

**Personal Independence Payment Assessment – Independent Review:**

**Joint Response from Inclusion Scotland and the Lothian Centre for Inclusive Living**

1. **Introduction**
   1. This response has been prepared jointly by Inclusion Scotland and the Lothian Centre for Inclusive Living (LCiL). It draws on evidence received at a joint consultation event on the Review organised by Inclusion Scotland and Grapevine, the LCiL Disability Information service. The event was held on 19 August 2014 and was attended by disabled people who have claimed Personal Independence Payment (PIP), or are likely to claim PIP in the near future, and some advocacy workers who work with disabled people. Comments have also been received from people, who have had assistance from Grapevine with their claim for PIP.
   2. **Inclusion Scotland** is a network of disabled peoples' organisations and individual disabled people. Our main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people’s everyday lives and to encourage a wider understanding of those issues throughout Scotland.
   3. **Lothian Centre for Inclusive Living** (LCiL) is a user controlled organisation which supports disabled people, people with long-term conditions and older people, to live independently in their communities.All services respond to needs identified by disabled people in order to promote their equal participation in all aspects of society. **Grapevine** provides free, confidential information and advice to disabled people, their families and any other organisation or individual looking for disability related information in Edinburgh, East Lothian and Midlothian
2. **Claimant Experience**

**Question 2: a) How easy is it for people to understand the whole process?**

* 1. For many disabled people, particularly those with a mental health or debilitating condition, the process of claiming PIP can be a stressful process. The anxiety and uncertainty, particularly given the very lengthy period from making a claim to receiving a decision, can lead to a deterioration of their condition.
  2. The delays caused by the PIP claims process have led to individuals having to rely on hand-outs, such as crisis grants, food banks and financial assistance from friends and family who can afford to give them it until they get a decision.
  3. Many are concerned about what might happen if they are not awarded PIP, as this may lead to them losing their care package, housing benefit and other support.
  4. This anxiety is sometimes caused by disabled people’s experience of the Work Capability Assessment process for Employment Support Allowance (ESA).

**Question 2: b) How easy is it for people to make a claim?**

* 1. A number of concerns were raised about the requirement to make the initial claim by phone. In particular, making the phone call could be a barrier to those with a mental health problem or debilitating illness:

“People I work with really struggle. This is a barrier. They won’t phone up. People haven’t phoned. [They are] put off, and then their DLA runs out.”[[1]](#footnote-1)

“I am worried about having to make a phone call because phoning makes me anxious. People’s conditions could be made worse by the claiming process.”

* 1. Whilst some participants found no problems with the initial phone call, others found it intrusive and unhelpful.

“I don’t want to talk about personal stuff with someone over the phone. It is different from filling in a form.”

“I feel they are trying to catch me out, that I’ll say the wrong thing.”

“I felt as if the person taking the call was reading from a script and that it was an interrogative interview rather than a fact-finding one.”

Claimants needed to be made aware what sort of information they might need before making the initial call, for example bank details and information about their impairment or condition.

“I was on phone for just short of half an hour. They asked difficult questions about things not on the list they had given in their contact letter which obviously you have not looked out or thought about.”

* 1. A particular concern is that the DWP insist on speaking to the person the claim is for, even if they cannot talk because of their condition or because they are very distressed, rather than with someone speaking on their behalf.

“The person on the other end of the phone mentioned long statements to Mr A personally which he was expected to agree/not agree to.  He did not understand a word of it and was extremely confused and anxious. I could not hear all of what was said during these long statements because the questioner was talking to Mr A to get his personal permission for various things to happen.  I just had to nod to him to agree to it all.  He was very confused and upset by it all”

* 1. **It is clear that the requirement to start the claims process on the phone is a barrier to some people claiming PIP, which can lead to delays in them making a claim, or even failing to make a claim altogether. Claim forms should be available to anyone who requests one without the need to go through the initial phone process, which appears to be more about the administrative arrangements within the DWP than meeting the needs of claimants and disabled people.**
  2. The length of the PIP2 Claim Form was felt by many to be intimidating, and off-putting. Without assistance from a worker many would have been unable to complete the form, and the time limits for returning the form may make it difficult to get it back on time. Many have had to request extensions so they can get support needed.

