



Consortium for the Regional Support for Women in Disadvantaged and Rural Areas

Response to: Second Independent Review of the Personal Independence Payment (PIP) Assessment Process in Northern Ireland

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**Foyle Women's
Information
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Women's Regional Consortium: Working to Support Women in Rural Communities and Disadvantaged Urban Areas

1. Introduction

1.1 This response has been undertaken collaboratively by the members of the Consortium for the Regional Support for Women in Disadvantaged and Rural Areas (hereafter, either the Women's Regional Consortium or simply the Consortium), which is funded by the Department for Communities and the Department of Agriculture, Environment and Rural Affairs.

1.2 The Women's Regional Consortium consists of seven established women's sector organisations that are committed to working in partnership with each other, government, statutory organisations and women's organisations, centres and groups in disadvantaged and rural areas, to ensure that organisations working for women are given the best possible support in the work they do in tackling disadvantage and social exclusion.¹ The seven groups are as follows:

- ♀ Training for Women Network (TWN) – Project lead
- ♀ Women's Resource and Development Agency (WRDA)
- ♀ Women's Support Network (WSN)
- ♀ Northern Ireland's Rural Women's Network (NIRWN)
- ♀ Women's TEC
- ♀ Women's Centre Derry
- ♀ Foyle Women's Information Network (FWIN)

1.3 The Consortium is the established link and strategic partner between government and statutory agencies and women in disadvantaged and rural areas, including all groups, centres and organisations delivering essential frontline services, advice and support. The

¹ Sections 1.2-1.3 represent the official description of the Consortium's work, as agreed and authored by its seven partner organisation

Consortium ensures that there is a continuous two-way flow of information between government and the sector. It also ensures that organisations/centres and groups are made aware of consultations, government planning and policy implementation. In turn, the Consortium ascertains the views, needs and aspirations of women in disadvantaged and rural areas and takes these views forward to influence policy development and future government planning, which ultimately results in the empowerment of local women in disadvantaged and rurally isolated communities.

1.4 The Women's Regional Consortium appreciates the opportunity to respond to the Department for Communities consultation on Personal Independence Payment (PIP). The ability to carry out research has been restricted by the Coronavirus pandemic and subsequent lockdown. Our submission is therefore based on the results of an online questionnaire distributed to women by the network of local Women's Centres across Northern Ireland working in disadvantaged areas and the wider Women's Regional Consortium alongside a number of individual telephone interviews with women.

1.5 Throughout this response the Consortium has sought to ensure the voices of women are clearly represented. We believe that it is essential for policy makers and the Government to listen to the voices of these valuable lived experiences of PIP. Their experiences and suggestions for improvements to the system are the most real indication of where the problems are and how these can be fixed. These voices are included throughout this response in purple boxes and provide the context around which this response is made.

2. General comments

Since June 2016 the Department for Communities (DfC) began to replace Disability Living Allowance (DLA) for working age claimants with Personal Independence Payment (PIP). PIP is a benefit designed to help with some of the extra costs caused by long-term ill health or disability that is expected to last for 12 months or longer. It is not about diagnosing a disability or health condition but based on how the condition affects a claimant.

The most recent PIP claimant statistics² highlight the following points:

- Total claims in payments at May 2020 – 146,310 (74% of these were reassessed DLA claims)
- Award rate for new claims – 48%
- Award rate for DLA reassessments – 76%
- Overall award rate – 65%
- 42% of awards have psychiatric disorders as the main disabling condition
- 29% of PIP decisions to date have resulted in a request for reconsideration (MRs)
- By the end of May 2020, 83% of new claims and 78% of reassessed DLA reconsiderations resulted in no change to the award. The majority of reconsiderations result in no change in the award.

Northern Ireland has traditionally had a much higher proportion of people claiming disability benefits than other areas of the UK. Prior to the introduction of PIP around one in nine people in Northern Ireland (208,760 people) were on DLA.³ At that time Northern Ireland had proportionately twice as many people claiming DLA compared to the rest of the UK. The latest PIP statistics available show that there were 146,310 PIP claims in payment as at May 2020⁴ and of these 77,230 (53%) were paid to women.⁵

“Disabled women do not have a voice. The welfare reform process, and the change to the cruel PIP assessment process, has removed our much-needed support systems. We do not deserve this.”

- Questionnaire Respondent

² Personal Independence Payment (PIP) Experimental Statistics, Department for Communities & NISRA, May 2020

<https://www.communities-ni.gov.uk/system/files/publications/communities/personal-independence-payment-statistical-bulletin-may-2020.pdf>

³ Northern Ireland Benefits Statistics Summary, Department for Social Development, November 2015
<https://www.communities-ni.gov.uk/sites/default/files/publications/dsd/benefit-statistics-summary-november-2015.pdf>

⁴ Personal Independence Payment (PIP) Experimental Statistics, Department for Communities & NISRA, May 2020

<https://www.communities-ni.gov.uk/system/files/publications/communities/personal-independence-payment-statistical-bulletin-may-2020.pdf>

⁵ <https://www.communities-ni.gov.uk/publications/personal-independence-payment-statistics-may-2020>

“We have spent so many years getting GPs/consultants to take our pain seriously (even more so as women) and then PIP can just say ‘No! You don’t need this support/we don’t believe you’, it’s infuriating!”

- Questionnaire Respondent

Northern Ireland has a higher incidence of mental health conditions per head of the population than GB.⁶ PIP claimant statistics show that psychiatric disorders are the main disabling condition accounting for 42% of awards.⁷ **The high claimant rate for PIP in Northern Ireland and the prevalence of claims for psychiatric disorders must be important considerations for this Review.**

The introduction of PIP has been controversial in Northern Ireland with many claimants reporting they have lost the benefit after inaccurate assessments carried out by private firms. The PIP assessment process has been widely criticised and labelled “*demeaning and degrading*”⁸ by many claimants, voluntary and community organisations as well as local politicians.

PIP Appeals

Figures from the DfC⁹ show that more than 40% of DLA claimants in Northern Ireland had their benefit cut or stopped when they were assessed for PIP. DfC figures quoted in a NI Audit Office report on Welfare Reform¹⁰ show that almost a quarter of all PIP decisions (24%) were challenged by claimants and more than half (55%) of cases were overturned at appeal.

⁶ Mental Health in Northern Ireland, Northern Ireland Assembly Research and Information Service, NIAR 412-16, January 2017

<http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2016-2021/2017/health/0817.pdf>

⁷ Personal Independence Payment (PIP) Experimental Statistics, Department for Communities & NISRA, May 2020

<https://www.communities-ni.gov.uk/system/files/publications/communities/personal-independence-payment-statistical-bulletin-may-2020.pdf>

⁸ <https://www.bbc.co.uk/news/uk-northern-ireland-43968546>

⁹ DLA to PIP Reassessment, June 2016 to May 2018, DfC, September 2018

<https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dla-to-pip-reassessmentsummary-may18.pdf>

¹⁰ Welfare Reforms in Northern Ireland, Northern Ireland Audit Office, 17 January 2019

<https://www.niauditoffice.gov.uk/sites/niao/files/media-files/Welfare%20Reform%20Report%202019.pdf>

A written answer to an Assembly Question asked by Rachel Woods MLA in September 2020 on the number of successful PIP appeals as a percentage of all PIP appeals received highlights the rise in the numbers of successful appeals over the last number of years. **The percentage of PIP appeals that were successful has risen from 0.2% in 2016/17 (PIP was introduced in June 2016), to 20% in 2017/18, 35.3% in 2018/19 and to 76.4% in 2019/20. This clearly points to the fact that there is something wrong with the assessment process for PIP.**

A written answer to an Assembly Question asked by Andy Allen MLA on PIP appeals¹¹ has highlighted the importance of representation at appeals with appellants being twice as likely to be successful with representation than without. During the last three years there have been 14,198 PIP appeals, 59% of which have been successful and 41% have been unsuccessful. Of these appeals 10,154 had representation resulting in 64% being successful and 36% being unsuccessful.

First Independent Review of PIP

An independent review of the PIP assessment process in Northern Ireland was carried out by Walter Rader and published in June 2018 making 14 recommendations for improvement and change.¹² It will be important for this Review to carefully consider the recommendations in Walter Rader's report to determine if any real progress has been made. In his overview of findings he said:

"It is a fragmented process that impacts negatively on both claimants and those who seek to support them. In particular the face-to-face assessment causes fear, anxiety, stress and frustration. This in turn has a knock on impact on the health and well-being of claimants, their family and wider support networks, placing even more demands on already stretched services."

¹¹

<http://aims.niassembly.gov.uk/questions/writtensearchresults.aspx?&qf=0&qfv=1&ref=AQW%203545/17-22>

¹² Personal Independence Payment, An Independent Review of the Assessment Process, Walter Rader, June 2018

<https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-independent-review-pip-assessment-process-june-2018.pdf>

‘Own Initiative’ Investigation by Northern Ireland Ombudsman

The Northern Ireland Ombudsman, Marie Anderson, announced in 2019 that she has chosen PIP as her first area for investigation under her new ‘Own Initiative’ power – she can investigate if her office suspects “systemic maladministration.” She pointed out the high number of PIP decisions which have been overturned at appeal and the significant number of complaints made about the benefit to her office in making her decision.¹³ This move by the Northern Ireland Ombudsman is concerning in itself suggesting that there remains significant and ongoing problems with PIP.

