Response to the Social Security Committee's call for evidence

August 2017



Scotland

At Leonard Cheshire Disability, we work for a society in which every person is equally valued. We believe that disabled people should have the freedom to live their lives the way they choose - with the opportunity and support to live independently, to contribute economically, and to participate fully in society.

1. As control of a number of existing social security benefits is devolved to the Scottish Government, the draft Social Security (Scotland) Bill provides a framework for the creation of a new social security system. This provides an opportunity to create a system that is able to meet the needs of people who rely on it, specifically disabled people in Scotland, enabling independence through security.
2. We welcome the opportunity to respond to the Social Security Committee's call for evidence, focusing our response primarily on Personal Independence Payment (PIP). We have based our response on the following evidence:
 - Disability Benefits Consortium (DBC) PIP Monitoring Survey (2013), which was used to underpin the DBC response to the Independent Review of Personal Independence Payment (PIP).
 - A PIP Survey for Scotland was used to gather disabled people's experiences of applying for PIP in Scotland. We conducted the survey in July and August 2017.
3. Our recommendations include:
 - Make the initial part of the PIP claim into a one stage process instead of a two part claim, and make the initial telephone call optional. This will make the initial application stage simpler.
 - Ensure disabled people are given the opportunity to fully explain the impact of their condition on their ability to carry out daily activities, in both the PIP claim form and in the face-to-face assessment.
 - Improve communication with claimants throughout the entire claim process in order to ensure people have the right information at the right time. Claimants should have one main person who they can contact at any point with any questions regarding their claim.

- Ensure the new social security system takes into account the extra costs associated with being disabled. We recommend the Scottish Government and Social Security Committee take the opportunity to fully explore the extra costs disabled people face when re-designing how PIP is delivered in Scotland.

The Bill proposes that the Scottish social security system will be based on seven principles.

Q. What are your views on these principles and this approach? Please explain your answer

4. Leonard Cheshire Disability welcomes the principles that the Scottish Government have outlined in this Bill. The principles reflect an approach to social security which recognises the importance of creating financial security for individuals in a way which respects both their dignity and human rights. This means providing an income when they are unable to work due to their disability, or providing the financial security needed for them to self-manage their condition. It is, therefore, essential that the new social security system for Scotland meets these extra costs. These include paying for taxis to hospital appointments, paying for electric wheelchairs, or paying someone to undertake jobs around the home. We discuss the impact of these extra costs more fully in paragraph 25.
5. We are keen for the Scottish Government to set out how the principles will be translated in policy; we set out these concerns in more detail below.

The Bill proposes that there will be a publicly available social security ‘charter’. This will say how the Scottish Government will put the seven principles into practice. It will also say what is expected from people claiming benefits.

Q. Do you agree with the idea of the charter? Please explain the reason for your answer.

6. The social security charter provides a platform on which the Scottish Government can communicate the principles of the new social security system, setting out clearly to individuals their rights and entitlements.

Q. Is there anything specific you would like to see in this charter?

7. We would like to see the Scottish Government set out how these principles will be implemented in practice. It is currently unclear whether the charter will enshrine the seven principles in legislation. This is something we would welcome, as a way of ensuring these principles become a reality for the disabled people who rely on social security.

8. A recent report by the Equality and Human Rights Commission found that while ‘dignity’ is a core concept in human rights law, it is a poorly defined one, and ‘respect’ has no legal definition.¹ The Commission recommends that it is necessary to establish what these two terms mean in the context of social security. We are supportive of the Commission’s conclusions and recommend the Committee considers creating a legal definition of dignity and respect in the context of social security. This should set out exactly how individuals can be expected to be treated when applying for social security in Scotland.
9. It is not clear how disabled people can expect to be treated if the new Social Security Agency fails to meet the standards set out in the principles and charter. We recommend that this be set out in detail in the charter.
10. As part of ensuring the system is accountable to those who use it, it is essential that individuals are able to appeal if they do not feel these standards have been met. It should be made clear how and under what conditions an individual is able to appeal. This information should be made available in a range of formats to ensure it is accessible (for example, braille and easy read).
11. We would recommend that an independent advocate be provided if this support is specifically needed to ensure that everyone who would like to appeal is in a position to do so.

The Bill proposes rules for social security. Do you have any comments on these rules?

12. The rules proposed in the draft legislation relate to a number of important processes. These include how decisions relating to benefit applications are made, how to apply for social security and what information people should provide, as well as how decisions can be challenged. In order to get this right it is essential the rules are co-produced with disabled people.
13. We welcome the Scottish Government’s commitment to consulting with experience panels of over 2,400 volunteers who have experience of the current benefit system. It is integral that the Scottish Government engages in a two-way conversation where people with lived experience are able to help design, implement and evaluate the new system.
14. It is important that the standards which the new Social Security Agency will follow in delivering these benefits are made clear, and that the Agency is accountable to those it delivers services to. We set out in

¹ EHRC, Social security systems based on dignity and respect, (2017), <https://www.equalityhumanrights.com/en/publication-download/social-security-systems-based-dignity-and-respect>

paragraphs 21-29 some of the standards which we think the Agency should meet in order to ensure the system is fit for purpose.