“The form was woolly, too long and I did not want to fill it in as a result. I needed the support from Grapevine in order to fill it in.”

“I looked at it and I didn’t know what they were asking, so I accessed support from LCiL. I sat with a worker for two and half – three hours.”

* 1. There is a need to ensure that the claim form asks questions in a way that links to the way that points are allocated in the assessment. Many participants in our consultation pointed out that the prompts in the form did not correlate to the way points are actually allocated**. Most questioned why a list explaining how points are allocated under each activity are not explained on the form**. In particular, the importance of what is meant by being able to do the activity safely, to an acceptable standard, as often as needed and in a reasonable time must to be stressed.

“I would be guilty of answering ‘Yes, I can do that.’, but actually on further reflection I can only do it because of the help I can get. People may not consider the circumstances under which they can do certain things.”

“When people see ‘can you prepare a meal?’ well yeah, but it takes me so long to get it on the table that it’s all cold.”

“The questions on the form are relevant to my disability, but I am only able to do some of the tasks at particular times of the day, because I get tired.”

* 1. The form does not reflect the particular requirements of those with mental health issues or fluctuating conditions. It can be difficult for a person for a mental health problem to admit that their condition may last for a further 9 months. People with eating disorders may not accept that they need assistance to ensure they eat properly. People with depression might not want to admit that they may go for days without washing and dressing. Fluctuating conditions such as Chronic Fatigue Syndrome (ME) or Multiple Sclerosis (MS) can be difficult to assess as people can have good days and bad days. People may also be reluctant to put on the form assistance they need that they may find embarrassing.

“Mental health is not represented well on the form as it is focused on the physical aspects of disability rather than the problems that are caused by mental health.”

“I need help to wipe my bottom. It is undignified and questions don’t help.”

* 1. **Given the complexity and lengthy of the application form, more support needs to be given to advice and advocacy agencies to allow more people to get the help and assistance they need to fill in the form correctly.**

“Everybody should be given help filling the application in because for the lay person it is too difficult.”

“Having applied for PIP the form which was sent was pretty hard to understand and fill in due to length and words used. Our experience using Grapevine was fantastic because we would not have been able to fill in these forms properly or understand different parts of the form.”

1. **Face to Face Consultation**

**Question 3: Please tell us about the experience of having a face to face consultation with an Atos or Capita health profession.**

* 1. Many disabled people have had a bad experience of Work Capability Assessments operated by ATOS, and so are very anxious about what will happen at the PIP assessment.
  2. There are issues around the accessibility of the assessments centres. Claimants may have to travel a considerable distance, and public transport may not be suitable or available, and too few disabled parking spaces. Some claimants may suffer from mental health conditions that cause anxiety in public spaces such as waiting rooms.
  3. Whilst one or two of our participants had found the assessor to be helpful, most considered that the assessors were too concerned with standard questions and getting short “yes” or “no” answers rather than allowing the claimant to explain full picture of their condition. This is a particular concern for those with fluctuating conditions.

“I was treated with little respect and told to stop talking and give a ‘yes’ or ‘no’ answer for everything. These answers do not take account of the fluctuating nature of my condition from good to bad days.”

“If we didn’t answer within a few seconds, she would say she doesn’t want all the information, just answer the question. She was obsessed with time.”

“He allowed more expression, but still had set questions. Someone was sitting at the back with a notepad, it made me feel uncomfortable.”

* 1. Some participants felt the assessors were trying to catch them out, for example by watching if they could make it from the bus stop to the assessment centre and looking for discrepancies about what is said and what is on the application form. People may also be reluctant to admit what they cannot do.

“The bus stop was at the top of the road and they could see you walk up. The first thing they say is ‘how did you get here?’.”

“You have to be careful to express tings in the same way as on the form.”

“People do not want to admit the things they can’t do.”

* 1. **A particular concern is whether the assessor has sufficient knowledge of the condition that the claimant has to be able to make a valid assessment.** Again this is of particular important for people who have a mental health or fluctuating condition.

“Face to face interviews should be carried out by an expert in the relevant condition. If someone is claiming PIP on the basis of underlying mental health problems then there should be an expert on mental health to conduct the assessment.”