The investigation will look at the availability and application of further evidence (such as GP records, Occupational Therapist assessments, carers’ reports etc.) in the decision making, mandatory re-consideration and complaints processes. In doing so, the Ombudsman will examine the actions of the Department and service provider Capita in administering PIP with a focus on availability and application of further evidence in the PIP benefit decision making and internal complaints. The outcomes of this investigation must also be an important consideration for this Review.

UN Special Rapporteur on Extreme Poverty and Human Rights

In 2019 Professor Philip Alston, the UN Special Rapporteur on Extreme Poverty and Human Rights said in his final report on the UK¹⁴ that disabled people “*were some of the hardest hit by austerity measures.*” Further, Professor Alston stated that cuts to public spending, highly regressive changes to taxes and benefits and the government’s refusal to carry out an assessment on the impact of these cuts and austerity on disabled people had led to the UK government’s breach of the principle of non-discrimination enshrined in international law.¹⁵

Impact of Austerity

Pre-Covid-19 the Women’s Budget Group¹⁶ highlighted that disabled people have been disproportionately affected by austerity cuts since 2010. Disabled women are set to lose

¹³ <https://nipso.org.uk/site/wp-content/uploads/2019/01/Own-Initiative-investigation-PIP-statement.pdf>

¹⁴ Report of the Special Rapporteur on extreme poverty and human rights, Visit to United Kingdom of Great Britain and Northern Ireland, April 2019, Paragraph 76
<https://undocs.org/A/HRC/41/39/Add.1>

¹⁵ Ibid, paragraph 68

¹⁶ Disabled Women and Austerity, Women’s Budget Group, October 2018

13% of their annual net income by 2021 from cumulative tax-benefit changes. Disabled lone mothers lose out the most from tax and benefit changes since 2010. By 2021 they will lose 21% of their net income if they do not have a disabled child and 32 % if they do.

Impact of Covid-19

Covid-19 has impacted on many aspects of life including the social security system and the PIP process. It has impacted on the activity of claimants and operational activity within the Department which led to the implementation of Departmental emergency measures for processing claims. Emergency measures implemented by the Department for Communities included the suspension of face-to-face assessments with all medical assessments to be carried out by telephone and a temporary suspension of PIP award reviews (award review activity has now resumed from 21 July 2020, however measures have been put in place to ensure PIP payments continue as normal until the review has concluded).

The impact of Covid-19 on the PIP process is another area of potential concern for this Review. While the pandemic is unprecedented and there is a need to limit the transmission of the virus there are concerns about the impact of these measures on claimants. There may be negative implications in terms of lengthening the process as well as concerns about the potential impact on how PIP decisions are made.

In addition, many disabled people are considered to be at risk, or vulnerable, if they catch Covid-19. A large number of disabled people have been self-isolating for a long period of time and stress levels may be higher. The impact of Covid-19 on a vulnerable group going through an application process needs to be considered. **There is a need for the Department to collect and publish data to enable the monitoring of the impact of the emergency measures introduced as a result of the pandemic carefully.**

Women's Centres have also been impacted in their ability to provide advice on benefits. Advice provision cannot take place in person and has moved to telephone advice which has implications for demand and resourcing.

PIP and Carer's Allowance

While there are no significant gender differences in claimant numbers for PIP (53% of PIP claims in payment were paid to women) there are implications for women if the person they care for is turned down for PIP on migration from DLA. If the person they care for loses their PIP award then they will lose their Carer's Allowance payment (although this is currently mitigated for one year). This is likely to have greater implications for women than men as statistics show that women are more likely to be carers than men (64% of carers are women)¹⁷ and women are more likely to be in receipt of Carer's Allowance than men (69% of Carer's Allowance recipients are women).¹⁸

"I am a carer for my adult son who has Asperger's. We have been waiting over a year on appeal after losing DLA on assessment for PIP. I was getting Carer's Allowance for him but it stopped before Christmas (you only get it for a year while on appeal). I got a letter a week after it stopped but I didn't understand it. I had to phone up to ask why. I am down £250/month with the loss of Carers Allowance. We are really feeling the pinch. We have cut down on other essentials to make up for the loss of this money. My husband works extra hours when he can and we have no social life. I know I'm not getting that money so I don't go out. It is very isolating and causes problems with your mental health."

¹⁷ <https://www.carersuk.org/northernireland/news-ni/facts-and-figures>

¹⁸ Carer's Allowance Summary Statistics, May 2020, Department for Communities & NISRA, August 2020
<https://www.communities-ni.gov.uk/publications/benefits-statistics-summary-publication-national-statistics-may-2020>

Diminution of Rights

The move from DLA to PIP has meant that some DLA claimants have suffered a loss or reduction in their benefits. In order for claimants not to suffer diminution in their rights the support for disability should not fall below what it was when a person was on DLA.

“My disabilities have made my life full of extreme pain, fatigue and struggle. My disabilities are the biggest barrier in my life, yet I still wasn’t disabled enough for PIP to get the support I previously got on DLA. How can my pain and struggles that dominate my life not be enough for them? How much worse does my life need to be before they will give me the support I need?”

- *Questionnaire Respondent*

Specific Comments

Questions for individuals or organisations with experience of the PIP assessment process

About you

Q1. Are you responding as;

- ☐ An individual
- ☒ An organisation or part of an organisation

If responding as an organisation or part of an organisation;

Name of organisation: Women's Regional Consortium for Northern Ireland

Who does the organisation represent: We represent women living and working in disadvantaged and rural areas of Northern Ireland (for full description of the Consortium and its work see Section 1).

Where applicable, explain how the views of the members were gathered:

Under normal circumstances the views and experiences of women would have been gathered through focus group discussions in local women's centres and with Consortium partners. However due to Covid-19 and lockdown measures this was not possible. Therefore, an online questionnaire was developed to gather the views of women on the PIP process through from application to assessment and award. In addition, a number of individual telephone interviews were carried out with women to explore in more detail their experiences and views on the process.

Does your organisation directly support people claiming PIP? Yes. Many local Women's Centres provide advice on social security benefits including PIP and can also provide signposting to advice centres for more complex issues and advocacy work. Consortium members also send out information updates from the Department for Communities on benefits including PIP and will signpost

people to welfare rights organisations for help and support on making claims and attending tribunals.

Q2. We may want to seek further information from you, are you happy if we contact you?

☒ Yes

☐ No

If yes, please complete your contact details:

Name: Women's Support Network (on behalf of the Women's Regional Consortium)

Address: 109 – 113 Royal Avenue, Belfast, BT1 1FF

E-mail: policy@wsn.org.uk

Telephone Number: 07764 224 360 (Siobhán Harding mobile)

Claimant experience

Consider the PIP claim process. This includes making a claim, the assessment and getting a decision.

Q3. From your experience, how could the PIP claim process be improved? Please provide examples or suggestions.

The views shared by the women in the online questionnaire and telephone interviews gave evidence on the problems they experienced with the PIP process and this led to a series of suggestions for improving it. It was clear from what they said that they felt that claimants needed to be treated with more compassion throughout the entire PIP process. A number of the women also reported problems understanding the correspondence they received from PIP. 32% of the women who responded to the questionnaire felt that the information sent to them by PIP (including letters and other correspondence) was not easy to understand.

Recommendations:

- **There is a need to treat claimants with compassion throughout the PIP process and for it to be more people-centred.**
- **There is a need to simplify the language used in communications between PIP and claimants including the claim form, letters and all other correspondence.**

“The Department needs to start treating people with compassion.”

- *Questionnaire Respondent*

“The application process itself had a terrible impact on my mental and physical health, and to me this makes no sense at all. Why are we making disabled people sicker through this horrific application and then giving them points based on “how disabled they seem”. It is inhumane and cruel. I barely survived this process and I am lucky to be alive today in spite of it.”

- *Questionnaire Respondent*

“The assessment is a small lens view of how widely disability impacts people. Disability impact generally fluctuates and this cannot be reflected in the form or in the interview. The assessment could feel less like an interview under caution and be more sensitive towards the claimant’s disabilities. It feels like they are trying to catch people out or reduce claim awards. It is a demeaning, humiliating and anxiety inducing process. I feel that the staff need to be trained on mental health and treat people with respect and empathy.”

- *Questionnaire Respondent*

“I get PIP but I don’t understand it and what way it works. A lot of the letters are confusing, it’s the way they word things and I don’t understand them. I panic and worry about what they mean. My daughter has to sort it out for me.”

- *Questionnaire Respondent*

“You are made to feel like you are nothing.”

- *Questionnaire Respondent*

“I only find correspondence from PIP easy to understand on my good days, on my bad days I can’t look at any post and time sensitive mail gets lost by the wayside.”

- *Questionnaire Respondent*

“A lot of people are not brought up with that kind of language so they don’t know what it means.”

- *Telephone Interview*

“It’s the way they word things. It’s easier if it is just in layman’s terms rather than a lot of medical or governmental terms. They understand but we don’t.”

- *Telephone Interview*

“I understand parts of the letters but where I don’t I get my son to check it. Some of the letters are 3-4 pages and it is hard to take it all in and what they mean. My son would read them to me sometimes.”

- *Telephone Interview*

“I don’t find the letters easy to understand, I usually have to ask my mum to help me or bring it into the Women’s Centre and they help me understand what they mean and what I have to do.”

- *Telephone Interview*

Making a Claim

Most of the evidence received from women with regards to making a PIP claim centred around the completion of the application form. Their experience of completing the form was dominated by complaints about the length of the form and how exhausting and distressing it was to complete. They felt that the questions were very repetitive basically asking the same thing over and over

again in slightly different ways. This led to many of the women feeling that the form was designed to put them off, that the questions were trying to 'trick' them and it created a fear of writing the 'wrong' answer which could potentially mean that they lose everything.