The Bill proposes that a new type of short-term assistance will be introduced. This will be for someone who is challenging a decision to stop or reduce a Scottish benefit.

Q. What are your views on this proposal?

15. We welcome this proposal. The assistance will be crucial in helping disabled people to avoid potential financial turmoil when there is a delay in their benefit claim. Alongside other member organisations of the DBC, we have heard from individuals who have found themselves struggling to cope as they wait for a decision on their benefit claim. The following quote highlights the negative impact of delays to PIP claims:

Kate said:

‘After my husband became ill I made a claim for PIP in June last year and we had to wait until February to get a payment. As a result we have had to sell our home and are facing bankruptcy. The delays in PIP meant we ran up debts to keep us going when we had no income. I have had to become a full time carer for my husband and daughter who is also disabled. I cannot believe the situation we now find ourselves in. At one point we had to go to a foodbank and it has been a terrible time for us all.’

Response from Leonard Cheshire Disability on the Public Accounts Committee on the Department of Work and Pensions delivery of Personal Independence Payment (June 2014)

16. Whilst we welcome the fact that the Scottish Government will provide short-term assistance, further detail is needed to ensure there are no inadvertent disadvantages for applicants. When this detail is provided, we would welcome the opportunity to work with the Scottish Government to ensure this short-term assistance is delivered in a way which is fair and meets the needs of disabled people.

17. We have previously recommended the following ways in which compensation may be delivered to disabled people suffering hardship as a result of delays to PIP. These recommendations could help inform the development of this policy:

- There should be automatic compensation to be paid at a daily rate when a decision comes after a certain period and PIP is ultimately awarded. The rate and length of the period would need to be negotiated - with a possible increase in the rate the longer the delay.

- Claimants who incur financial hardship and penalties in direct response to the waiting period, for example but not limited to non-payment of fines, overdraft fees, rehousing costs, should receive compensation above the level set out above, if the costs incurred are more than the compensation payable.²

The Bill proposes that discretionary housing payments continue as they are.

Q. Do you agree that discretionary housing payments should continue largely as they are?

18. Discretionary housing payments provide essential assistance, mitigating some of the hardships disabled people face when they are unable to afford their rent. We recommend the Bill includes legislation which sets out clearly who is entitled to these payments and under what circumstances. Disabled people should be clear about entitlement and how to appeal if they are denied the payment by their local authority.

Q. Is there anything else you want to tell us about this Bill?

19. We are encouraged by the principles set out in the Bill. The principles provide the potential for creating a social security system which is fair and helps to ensure disabled people are able to live independently. We set out here some recommendations for standards the new social security agency should follow to ensure these principles become a reality. Our recommendations are based on our experience of disabled people's experiences of the current delivery of PIP. Our evidence helps to highlight where the current system is failing them and should help to inform the Scottish Government to create a better system. We cover:

- The initial application.
- The face to face assessment.
- The communications disabled people receive throughout their claim.
- Finally, we make suggestions for how the Scottish Government could explore how the benefit can be re-designed to better reflect the costs that disabled people face.

The initial application

20. A fair process must be in place that is easy to understand and does not create unnecessary barriers and stress. The initial part of the PIP claim

² Independent Review of Personal Independence Payment (PIP) - Response from the Disability Benefits Consortium (DBC), <https://www.rcpsych.ac.uk/pdf/DBC%20PIP%20independent%20review%20submission%20Sep%202014.pdf>

should be made simpler. Over four in ten (42%) respondents to DBC's survey reported that they found the initial claim process to be difficult.³ Along with the DBC, we recommend that it is not necessary to have a two part claim. This means that people who require a support worker to apply for PIP on their behalf only need to make one advice appointment instead of two. The initial telephone call should be made optional, for individuals to log the beginning of their claim. This phone call should only require a name and National Insurance number, rather than all the information that is necessary now.⁴

21. Both the DBC's PIP Monitoring Survey and our recent survey found that the current process consistently denies disabled people the opportunity to fully explain the impact of their condition on their ability to carry out daily activities. The following quotes relate to people's experiences of filling out the 'How your disability affects you' form, and how they felt the questions asked did not allow them to explain the impact of their condition in a meaningful way.⁵

'The focus of questions on the PIP form [is] largely stupid and irrelevant to my physical conditions. These are more for mental health which I feel fine. [I] would like more focus for those with physical [conditions] and how this affects us more daily, as opposed to 'can I count money.' The form is repetitive but still with not enough focus. To be honest, it's like someone has put answers into a hat, picked and applied them. These questions are coming from able-bodied people with no insight whatsoever into what's it's actually like to have any physical or mental problem.'