“If you go on a good day you won’t be as successful. It is more difficult to get support for variable conditions.”

“I could tell [the assessor] was a state registered nurse. I do exercise. She didn’t know what I was talking about.”

**Claimants should be automatically advised of the qualifications of the person carrying out their assessment.**

1. **Further Evidence**

**Question 4: Consider how further evidence is used in the PIP process.**

* 1. The main concern of applicants is that they may be charged by health professionals, particularly GPs, for the written evidence they need to support their claim.
  2. The notes on the PIP2 application form advise claimants to provide any relevant evidence information they already have that explain their circumstances, including prescription list, care plans and information from professionals such as a GP, hospital doctor, community psychiatric nurse, occupational therapist, social worker or counsellor of support worker.
  3. The information booklet, however, advises applicants not to request documents which might slow down their claim for which they might be charged a fee. It then states that if the evidence is needed the DWP will ask for it themselves.
  4. More clarity about what documents should be provided as evidence and what will be requested by the DWP if required would be helpful, as would clarification of whether GP or other medical reports will be requested routinely by the DWP, or only in exceptional cases.
  5. Some of the participants at our consultation were concerned that additional evidence they had provided was not being taken into account by the assessor.

“I took a letter regarding my early retirement I had to have a letter from the Registrar to get early retirement. They took it, but didn’t refer to it.”

“Yeah, they will photocopy [letters from psychiatrists], but don’t look at them at the time.”

1. **Assessment Criteria and process**

**Question 5: Please describe how effective the PIP assessment is.**

* 1. The use of the activity based points system is failing to reflect the full picture of people’s disability, and in particular the support, and additional costs, that disabled people need to live an ordinary life, and have the same the same freedom, choice, dignity and control as other citizens at home, at work and in the community.

“The focus on points takes away the full picture of my disability.”

* 1. The descriptors are meant to take account of whether the person can do the activity safely, to an acceptable standard, as often as needed and in a reasonable time. They are also meant to take account of how frequently a person can do this, ie more or less than 50% of the time over a 12 month period.
  2. However, it is unclear whether the application form and assessment taken together allow for a clear picture to be drawn of the extent to which a claimant meets the criteria.

“The questions were not well explained and needed interpretation to be able to answer in a manner the fully represented the true nature of my disability.”

* 1. For those with multiple conditions, people were asked about which condition affected they ability to carry out the activity, rather than their ability to carry out the activity.

“It’s because I’m not well. It may be because of my COPD initially, but also my osteoarthritis. For lots of things both applied.”

1. **Reconsideration and Appeals**
   1. Requests for reconsiderations and appeals will be made where claimants are unhappy with the decision reached on their claim. However, there are concerns that the mandatory reconsideration process discourages people from making legitimate requests to have the decision reconsidered because the process is too complicated, the fear that the PIP already awarded might be reduced, and the stress of going through the process.

“The mandatory reconsideration process is too complicated and bureaucratic.”

* 1. Mandatory reconsiderations add further delay into an already over-lengthy process for disabled people claiming the support they need to assist them live an ordinary life. They also add to the stress and anxiety that disabled people already have about the whole PIP process, which impacts on their health and well-being.

“It’s unpleasant and leaves you short of the money you need.”

* 1. Others are put off from requesting a mandatory reconsideration or an appeal because of a previous negative experience.

“I did not appeal the original decision because of my experience with claiming Employment Support Allowance.”

1. **Improvements**

**Questions 8 and 9: The time it takes from making a claim to getting a decision, and the impact of this.**

* 1. The time taken from making a claim for PIP and receiving a decision is unacceptably long. This can leave claimants, whether new applicants or those transferring from DLA without the support they need. As previously stated, many disabled people find the whole PIP process distressing, and having to wait such a long time for a decision adds to anxiety and stress, often impacting on their health and wellbeing.
  2. One concern is the impact that not getting PIP may have on other passported benefits, such as carers allowance, blue badges and concessionary travel, and on the ability to pay for care packages and even housing costs.
  3. People may be unable to pay for the care they need whilst waiting for the decision. This may be for new claims, or for claims to have the award upgraded because their condition has deteriorated. In some cases, it may be because a person has failed to apply for PIP in time when their current DLA award has run out, perhaps because of their underlying condition, not knowing how to apply, or because of anxiety they have about applying and filling in the form.