Some of the women reported that it was difficult to complete the form due to the nature of their condition. They felt that it was difficult for some conditions to 'fit' in the form the way it is structured and this meant that they found it difficult to describe fully how their condition impacted them. Others reported that it was difficult to detail how they were impacted on their 'bad' days as well as their 'good' days.

Other women reported difficulties understanding the information required by the form and stressed the need to get help to complete it. Many of the women (51%) reported getting help to complete the form stating that they would have felt unable to complete it effectively themselves. For many this involved getting help from family members/friends, independent advice agencies and women's centres. In some instances women reported that the deadline for completion of the form was too tight making it difficult for them to complete it properly within the deadline.

Specific details on the problems with further evidence are dealt with in Questions 8 - 12 of this response but in summary most of the women felt it was important to submit further evidence and many were unclear about what they needed to provide as further evidence.

Recommendations:

- **Extend the deadline for completion of the PIP application form.**
- **The length of the claim form and the repetitive nature of the questions contained within it can deter claimants and cause frustration and anxiety. There is a need to review the claim form to determine how it can gather the required information without unnecessary repetition and undue length.**
- **There is a need to review the claim form in relation to how it effectively**

gathers information on mental health issues.

- The Department should increase the range of options for completing the claim form including online and the facility for some claimants to be able to vocally record the answers to the claim form questions.
- The chances of having a successful outcome for PIP at all stages of the process are significantly increased with access to appropriate advice. Sufficient resourcing should be available to ensure that every claimant can access independent advice on completion of the claim form should they wish to avail of it. It is important that claimants know where and how to access free and independent advice.
- There is a need for a clearer process (including accessible guidance) around submitting further evidence including what should be submitted and who bears responsibility for submitting it. There is an urgent need for an agreed process for obtaining medical evidence from GPs. Within this there should be an agreement that claimants should not have to bear the cost of providing this evidence.
- There should be greater flexibility in how claimants can submit additional evidence including the possibility of submitting it online and during the assessment.

“The form is far too long. I have severe anxiety and completing forms make it worse. I was unsure of what to write and seemed to have to repeat everything throughout the form/booklet.”

- *Questionnaire Respondent*

“I think everyone should have help filling out the form, this should be mandatory.”

- *Questionnaire Respondent*

“I found it tiring and repetitive and not tailored to my individual disability whatsoever.”

- *Questionnaire Respondent*

“It took over a week to fill out the form and it was very difficult. I always have problems when filling out these types of forms but the change of focus on the questions meant that in some areas there was no way to fully explain how my illness affects me.”

- *Questionnaire Respondent*

“The form took me weeks to complete, and I found it to be one of the most stressful and panic inducing periods of my life. I was extremely uptight while trying to complete my form, I was confused by their questions and didn't understand the differences from DLA to PIP. I was also constantly terrified that I would lose support, as answers were now given points and I didn't know how to fully describe my conditions or if it would meet their points system. It was one of the most degrading experiences I've ever had - being given points if I could go to the toilet or wash myself, and I felt really alone. I had to request several extensions for sending back my forms as I struggled to write and didn't want to humiliate myself asking someone else to write down things like "I can't wipe myself after the toilet".”

- *Questionnaire Respondent*

“I had to fill it out with help from my partner due to lockdown and shielding. and I was so worried I'd word something in a way they would use against me. I struggle with form filling and found the process more anxiety inducing than normal.”

- *Questionnaire Respondent*

“Found it overwhelming to complete, especially as I have mental health difficulties and could not concentrate for long periods. Almost decided not to claim PIP, but I had just lost my job due to mental health issues and long-term sick leave.”

- *Questionnaire Respondent*

“The form is easy but it is not fit for purpose when considering invisible disabilities. It is also re-traumatising when filling out regarding disabilities as a result of an accident.”

- *Questionnaire Respondent*

“As I am a qualified social worker and used to filling out these forms for other people, I did find understanding the form to be OK. I did however find the physical task of completing it to be exhausting and hard work. I think it took me at least a week to fill it out as I had to take breaks. It would be easier if there was an online form you could type on to.”

- *Questionnaire Respondent*

“Distressing completing the form, writing your ailments so someone can judge you. Took about 3 hours.”

- *Questionnaire Respondent*

“I was totally stressed out physically and emotionally filling out the PIP forms. The amount of repeated questions only with a couple of words changed is a complete joke.”

- *Questionnaire Respondent*

“Form was very personal - got depressed filling form in especially the Care Component - form is very lengthy.”

- *Questionnaire Respondent*

“The form was very complicated the questions were misleading. The questions did not ask how your disability affected your day to day life. Just because you can manage money and get from A to B doesn't mean that your disability doesn't have an adverse impact on your life.”

- *Questionnaire Respondent*

“The PIP form was very complicated. The questions were specific and didn't leave a lot of room for explanation or expansion. I found it quite difficult to fill out and even to understand what the questions were even asking. I was also so nervous about my answers as I knew the record of unsuccessful applications.”

- *Questionnaire Respondent*

“It was a very lengthy process to complete. I felt it didn't cover the night time routine well in the way DLA forms do. I felt the question did not address the issues I face in what is normally seen as an invisible disability, dealing with chronic pain. It took me a few days to complete as I couldn't do it in one sitting.”

- *Questionnaire Respondent*

“I found it really challenging and difficult. It took me multiple hours to complete. I found it very stressful to know how best to put it together that accurately reflected my everyday difficulties in a way that was relevant to the form. It caused me severe anxiety.”

- *Questionnaire Respondent*

“It felt like If I wasn't careful I could write the "wrong" answer and lose everything.”

- *Questionnaire Respondent*

“The form is too big – it's massive. Some of the questions I thought didn't relate to my conditions. It doesn't allow you to talk about worst days and how it impacts on your daily living. A lot of my conditions are around balance, memory and my speech but it doesn't focus on these more cognitive things.”

- *Telephone Interview*

“I wouldn't have had a clue to put on the form about my worst days. Without CAB help I wouldn't have went for PIP – I just didn't understand it.”

- *Telephone Interview*

“I had to get help from my local CAB to complete the form. It's very complicated they ask the same question over and over in slightly different ways.”

- *Telephone Interview*

“I feel having other options instead of filling out a physical form like being able to vocally record answers, or even video record answers, would make the initial making of a claim more accessible to applicants. Especially those with muscular or motor difficulties.”

- *Questionnaire Respondent*

“I have MS so I am tired a lot and my concentration is an issue. It took longer to fill out the form. I tried to write half of it on my own but I thought it was too complicated and I couldn’t do it by myself. I rang CAB and they helped me to fill out the rest.”

- *Telephone Interview*

“It would be beneficial if you could have the choice of a paper form or an online one. It’s easier to fill in online. I don’t like writing in forms.”

- *Telephone Interview*

“The forms are far too complicated. There’s a lot of information on the form. They just keep asking the same thing over and over again like they’re trying to catch you out. They ask things in a roundabout way.”

- *Telephone Interview*

“I really needed help with the form. They are looking for a lot more detail than what I would have given. Where I would say a couple of words or two lines they need to know more. CAB really helped me to word it in the right way.”

- *Telephone Interview*

“The form doesn’t deal with mental health properly it doesn’t ask the right questions. It doesn’t take into account the impact of mental health on communication and social interaction. It’s not just being able to go out of the house it is the experience of what happens when you go out.”

- *Telephone Interview*

“The process is not great for mental health issues. It needs some adjusting as not one question fits all people. Even with mental health it does have a physical element but it’s hard to explain that on the form. In the assessment all they want to know is if you can walk a certain distance and while that might be possible physically on the flipside you might not go out very much due to mental health issues.”

- *Telephone Interview*

“I have dyslexia so it is hard for me to understand what they want from the form. It confused the life out of me. Such a long form and they ask the same question over and over again in a different way but it means the same thing.”

- *Telephone Interview*

“People can give up because of the process. It causes more stress filling in these forms.”

- *Telephone Interview*

“I don’t think the PIP form is good for mental health. I deal with depression and anxiety and that doesn’t stop me walking up and down the street and speaking to people - it is not good for more hidden things.”

- *Telephone Interview*

“I have never been as depressed, anxious and utterly hopeless than I was when going through the application for PIP. I found myself hysterically crying every time I tried to fill out their questions on the form. They give you points for things like not being able to wipe yourself after the toilet, and it was totally humiliating to have to write this information down and go through it with an assessor. I struggled with writing because of my disabilities, but was too ashamed to ask others to write this embarrassing stuff down for me. To have to try and write my human experience, my daily struggles, my lifelong disabilities, down on a form and get points for them felt totally degrading. It should never be OK to rank disabilities based on scores or numbers, we are people, we are humans!”

- *Questionnaire Respondent*

“It was extremely challenging. I am a former journalist, used to marshalling facts and writing persuasively yet concisely. I've successfully managed both my own and a friend's previous benefits applications. But my DLA to PIP transfer came hard on the heels of an ESA re-assessment, both of these during two years in which my health got a lot worse, and the PIP application form used a different (and frankly illogical in places) scoring system which clearly will not adequately convey some people's disabilities. It was particularly frustrating that despite having written in great detail about my disabilities for the ESA form, I couldn't simply transfer the same text (I compose my answers on the computer first) into the PIP form, both because questions are asked differently and because I feared that re-using answers (even though in many cases, you're basically saying "all of this is the same as before, plus here are some new details") would be seen as cheating the system in some way.