'I completed the form on behalf of my 28 year old daughter. She has the mental age of a new born baby, has quadriplegic cerebral palsy, is blind, deaf, epileptic, asthmatic and is nil by mouth, getting all nutrition and medications via a PEG for more than 20 years. She scored top marks for being capable of managing her own medications and also did well in the section on being able to feed herself. Overall her score meant she qualified for PIP but I was shocked that when all the back up evidence was supplied confirming the extent of her disabilities such mistakes could be made. I think the form is a horrendous thing to expect some of the most vulnerable in our society to complete. The photocopying of all the supporting documentation would be a vast expense for those on a limited budget and any decent government should be willing to trust the assessments of the health care professionals who know the individuals rather than creating all these extra obstacles.'

³ PIP Monitoring Survey, 2013

⁴ Independent Review of Personal Independence Payment (PIP) - Response from the Disability Benefits Consortium (DBC), <https://www.rcpsych.ac.uk/pdf/DBC%20PIP%20independent%20review%20submission%20Sep%202014.pdf>

⁵ PIP Survey for Scotland, 2017

Face-to-face assessment

22. The face-to-face assessment also fails to enable many disabled people to explain fully the extent to which their condition impacts their life. The PIP Monitoring Survey found that a third of respondents felt that the assessor did not give them the opportunity to explain how their condition or disability affects them differently on different days, or at different points during the day.⁶ The following quotes from our recent survey also highlight this issue.

Speaking about the PIP face-to-face assessment:

‘The PIP assessment face to face interview didn't seem to take account of the fact that some days I'm much worse than others, which meant I lost the 4 points I'd have needed to qualify for a mobility car.’

‘When being assessed I found it very stressful, constantly having what I said being changed to what [the] assessor wanted to hear, and he also made assumptions about my ability to do things but never requested I show him.’

23. It is, therefore, essential that the assessor asks probing questions about any assumptions they make. For example, if the individual walked into the assessment centre, it is important to understand whether they would be able to do that walk again that day and what pain it might have caused them. This should happen as standard as part of the ‘safely, reliably and repeatedly regulations’, whereby an individual is assessed for each descriptor as to whether they are able to do the activity safely, reliably, repeatedly and in a reasonable time period. The following quote from our recent survey on PIP demonstrates the failings of the current system in not gathering the right information.⁷

Speaking about the impact of their face-to-face assessment on their PIP award:

‘In my decision letter I was told, on more than one occasion, that I was able to crouch down and back up again unaided. I was never asked to do this at the assessment and would have been unable to do it unaided. I was not believed when I said I could not plan and carry out a journey on my own.’

⁶ PIP Monitoring Survey, 2013

⁷ PIP Survey for Scotland, 2017

Communication throughout the application

24. Better communication is also integral to improving the application process for individuals, helping to ensure it is as stress-free as possible. The DBC's PIP Monitoring Survey found that 73% of respondents found the face to face assessment to be a stressful experience, with 51% finding it had a negative impact on their mental health, and 51% also finding it had a negative impact on their physical health.⁸ It is important that claimants are told when they can expect to hear about the status of their claim from start to finish. In addition, claimants should have one point of contact who they can reach at any point with any questions regarding their claim. Having the right information at the right time can provide a less stressful experience and ensure that disabled people are treated with dignity and respect.
25. Our evidence highlights the need for a different approach. We believe this Bill represents a fresh opportunity for the Scottish Government to improve the entire process. It also provides the chance for the Scottish Government to look at benefits such as PIP anew and re-design them to truly reflect the extra costs disabled people face. For example, The Extra Costs Commission by Scope found that disabled people will spend £200 a week on costs related to their disability. For someone with a physical impairment these costs will be almost £300.⁹ We recommend the Scottish Government takes this opportunity to research the costs that disabled people face in Scotland so PIP reflects the reality that many disabled people face. We would welcome the opportunity to work with the Committee and the Scottish Government on this.

For more information about this response, please contact: Ashleigh de Verteuil, Policy and Research Officer, T: 0131 346 9040 or E: ashleigh.deverteuil@leonardcheshire.org

⁸ Independent Review of Personal Independence Payment (PIP) - Response from the Disability Benefits Consortium (DBC), <https://www.rcpsych.ac.uk/pdf/DBC%20PIP%20independent%20review%20submission%20Sep%202014.pdf>

⁹ Extra Costs Commission (2015), Driving down the extra costs disabled people face, <https://www.scope.org.uk/Scope/media/Interim-report/Extra-Costs-Commission-Final-Report.pdf>