“I had someone whose DLA had stopped. They put in a claim in July but didn’t get payment until the following May. Support for the Council stopped because she couldn’t contribute anymore.”

* 1. Those currently in receipt of DLA who transfer to PIP continue to receive DLA until 28 days after the decision on their PIP claim is determined, after which they will receive PIP. Where the decision is to award PIP at a higher rate than DLA, the award is not backdated to the date of claim, despite the fact that disabled person would have been receiving the higher award but for the delays in the assessment process.
  2. There is a particular issue regarding the special arrangements for those claiming PIP because of terminal illness. Despite the clear policy intention that those suffering from a terminal illness receive PIP as quickly as possible and from the date of claim, current regulations appear to prevent those who are already in receipt of DLA from receiving an enhanced rate of PIP until 28 days after the assessment determination.

**Question 10: The whole PIP process**

* 1. The overwhelming conclusion from the consultations that Inclusion Scotland and LCiL Grapevine has had with disabled people is that the PIP Assessment process is too complex; takes too long; fails to take account of mental health or fluctuating conditions; and is degrading and stressful process for the applicant. **You should not require the support of an advice worker to claim a benefit you are entitled**.

“It can be difficult to get your head around what to do and how to proceed.”

“Everybody should be given help filling the application form in because for the ordinary lay person it is too difficult.”

“The prospect of assessment causes worry.”

“The group agreed that the impact of the PIP process often leads to a worsening of folks health symptoms.”

* 1. A particular concern is that people whose condition will not change, or can only deteriorate, will have to go through the whole process again in 2-3 years. This seems an unnecessary waste of resources, and something that will cause needless stress to disabled people.

“They said on the award letter there’ll be a review in two years’ time. I started to panic and I didn’t have mental health problems, got a bit worked up. It’s like a threat. With COPD you’re not going to get better.”

“It is not that I have cerebral palsy, it’s that I have to say it over and over again. Can’t they reintroduce indefinite awards, especially for long term non-changing conditions?”

* 1. Some key improvements that would help improve the experience for disabled people include:
* **Making it easier to get a claim form, without having to phone up for one.**
* **Ensure all DWP and assessment staff dealing with PIP claims are fully trained in disability awareness and disability equalities.**
* **Include the descriptors and criteria for awarding points on the application form or accompanying information booklet.**
* **Only require a face to face assessment where this cannot be done using the information form the application form and additional information provided by the applicant or at the request of the DWP.**
* **Conduct more face to face assessments in the applicants own home.**
* **Ensure that those carrying out assessments have knowledge of the condition the claimant has.**
* **Reduce the delays between application and assessment, and assessment and decision.**

1. **Claimant Satisfaction**

“The PIP claim process had been ruined by the attitude of the assessor.”

“The whole assessment process needs to be fairer.”

“I feel they’re trying to catch me out, that I’ll say the wrong thing.”

“It’s their job to get people off benefits – that is the impression people have of the system.

* 1. The principle behind Personal Independence Payment is to make a contribution to the additional costs faced by disabled people and those with long term conditions that face the greatest barriers to independent living.
  2. Experience to date, however, suggests that the PIP Assessment process is not about identifying what support people need to live an ordinary life, and helping people to get that support, but about reducing the number of people who receive this support.
  3. **We believe that support and services for disabled people should be provided according to human rights principles, including the right to Independent Living enshrined in Article 19 of the United Nations Charter on the Rights of Disabled People (UNCRPD), and that the current approach to PIP is failing to deliver these rights.**

If you have any questions on this submission, or for further information, contact:

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Visit our website:: [www.lothiancil.org.uk](http://www.lothiancil.org.uk)

1. Quotes in this submission are from participants in the Consultation event held by Inclusion Scotland and LCiL Grapevine on 19 August 2014. Participants were disabled people who had made a claim for PIP, or were likely to do so in the near future, and advocacy workers who work with them, or from people who have had assistance from Grapevine to claim PIP. [↑](#footnote-ref-1)