- *Questionnaire Respondent*

“I wasn't allowed to give new evidence at my face to face assessment. Since sending in my form I had been approved for a blue badge and had a letter from my GP regarding my mobility. Even though I had the paperwork with me I had to post it in separately.”

- *Questionnaire Respondent*

The Assessment

Feedback from the questionnaires in relation to the assessment showed:

- 34% of the women had their PIP assessment at home, 47% in a PIP assessment centre and 19% by telephone.
- 45% of the women ‘strongly disagreed’ that their assessment with Capita provided an accurate reflection of how their condition affected them, 15% ‘disagreed’ with this statement, 17% ‘agreed’ with the statement and only 4% ‘strongly agreed’.
- 57% of the women thought their assessment report did not accurately reflect what happened at their face to face assessment with Capita with 19% thinking that it did accurately reflect their assessment.

Women found the PIP assessment process overwhelmingly negative. Some reported a lack of empathy from assessors and felt that they were trying to 'trick' them or were hostile to them during the process. A number of the women reported issues with the fact that the assessor was typing during the assessment and there was little eye contact or apparent interest in what they had to say. Many felt intimidated and extremely anxious about the process feeling like they were being 'grilled' akin to a courtroom scenario.

Some of the women reported that the assessment process was very prescriptive and some of the tests were not reflective of how their condition affects them. They felt that these tests were not reflective of how their condition impacts on their lives on both 'good' and 'bad' days. Others felt that while they may be able to complete the activities in the assessment it was not reflective of the impact that this effort would have on them afterwards.

A number of the women expressed frustration that the assessors did not understand their condition or were not sufficiently trained in how different conditions are likely to impact on a person's ability to live their life. Many felt that these assessors should be medically trained in order to be able to carry out an assessment properly. This may help to improve issues with the disparity of decision-making between different assessors. Others felt that assessors made assumptions on their ability based on unrelated issues such as looks, age, dress, education, etc.

Some of the women found the assessment very long which in some cases exacerbated their health conditions both mentally and physically. They also reported that the questions in the assessment were repetitive and they felt frustrated that these questions had already been answered on the application form.

Recommendations:

- **There is a need to make better use of the further evidence submitted as part of a claim. The information contained in the further evidence can be very valuable and is often provided by someone who has known the claimant for a considerable length of time. In particular, where medical evidence is provided this should be trusted and used more fully as the basis for making decisions.**
- **The process of having a PIP assessment is hugely stressful for claimants in some cases exacerbating existing conditions particularly mental health issues. There is a great need for the assessment process to be less formal and more claimant friendly.**
- **Various options should be provided to claimants for a PIP assessment including not only the possibility of having an assessment in the PIP centre or in their own home but more widely by telephone or video call.**
- **Many claimants feel that assessors do not understand their conditions and the likely impacts of these on their daily lives. It would make the assessment a fairer and more trusted process if the assessor was medically trained and had an understanding of the specific conditions presented by the claimant.**
- **Assessments should be digitally recorded as standard. The responsibility for recording the assessment should be the Departments and a copy should be provided free of charge to all claimants in a timely manner when requested.**
- **Assessors should be given adequate time after the assessment to use digital recordings to type up notes rather than during the assessment.**
- **More needs to be done to improve the PIP process for those suffering from mental health issues including more emphasis on mental health in the assessment.**
- **There should be an agreed process where carers/companions can input into the assessment and their evidence should be given sufficient weight in the decision making process.**
- **The chances of having a successful outcome for PIP at all stages of the**

process are significantly increased with access to appropriate advice. Sufficient resourcing should be available to ensure that every claimant can access independent advice and advocacy in relation to the PIP assessment should they wish to avail of it. It is important that claimants know where and how to access free and independent advice.

“I would prefer not to have a face-to-face at all! My GP and letters from mental health experts involved in my care should suffice.”

- *Questionnaire Respondent*

“I find the face to face interview very repetitive, just asking the same questions you already stressed yourself out filling in the forms.”

- *Questionnaire Respondent*

“Migraine is listed as one of my conditions and the person assessing me related this to his personal experience and discounted how this affects me because “he got migraines himself and he'd never heard of the symptoms I described”. I was also told that I had to complete the physical movements part of the assessment as it was “essential”, even though they were painful and I lost my balance. This was not reflected in the report - it simply said I was able to carry them out and didn't mention I was holding on to a wall to do them. My daughter was with me during the assessment and on a couple of occasions had to help me remember things and fill in words when I stuttered but this wasn't reflected in the report either.”

- *Questionnaire Respondent*

“I had to try and focus on the worst days. There is an issue about saying things like “I’m not too bad” at these assessments “The assessment was extremely intense, I wasn’t expecting it to be as intense. I was shocked by it – reliving things – for people to have to go through this and their experiences especially if they are in recovery, it’s shocking.”

- *Telephone Interview*

"The first time I was assessed, they gave me very little notice and showed up to my house the day after I got steroid injections in both shoulders and was bed bound. They made me get up and try and show them physical exercises even though I was told to rest for 3 days in bed by my doctors. They didn't know what my conditions were and asked me extremely invasive questions in front of my family, information I had already given in my application form. In my report, they wrote things like: "She is studying a Masters and seems to be intelligent and aware of her own conditions - unlikely to suffer mentally like she states", "She opened a diary while talking to describe her work week. Clearly can use hands without issue and mobility issues aren't as she has stated in her application", "She can drive a manual car to work, issues with chronic pain unlikely", "She has started a new course of disease modifying drugs - likely condition will improve" - even though my conditions can never get better, the drugs were to prevent further bone erosion. Capita assessors are unqualified, do not understand enough about medical conditions, disregard medical evidence from specialists and misinterpret assessments in their reports."

- *Questionnaire Respondent*

"I felt the physical tasks they made me do to test the extent of movement did not in any way reflect my particular disability and the day to day issues I might face with it."

- *Questionnaire Respondent*

"The report was inaccurate and medical evidence was ignored. The assessor was not deaf aware and was offensive. They asked me to perform irrelevant physical movements that did not take into account the energy limiting nature of my illness. Assumptions were made based on how the assessor thought I appeared during just one hour which tells them nothing about the impact of my disability on my life."

- *Questionnaire Respondent*

"I think I got quite lucky because my assessment went ok."

- *Questionnaire Respondent*

“It would have been nice to have had some empathy from the assessor. Also my report was full of inaccuracies and downright lies.”

- *Questionnaire Respondent*

“An understanding that invisible disabilities present differently. More nuance, leaving out aspects of the assessment not relevant to your condition.”

- *Questionnaire Respondent*

“The physical tests were not the ones that show how my illness affects me. I can grip a finger but struggle with stairs or standing for a long period.”

- *Questionnaire Respondent*

“The assessor did not listen to me or seem interested at all, she typed her report while I sat there, she did not ask me to elaborate at all.”

- *Questionnaire Respondent*

“The assessor spent most of the time typing up the responses with very little eye content.”

- *Questionnaire Respondent*

“They appeared to have little knowledge about my condition and how it can affect someone.”

- *Questionnaire Respondent*

“The assessor was aggressive and hostile. She wasn’t helpful and I felt she was trying to catch me out.”

- *Questionnaire Respondent*

“The lady that completed the assessment was polite but all of the information I provided was treated with contempt and this was reflected in the decision. I was turned down initially and scored zero points despite providing a wealth of evidence. I felt like it was a courtroom rather than a medical assessment and felt like I had to prove everything I was saying and it was just the most disheartening, demoralising, awful experience.”

- *Questionnaire Respondent*

“The assessor spoke over me and spoke to my male partner as if my word on my lived experience meant less. It felt like my word was worth less.”

- *Questionnaire Respondent*

“My first assessment report didn’t match what happened at the assessment. The report that came back said she can cook, she can eat, she can go to the cinema. I said where’s the BUT.....”

- *Telephone Interview*

“For conditions that change they don’t seem to care about the bad days they just look at the good days. It doesn’t cater for up and down days.”

- *Telephone Interview*

“The people who do the assessments need to have more knowledge about mental health not just depression and anxiety but complex conditions such as psychosis and bipolar, etc. Assessors need to have more knowledge about how to handle these in a safe way. Not to push and re-traumatise someone.”

- *Telephone Interview*

“I’m someone who is quite capable due to the nature of my job but I wasn’t prepared for the impact of the assessment. I was just so shocked at how intense it was.”

- *Telephone Interview*

“The first time I applied an assessor came out to my house. She had been a nurse and I thought she was going to understand how my condition impacts on me. I was awarded no points! I cried the whole day.”

- *Telephone Interview*

“The assessor was lovely and talked away. She asked me to stand up and checked my weak side and said she could feel the weakness in my hand. The report came back saying my arm and leg on the weak side were fully functional. I was so upset I felt like they thought I was a liar.”

- *Telephone Interview*

“The process was terrible. I felt the assessor had no empathy. She was like a Sergeant Major. She had been a nurse and I thought that would have helped things but it didn’t.”

- *Telephone Interview*

“There was no consideration given to the mental health aspect even though this was detailed on the form.”

- *Telephone Interview*

“It really wasn’t nice, there was no empathy. The assessment didn’t even last 45 minutes. I felt it was not a fair assessment. A different assessor came out the next time and she was lovely. It was a totally different experience.”

- *Questionnaire Respondent*

“I had issues with my report. It said I had dressed appropriately. What has that to do with anything? It doesn’t take account of my bad days when I have to be encouraged to do everything.”

- *Questionnaire Respondent*

“I found the PIP process very humiliating and degrading and the questions were all so repetitive. I was highly embarrassed having to explain toilet needs etc. to a complete stranger on the day of my assessment.”

- *Questionnaire Respondent*

“It is horrible feeling like they didn’t believe you, you just weren’t being believed or that you were telling lies saying that you were worse than you were for just explaining your life”.

- *Questionnaire Respondent*

“It was very embarrassing trying to explain to somebody why you can’t reach the toilet in time.”

- *Questionnaire Respondent*

“It was generally a very degrading experience to go through and a humiliating experience to go through and it is shocking that when my doctor writes about the amount of conditions I go through, including incontinence, that I had to sit and explain them to a stranger”.

- *Questionnaire Respondent*

“After the assessment with Capita I ended up with shingles. The stress was awful.”

- *Questionnaire Respondent*

“People should be seen by their GP who knows them – not someone with no medical background and no knowledge of what they are looking for.”

- *Questionnaire Respondent*

“After the assessment with Capita I ended up with shingles. The stress was awful.”

- *Questionnaire Respondent*

"I had my initial assessment and in the report, got very low points in the mobility section, which I just presumed was accurate. Then I developed another condition shortly after and therefore had to re-apply. This time I got a much higher number of points in that section, even though the new condition wasn't mobility related.

This was good, for me because I was now eligible for the enhanced mobility rate, but it was unexpected - there was no reason for such a variation and I think it's probably an example of how big the disparity can be between different assessors. Thankfully I'm not one of them, personally, but I know that many people are very negatively disadvantaged because of that disparity. It feels kind of like a fluke. Now that my award is up for review, I'm worried that the outcome will be very different this time, even though things have got considerably worse, not better."

- *Questionnaire Respondent*

"Capita assessors need to be adequately trained on different conditions such as Cancer and Alzheimers, etc. They need to be trained and have an understanding of how certain conditions impact on people both mentally and physically. It meant the world to me that my assessor understood what I was saying about my MS at my assessment."

- *Telephone Interview*

"I knew by the attitude of the assessor that she had training on MS. Her attitude compared to the first time I had an assessment was night and day of difference. She asked me how it affected me, how it affected my mood, my memory, depression and anxiety. She didn't ask me to stand up as I was too ill. She was really interested in how my work was impacted. I felt that she got it – she understood how stress affects MS. I remember thanking her for being so good and very understanding."

- *Telephone Interview*

Getting a Decision

Most of the issues reported around getting a decision focused on the length of the decision. Many of the women felt that where there are chronic and lifetime conditions that the length of the award should be longer. They felt there was little point in continually reassessing people whose conditions were unlikely to change. Some felt this was a waste of money. Others suggested that the process for disagreeing with decisions could be better explained to claimants.

Recommendation:

- **The lifetime award for claimants with chronic or lifetime conditions should be reintroduced. Reviews of claims should not take place for those with lifetime conditions and claimants should have the option to submit further evidence if their conditions change or worsen.**
- **The Department should provide more information and clearer explanations to claimants on the processes for disagreeing with PIP decisions.**

“My award was for 18 months as the assessor felt things might improve for me with new treatments but they didn't. If she understood my condition better she would see it is chronic and so 18 months is very unrealistic. Now I have just put in my PIP renewal form so I am nervous about this outcome. I think awards should be for 2 years minimum and that they consider chronic conditions more fully so people don't have to go through the PIP process so soon again.”

- *Questionnaire Respondent*

“Having to reapply every few years for a chronic condition that will not improve is frustrating.”

- *Questionnaire Respondent*

“No reassessments for lifelong conditions. My award will be reassessed soon after an initial two-year award and I'm worried sick about the outcome.”

- *Questionnaire Respondent*

“They know my diagnosis is never going to change it will only get worse. I don’t understand why I have to be assessed again and feel my award should be indefinite.”

- *Questionnaire Respondent*

“With regards to getting a decision I think the process for disagreeing with the decision could be explained more. I should have appealed the decision based on my first assessment but I was unsure how this would affect payments I was receiving at the time or any future assessments.”

- *Questionnaire Respondent*

“I felt flayed. It is not good for my mental health to have to reiterate every detail of my incontinence and my worsening disease over and over again. My underlying conditions are progressive. Even if I end up having a multi-visceral transplant, it will not be a solution, merely a change of problems. That has been true for every medical intervention I’ve had so far. Continual re-assessments of people with incurable, progressive diseases are demeaning and, since that is apparently all the government cares about, also a waste of money.”

- *Questionnaire Respondent*

“When your claim is reviewed they could use previous claims and current medical evidence from GP’s etc. to automatically continue the claim if there have been no changes to the condition. Don’t send the assessment through another filter once done (my PIP was awarded by my face to face assessor then it went through an audit where someone who had never even met me overrode the initial award and gave me nothing).”

- *Questionnaire Respondent*

“Longer awards for people with long-term illnesses, my award is 2 years and I have to go through the whole thing again soon and won’t ever improve.”

- *Questionnaire Respondent*

“A person with life debilitating conditions that will not improve over time should not be forced to go through the same ordeal again and again, it’s difficult enough accepting many conditions without having to justify yourself to a stranger in writing and in person. There is no dignity left by end of the process.”

- *Questionnaire Respondent*

“It’s embarrassing having to fill it in on conditions that aren’t going to improve. Surely they should believe what your GP writes about you. It’s not like they are going to give false information.”

- *Questionnaire Respondent*

Women’s Suggestions for Improvement

As part of the online questionnaire the women who took part were asked to provide their suggestions for improvements to the PIP process. Many of their suggestions are summarised within the recommendations for change above but their individual comments provide valuable insights into what needs done to improve the PIP process. Some of their comments are detailed below.

“I am lucky I am astute with forms but I know that most people need help. Perhaps a quicker process and a fair hearing at assessment and also proper representation.”

- *Questionnaire Respondent*

“Online claims instead of writing and a realisation that not all disabilities are visible. Understanding that some days are a lot worse than others.”

- *Questionnaire Respondent*

“Assessors should be made more aware of particular illnesses. Why are Reviews being done if illness is progressive and will last a lifetime without a cure?”

- *Questionnaire Respondent*

“When making a claim the form could be better, allowing for more tailored questions on multiple conditions. If evidence is needed it should be made clear what evidence exactly is required. I genuinely believe my second assessment went better because I had included a print out from my GP surgery stating my diagnosis. This was no different to what I had written on the form on both occasions but it would appear that piece of paper held more weight than my word. The person carrying out the assessment should be more up front about what is and isn't necessary, as during my second assessment the assessor pointed out that sections of the physical test could be dangerous for me and I didn't have to do them but just talk through how I would feel.”

- *Questionnaire Respondent*

“Actually take the medical evidence on board and ban CAPITA from the process - they send assessors that don't have a clue about complex conditions and they then discredit evidence you have from your medical team. For life long regressive conditions, it should be a life time award. I only got a 2-year award and just one year after my first traumatic process of applying for PIP I had to do it all over again. It is the biggest stress in my personal life and I hate every minute of it.”

- *Questionnaire Respondent*

“The phone only option was not ideal, there are other options like Zoom or Microsoft Teams and captions need to be a standard on these. I also heard they used using a phone against people even though they offered no other option. There needs to be more clear information, throughout lockdown the lack of information was really stressful and it made the entire process worse than it has been historically.”

- *Questionnaire Respondent*

“They could actually use assessors that have knowledge on certain conditions. I had a nurse that wasn't even aware of the severe allergies I have and how they restrict my entire life. How is that fit to assess my conditions?”

- *Questionnaire Respondent*

“Reports and/or letters from experts (clinical psychotherapists, for example) involved in your care ought to be more valuable than an under-qualified PIP/DWP assessor.”

- *Questionnaire Respondent*

“People who understand the condition you have should do the assessment. GPs should be trusted. Assessment should be short and simple.”

- *Questionnaire Respondent*

“Take all medical evidence into account - the Department should not be able to override or ignore evidence. Have an easy, clear and free way of getting medical evidence. Educate assessors about disabilities and conditions. Generally, for the Department to stop hating disabled people.”

- *Questionnaire Respondent*

“My own GP and cardiologist have a deeper understanding of my conditions having treated me for many years. The decision should have been made using the evidence provided by them and not a 40-minute assessment by a physiotherapist.”

- *Questionnaire Respondent*

“Face to face assessments are extremely stressful. There has to be a better way of checking claims. Sending in vast amounts of evidence should show how much conditions impact someone's life. There should be a way of having shorter assessments or telephone assessments for people with multiple long term illnesses backed up by evidence.”

- *Questionnaire Respondent*

“I understand that due to Covid-19 that there are telephone assessments. If I had been given this option, I think I would have been able to explain my conditions better and it would have been less stressful.”

- *Questionnaire Respondent*

“People should be able to choose whether their assessment happens at a PIP centre, at home via telephone or video link, or at home with a visiting assessor. Everyone should be assessed by a medical person in the first place and a medical person should make the final decision. I realise that not all people with a medical background will be understanding or sympathetic or very understanding of the everyday minutiae of how our conditions affect us. But it's important for the claimant to have a choice about who assessors contact. If they trust someone on their medical team who has a particularly good grasp of their circumstances, then why can that person not be allowed to send an email or have a phone call with an assessor as standard? Why drag the claimant into a nerve wracking phone call, or appointment at a PIP centre, where we are very well aware that every move we make, every nuance of our speech, is being examined to see if we are lying or not? The current system hugely disadvantages people with neurodivergent conditions and mental health problems, to name just a few. I also think claimants need to have an option to bring an independent person in with them I know I need someone with me for moral support. You need someone on your side in that room. Assessments need to be digitally recorded as standard, with a copy provided to the claimant at the assessment centre's expense, and/or we need to be allowed to make our own digital recordings.”

- *Questionnaire Respondent*

“The assessment could be less prescriptive. The time taken from claiming to award is too long. My original claim took 10 months and this review claim is heading for the same timeframe.”

- *Questionnaire Respondent*

“Assessments should consider doctors reports without making face to face visits. They should also not assess on how they see people on the day because I could be having a good day when they see me rather than seeing me when I am really ill and unable to move.”

- *Questionnaire Respondent*

“I think having several assessments would also be more beneficial especially for those whose conditions fluctuate on a daily basis. Being able to speak with a real person would make the final decision easier to understand and easier to accept, instead of a black and white, copy-and-pasted letter saying your condition is not life limiting, you're fine, you don't need this money.”

- *Questionnaire Respondent*

“More flexibility with deadlines (a longer deadline) would help because the language around this is quite threatening. I also don't think there should be pressure to provide medical evidence because this can be very difficult to get, and I don't think people should be penalised for being unable to obtain this.”

- *Questionnaire Respondent*

Q4. From your experience, what impact do awards of PIP have on claimants' ability to stay in, or return, to employment?

Some of the women reported that their job (due to the nature of the work or hours worked) negatively impacted on their health but they couldn't afford not to work and so ended up having to stay in these jobs and ultimately make their health conditions worse. As a result of austerity and cuts many disabled people have reportedly been pushed into unsuitable work in order to survive.

The award of PIP enabled some of these women to be able to reduce their working hours so that they could both manage their condition and their work. For others it allowed them to stop working that job and provide them with an income until such times as they could find more suitable work. In addition, some other women reported that their PIP award allowed them to pay for the costs of transport to enable them to work or stay in work.

It is also important to note that awards of PIP are not just important in terms of the ability to stay in or return to employment. Where claimants are not able to work PIP awards can be transformative for their lives in terms of their

independence, the ability to socialise and travel and the ability to make their lives better through the purchase of specialist equipment/treatments.

“PIP provides me with money towards travel. I rely on taxis quite a lot for work.”

- *Questionnaire Respondent*

“PIP was no help either way - my illness dictated my ability to stay in/leave employment.”

- *Questionnaire Respondent*

“PIP has meant I can look at fewer hours which are flexible to suit my disability.”

- *Questionnaire Respondent*

“I was able to change employment to a more suitable role and PIP supplemented my income while I made the move.”

- *Questionnaire Respondent*

“Not receiving a PIP award put me in a cycle of working jobs that would make my health worse, because if I didn’t work, I would have no home or food. I had to choose between my health and money. Money won. But with no help from PIP.”

- *Questionnaire Respondent*

“I have ongoing mental health issues and cannot work at the moment. However, had I received PIP while still working, the money I received might have allowed me to reduce my hours without a huge financial penalty (inability to pay rent, for example), which might have meant I would not have lost my job in the first instance.”

- *Questionnaire Respondent*

“I’m petrified to let PIP know that the support they’ve awarded me, the Motability car with adaptations to meet my mobility needs and the extra money to cover the additional costs of living with a disability has completely and utterly changed my life. My pain levels, whilst still chronic and constant, are more manageable and I’m able to engage in therapies that I was excluded from before due to pain and anxiety. I’m able to be a fuller part of society, living rather than surviving. I’m able to attend therapies, exercise, socialise, study, volunteer and I’m about to start a job (albeit with reasonable adjustments and on a part-time basis). How can I ever tell them that I’m getting better because of that support, when they’ll just take it away and I’ll be back to square one. Even with a 10-year award, I’m still on edge that it could all be taken away at any moment. I’d like to be able to live without that fear.”

- *Questionnaire Respondent*

“I’ve had to stay in full time employment instead of cutting to part time which is worsening my health, including a month signed off sick.”

- *Questionnaire Respondent*

“It has been the worst experience of my life. I am constantly afraid of them taking more of my support away. They already took my car, which was the only way I could get to work. I had to spend £50 a week in taxis to get to work as a result and got severely depressed.”

- *Questionnaire Respondent*

“I had been working full time and relapsing 3 or 4 times a year. If I hadn’t been awarded PIP I would have had 2 options – keep working full time and end up very ill or get very ill and come out of work and claim the brew. PIP gave me options and allowed me some breathing space. I was able to work part-time hours and be able to afford to feed my children and look after my health. If I hadn’t been awarded it I would have ended up claiming Universal Credit and not working.”

- *Telephone Interview*

“Going through the PIP application process was one of the worst periods of my entire life. I went from high rate mobility on DLA to low rate mobility on PIP, and lost my only support that gave me any independence. I previously had a Motability car with adaptations which enabled me to work part time and study. When they took this away from me, my life completely changed and I spent months in bed crying. When I had my Motability car, I was able to make the short mile long journey to my work and had an accessible parking space for me at the door. When they took this from me, I had to spend £60+ a week to get to my place of work in taxis and spent many mornings at home crying and having panic attacks as I tried to explain to taxi drivers why I needed them to take me on a 3-minute drive each day.”

- *Questionnaire Respondent*

“In my assessment I felt like I was punished for working part time and furthering my studies. They took away my mobility support and it was the only thing that enabled me to work or study in the first place. I fell into a deep depression for two years after they removed my mobility support and struggled to get out of bed or out of my house due to the pain and anxiety I suffered in trying to get around without my car.”

- *Questionnaire Respondent*

“It allowed me flexibility to manage my condition which is lifelong. I have had to learn to manage something that I will have the rest of my life and PIP allowed me to do this. It allowed me to stay in work and has been a lifeline to enable me to do this. It helped me buffer a substantial loss in earnings. It has helped me to manage my home, my disability, my work and my health.”

- *Telephone Interview*

“It has meant that I’ve been able to go out more places and see my family, go to the women’s centre and do stuff with the other women there. Before I got the car I couldn’t do that. The wee women are great they keep me going.”

- *Telephone Interview*

“It gives me a bit of independence – I can go to classes in the women’s centre – it’s good to get out and meet other women.”

- *Telephone Interview*

“PIP has helped me to get the equipment I need. I can’t get grants for it elsewhere or through the NHS. Hearing is a big problem for me. I can’t hear without aids. I got vibrating pillows which cost £80 to help with everyday life. These are expensive and I would never have been able to afford them without PIP.”

- *Telephone Interview*

“PIP helps me to travel as well as I don’t drive. I get taxis as there are too many people on public transport and I get anxious. It helps me with my hospital appointments which are all about 6-10 miles away.”

- *Telephone Interview*

Q5. How does the PIP process compare to similar assessments (e.g. Employment and Support Allowance, an occupational health assessment)?

In March 2020 the Minister for Disabled People, Justin Tomlinson announced plans under the Health Transformation Programme for a single service to deliver all disability benefits assessments.¹⁹ This will reform assessment services for Employment & Support Allowance, Universal Credit and PIP. The statement discusses the “*transition towards an integrated assessment service, with a single digital platform*”. We note the Government’s intention to pilot this before rolling it out and their intention that assessments would be conducted by the DWP rather than being outsourced to providers. While we welcome the Government’s commitment to transform how disabled people are supported we would have concerns over any intention to use algorithmic decision making through the online platform. We do however welcome the intention for assessments to be carried in-house rather than being outsourced.

¹⁹ <https://questions-statements.parliament.uk/written-statements/detail/2020-03-02/HCWS138>

While we do not have feedback from women around how PIP compares with other assessments. However, it would seem that there have been less problems reported with the assessments for these other processes compared with PIP. That, in itself, should provide some indication of where the problems are for the PIP assessment process.

Q6. In your experience, what are the reasons for people making an appeal to The Appeals Service and what is their experience of this process? Please provide examples.

We believe there are a number of reasons why people would make an appeal to The Appeal Service:

- They were previously in receipt of a DLA award and were not entitled to PIP or were awarded a lower award of PIP
- They were not awarded PIP or received a low award and they strongly believe they are entitled or entitled at a certain level
- They did not have a good experience at their assessment and feel like it did not reflect their circumstances (they may have felt they were not listened to at the assessment or that their assessment report did not match what actually happened during the assessment)
- They asked for a Mandatory Reconsideration but there was no change to their decision.

Of those women who had experience of the appeal process most reported extremely negative experiences. Many discussed the legalistic and formal nature of this process and how it felt like a “court room”. They talked about feelings of extreme distress and anxiety and the impact that it had on their medical conditions before and even after the appeal. For many the appeal process re-traumatised them and they felt like it was designed to deter them. Others raised the length of time the appeal process took reporting that it was very long.

The appeals figures detailed in Section 2 of this response give rise for concern. The rises in the successful number of appeals over the last number of years most recently rising to 76.4% of successful appeals in 2019/20 illustrates that there is

something wrong with the assessment process. The fact that over three quarters of appeals are overturned is a clear indication that lessons must be learned from these appeals and fed back into the assessment process so that action can be taken to make it more effective. Appeals put claimants under enormous stress and sometimes even the thought of an appeal can be a deterrent from pursuing access to justice. In addition, appeals are very expensive. It would be more efficient in terms of spending public money if a more effective and fair assessment process was in place so that the right decisions are made at the start of the process.

“Dehumanising and anxiety inducing.”

- *Questionnaire Respondent*

“Utterly terrifying. Feeling like a criminal having to go to court and argue about a condition I live with every day. Again, it is re-traumatising, repeating things you have already written and discussed during the assessment and having to do it once again with people you don’t know. It felt humiliating and like my privacy was being invaded. Why a doctor and other medical specialists backing up your claim is not enough, I have no idea.”

- *Questionnaire Respondent*

“It was an awful experience and a very long process.”

- *Questionnaire Respondent*

“The appeal feels like a court and jury. It doesn’t feel like a medical thing it’s a really scary environment. I was really taken aback by how formal it is – it’s scary to face that. I felt guilty before proven innocent, I had to prove to 3 professionals that I have this condition. One of them was lovely but it was still really scary.”

- *Questionnaire Respondent*

“My original claim ended in February 2020 and it is being reviewed. My first claim was awarded on appeal and the experience was traumatic. I was extremely anxious and found the process overwhelming.”

- *Questionnaire Respondent*

“I felt the appeals process was a mountain to climb and hugely unnecessary if the original assessment just looked at all the evidence I had provided.”

- *Questionnaire Respondent*

“I didn’t appeal the decision because I was so broken down by the whole process. refused to buy my mobility car because I just didn’t want anything related to them.”

- *Questionnaire Respondent*

“The appeal process traumatised me, it made me sick and it made my condition worse.”

- *Telephone Interview*

“It was truly awful, when I went to tribunal I was given an immediate decision without having to sit in with professionals to pour over things, my medical evidence was sufficient and so why was it not accepted originally? A waste of your own time and resources.”

- *Questionnaire Respondent*

“I was sick to stomach with nerves the day of the Tribunal. I thought I’m going to have to go and prove to complete strangers that I’m sick.”

- *Telephone Interview*

“The whole contact process with them feels designed to make you give up.”

- *Questionnaire Respondent*

“When I walked into the Tribunal there was a lady in the back of the room on a typewriter and that immediately threw me. It was like a courtroom. There were 3 people there. One of them was quite abrupt and I remember thinking he doesn’t like me. The questions were OK until they asked who looks after me at home and when I talked about the children having to help me I started to cry. One of the panel members said that if I didn’t stop crying they would have to stop proceedings. I said this is very difficult, you don’t know me, it’s very traumatic talking about such personal things like incontinence.”

- *Telephone Interview*

“I took a relapse after the Tribunal and I had to go off work for about 8 weeks. I definitely attribute my relapse to the stress of the Tribunal. It affected my ability to work as I ended up completely housebound.”

- *Telephone Interview*

“I have MS. You shouldn’t have to prove that you have this illness. I felt that I had to prove it. I took a relapse 8 weeks after having to go to the Tribunal – it was very traumatic and I’ll never go through a Tribunal again in my life. It was the worst experience of my life by a mile. I was eventually awarded high rate care for a significant length of time and I thought finally I don’t have to prove that I have this.”

- *Telephone Interview*

“To be diagnosed is hard enough but to have to justify it is even harder. It is like being re-diagnosed again. I’ve had to put the Tribunal behind me.”

- *Telephone Interview*

“I wasn’t asked at my assessment or Tribunal about my mental health issues even though it was mentioned in my medical report. I take tablets for depression and suffer from panic attacks. This is all in my records yet I was never asked about it.”

- *Telephone Interview*

“If I had to go to a Tribunal again I’d rather lose my money. I’d tell them to keep their money unless the format had changed in some way.”

- *Telephone Interview*

“It was like a job interview, they were all staring at you and questioning you. I had all the same things wrong with me then as I do now and not much has changed. I felt that they didn’t believe a word that came out of my mouth. They didn’t care what state I was in and that I suffer from stress and anxiety. It brought on an asthma attack and I felt like they thought I was putting it on for badness.”

- *Telephone Interview*

“My sister came in with me but she wasn’t allowed to speak. She just sat and held my hand. She was disgusted with the process.”

- *Telephone Interview*

“Appeals should be less formal. It’s like walking into a lions den with their big booklets and clipboards and you don’t know what they are writing. It’s all very formal and they don’t put you at your ease – it’s scary.”

- *Telephone Interview*

Q7. Where you have evidence of any of the following, please describe how effective the PIP assessment is:

a. For people with one condition?

We believe that the PIP assessment may be more effective where claimants have only one condition particularly where the condition is not a complex one and where it manifests itself in one particular way. Where single conditions are more complex, for example, Multiple Sclerosis, the evidence suggests that the assessment is not always effective. We also have concerns about how effective the PIP assessment is for mental health conditions even if the claimant only has one mental health condition. 70% of the women who provided responses to the online questionnaire felt that the PIP assessment was ineffective for mental health conditions.

b. For people with more than one condition?

In questionnaire responses 79% of women felt the PIP assessment process was ineffective for multiple and fluctuating conditions. This is often the case where there are mental health issues among the claimant's conditions and a number of women reported that these had largely been ignored in the assessment.

"I felt the process to be extremely stressful. The form was confusing, all I had heard were horror stories about the assessment and I was so anxious about explaining my conditions and symptoms. I have multiple conditions and it was very difficult to address all of them. The assessor obviously hadn't heard of some of these conditions or understood what some of my symptoms meant."

- *Questionnaire Respondent*

"I have more than one condition that affects me, all of which are very debilitating in their own right but there is very little scope to explain this on the form."

- *Questionnaire Respondent*

c. For people with conditions that change (fluctuating conditions)?

In questionnaire responses 79% of women felt the PIP assessment process was ineffective for multiple and fluctuating conditions. Fluctuating conditions are difficult to assess by their very nature as claimants can have 'good' days and 'bad' days. There is a tendency for people to understate the impact of their health conditions on their life particularly when they have a 'good' day. The assessment does not do enough to tease out the impact of 'bad' days on the claimant.

"My condition fluctuates heavily. I didn't want to "put on" or act up for my condition. Some days I can seem almost completely normal. Other days I cannot move, cannot lift my head, cannot walk. I didn't feel a one-hour assessment gave an accurate representation at all and feel several assessments could've been more useful."

- *Questionnaire Respondent*

“I had my assessment on a good day in the middle of the summer. It was not a true picture of my day to day life. It didn't even take into account that I wear a hearing aid.”

- Questionnaire Respondent

“I honestly felt so vulnerable and embarrassed and like I had to prove that my condition was worthy of being considered, when there should be no question about it at all. I felt that the whole process was far too standardised without any real consideration for how varied disabilities are. The nature of my condition fluctuates and I also did not feel that was accommodated for by the process. I felt that I didn't really get a chance to showcase my individual condition as opposed to showing how my disability does/does not fit within a standardised narrative.”

- Questionnaire Respondent

“More awareness of fluctuations in symptoms, i.e. just because I can walk up the road on one day doesn't mean that it then doesn't impact on my energy levels for the next two days and make me bed bound. I kept getting asked how far I could walk - no idea, it changes with how my symptoms are presenting but they kept pressing for a definitive answer which then undermined and invalidated my condition.”

- Questionnaire Respondent

d. **For terminally ill people?**

The High Court in Northern Ireland has ruled that the different treatment of social security benefit claimants with a terminal illness is “*manifestly without reasonable justification and is, therefore, in breach of Article 14 ECHR in conjunction with Article 8 and Article 1 of Protocol 1.*”²⁰ In a decision handed down by Mr Justice McAlinden he said: “*I can find nothing to justify or indeed explain why those individuals who have a terminal diagnosis but are not expected to die within six months and those individuals with a terminal diagnosis and who are reasonably*

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<https://judiciaryni.uk/sites/judiciary/files/decisions/Cox%27s%20%28Lorraine%29%20Application.pdf>

*expected to die within six months but who survive beyond that six month period are treated differently."*²¹

This follows a case taken by Law Centre NI and the PILS Project for Lorraine Cox²² who was diagnosed with the terminal illness of motor neurone disease. Lorraine was refused access to the special rules for terminal illness because she could not demonstrate her death was reasonably expected within six months. The special rules for terminal illness allow terminally ill claimants fast track access to benefits without the need for additional assessment and conditionality.

The judgement makes it clear that the current treatment of different groups of terminally ill claimants is discriminatory. Law Centre NI advocated for a move towards the Scottish approach where *"medical practitioners will use their clinical judgment to determine whether an individual is terminally ill for the purpose of accessing disability assistance under Special Rules"*²³ making no reference to any time restriction of six months. Indeed, this was a recommendation made by the first independent review of PIP (Recommendation 6) which recommended the removal of the six months life expectancy criterion.²⁴

The Alliance Party MLAs Kellie Armstrong and Paula Bradshaw brought an Assembly motion on 6 October 2020 calling for the removal of the cruel six-month rule for benefit claimants:

"That this Assembly welcomes the recommendation, in the Walter Rader Independent Review of the Personal Independence Payment Assessment Process in Northern Ireland, that the six-month life expectancy criteria be removed from the terminal illness rule; notes the work of the All Party Parliamentary Group on Terminal Illness inquiry; recognises that there is significant evidence and support for reforming the six-month rule in all relevant welfare benefits among a wide range of local stakeholders; further

²¹ Ibid

²² <https://www.lawcentreni.org/news/high-court-decides-different-treatment-of-terminally-ill-claimants-is-discriminatory-1>

²³ <https://www.gov.scot/policies/social-security/terminal-illness/>

²⁴ <https://www.communities-ni.gov.uk/publications/independent-review-personal-independence-payment-pip-assessment-process-northern-ireland-report>

welcomes the recent establishment of an Assembly All Party Group on Terminal Illness; and calls on the Minister for Communities to bring forward immediately legislation to remove the six-month rule, provide guidance to health professionals and adopt a fairer definition of terminal illness.”

There was cross party support for this motion and the Minister for Communities has committed to look at the definition of terminal illness and change the Special Rules process which we welcome.

e. In identifying whether someone is eligible for the standard rate or the enhanced rate?

We have no specific evidence on this issue but we would point to the appeal figures and highlight that the number of successful appeals may be an indication that the assessment is not good at identifying this.

f. In identifying those eligible for the mobility component of PIP as a result of needs arising from their condition?

Again we have no specific evidence on this issue but we again point to appeal statistics which may point to the fact that the assessment is not good at identifying this.

Q8. In your experience what types of further evidence do claimants send in as part of their claim?

Women who responded to the questionnaire and individual interviews discussed a range of further evidence provided as part of their claim:

- GP notes and letters;
- Letters and reports from hospitals and hospital consultants;
- Letters and reports from mental health teams, occupational therapists, physiotherapists, support workers, specialist nurses, incontinence services, educational psychologists, speech and language therapists;
- List of medications and prescriptions;
- Blood and scan results;
- Copy of Blue Badge;

- Copy of medical aids purchased
- Letters from family members, carers, etc.

"I keep a record of all my appointments, all letters and correspondence as well as copies of my medications by photocopying the cover of my medication tray. I basically send all my medical records."

- *Questionnaire Respondent*

"I requested copies of my medical notes from my GP in advance of filling in the form. I sent copies of hospital letters, scan and test results, treatment plans and reports from surgeries and treatments. I also sent in a diary of a typical week of all my symptoms as well as a full list of my conditions, medications and all my consultants and doctors."

- *Questionnaire Respondent*

"I got a letter from my neurologist and speech and language therapist to prove my speech was affected by my MS. The neurologist wrote a letter and gave a copy of my report. My GP also wrote something about my mobility issues on one side."

- *Telephone Interview*

"I included the full 14-page report from my clinical psychologist, regarding my then recent diagnosis of Autism Spectrum Disorder. It's not the basis of my claim (I have three separate digestive diseases and am tube fed), but I knew I would be having a face to face interview and the autism diagnosis process had made clear to me that people often find me hard to read. I was worried that if I didn't make enough eye contact, the assessor would think I wasn't being honest. I forget whether I included a letter from the gastroenterologist about my other problems or not."

- *Questionnaire Respondent*

"I'm sending away my review application this week, and so far I've just got a letter from a family member about how I have been, from their perspective. I feel like I should probably ask one of my housemates if they would write something too, to add more quantity to my application but it's such a personal and sensitive thing to have people writing about, and I don't feel very comfortable asking for that, because I don't want other people to know that I struggle with very basic things like showering or changing clothes. I've also attached a photocopy of my medication script. I tried to get more evidence by asking my consultant if she could write anything, or if I could have copies of her letters, but she said this is considered 'private' work and she doesn't do private work, so I should ask my GP for those letters. But when I rang my GP, the receptionist said that they don't give this information out to patients and I would have to schedule a routine appointment with a doctor (which would take 3 weeks) and discuss the issue with them."

- Questionnaire Respondent

Q9. In your experience what further evidence does Capita request on claimants' behalf? Is this requested on time and used appropriately and fairly?

The process is unclear as to who should request the evidence whether it is the claimant or Capita. The Rader Review²⁵ states that: *"it is clear that there is either a breakdown in the sourcing of evidence by the Department and Capita for numerous claimants, or that the literature claimants receive does not contain clear advice. The net effect is that decisions are being made at various points of the process without access to all the relevant information."*

Q10. Is it clear what further evidence claimants' are being asked to provide. Please briefly explain your answer.

Questionnaire results backed up by individual conversations with claimants showed widespread confusion from claimants about what further evidence they should provide. 72% of those who completed questionnaires stated that it was

²⁵ Personal Independence Payment, An Independent Review of the Assessment Process, Walter Rader, June 2018, Page 50
<https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-independent-review-pip-assessment-process-june-2018.pdf>

not clear what further evidence they were being asked to provide to support their PIP claim.

“The list of possible sources confused me a bit. I contacted my GP and consultant to ask for some of my notes as the form requested this, but they both told me that they don't give that out to patients and PIP would have to contact them directly themselves.”

- *Questionnaire Respondent*

“Very confusing as to what to submit.”

- *Questionnaire Respondent*

Q11. From your understanding, when a claimant submits their claim how important do they think it is to submit further evidence? Please briefly explain your answer.

The majority of the women who completed online questionnaires felt that the submission of further evidence to support their PIP claim was important. 66% felt it was very important with a further 13% reporting it was slightly important. 19% were unsure of its importance and only 2% felt it was not important to submit further evidence.

We believe that it is important that assessors have access to expert evidence. In the absence of this evidence the assessment is based on a short examination/discussion of the claimant's condition and many assessors do not have specific knowledge of all the conditions which they may be required to assess. We would stress that the provision of expert experience as part of making a claim will lead to a better assessment of entitlement to PIP and ensure that claimants are less likely to have to go through the mandatory reconsideration and appeals processes. This will ultimately result in a more robust process, lessening the distress felt by claimants and avoiding the need to have to access the costly appeals process.

Q12. From your understanding are there any barriers for a claimant in providing further evidence? Please provide examples.

There were a number of barriers discussed by women in providing further evidence to support their claims. Initially some of the women were unclear what needed to be provided (see answer to Question 10). Clear and accessible guidance is needed to help claimants understand what evidence they should provide to support their application.

Women reported reflecting on all the different health professionals they had interactions with and trying to get evidence from each of them. This placed a burden on the woman trying to gather this evidence and often within a relatively tight timeframe. This caused them stress and anxiety and they also acknowledged that they were putting the health professionals under pressure for this information when they were already very busy. This is only likely to increase as a result of the Coronavirus pandemic.

Obtaining medical evidence can be more difficult than other types of evidence and is often given more weight in these assessments. However, the policy of providing medical evidence to patients varies considerably between practices. Some GPs have a policy of not providing medical evidence and others do provide evidence but will charge for this. 17% of the women who answered the questionnaire reported that they had to pay to get their medical evidence. The amount they had to pay varied between a £10 administration fee to £50. This is clearly a barrier to providing further evidence especially for those on the lowest incomes. There is an urgent need for an agreed process for obtaining medical evidence from GPs.

Some claimants may not have the relevant evidence to support their claim particularly those with long-term conditions who have no ongoing engagement with their health care professional.

Others may face issues due to long waiting lists for medical appointments. This can impact on their ability to provide the necessary information to support their claim. This is particularly the case in Northern Ireland where waiting lists have been described as being in crisis and waiting times are significantly higher than GB. The draft 2020/21 Ministerial diagnostic reporting turnaround target is: *“By March 2021, 75% of patients should wait no longer than 9 weeks for a diagnostic test, with no patient waiting longer than 26 weeks”*.²⁶ However the most up to date figures show that this was not achieved by Northern Ireland as whole with 73.8% of patients waiting longer than 9 weeks. This figure had increased significantly from the 2019 figure of 55.1%. In addition, 35.1% of patients were waiting longer than 26 weeks for a diagnostic test.²⁷ These issues must be noted by decision makers and in these circumstances guidance should state that the claimant’s own evidence and any evidence from other sources should be given greater weight.

While medical evidence is often given more weight in assessments the value of evidence submitted by companions (including carers, family members and friends) seems to be less clear. This is despite the fact that they can often give very valuable insights into how the claimant’s conditions impact on their everyday life. Many claimants, particularly those who are more vulnerable and those suffering from mental health conditions, greatly benefit from the input of companions. Not only can companions provide support with the stress/anxiety often experienced during the assessment but they can often describe better how a condition impacts on a claimant, prompt them to remember issues they have and talk about issues that the claimant may be too embarrassed to discuss.

Indeed, the benefits of companions was highlighted by the Work and Pensions Committee²⁸ *“Some claimants may be unable or embarrassed to explain the full*

²⁶ Northern Ireland Waiting Time Statistics: Diagnostic Waiting Times Quarter Ending June 2020, August 2020
https://www.health-ni.gov.uk/sites/default/files/publications/health/hs-niwts-diagnostic-waiting-times-q1-20-21_0.pdf

²⁷ Ibid

²⁸ PIP and ESA assessments, House of Commons Work and Pensions Committee, HC 829, February 2018

implications of their condition to their assessor. Companions can help them to articulate these and support claimants during a potentially stressful process. Their role in assessments is vital.” Despite the fact that this input can be very valuable many claimants report that companions are not given an opportunity to speak at the PIP assessment. There is a need for detailed guidance on how and when companions can provide evidence for PIP as was recommended by the Work and Pensions Committee.²⁹

We also believe that many companions at assessments are women. This may be particularly the case where a young person is moving from DLA to PIP at age 16. It is likely that in many of these cases it will be the mother of the child who will act as the companion at the PIP assessment. We would like to see gender disaggregated data on the number of companions who attend assessments.

There is a perception among some claimants that medical evidence submitted to support their PIP claims is being ignored within the assessment process. This clearly suggests to claimants that this further evidence is not viewed as important and devalues its worth within the process.

“I submitted letters from my GP, mental health team, OT, physio and rheumatologist but all of this information was ignored by my assessor.”

- *Questionnaire Respondent*

“I submitted letters from health professionals and medical appointment letters. My medical evidence was ignored by PIP assessors.”

- *Questionnaire Respondent*

<https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/829.pdf>

²⁹ Ibid, page 29, paragraph 50

"I'm not sure it's worth sending further evidence, they didn't even contact my consultant, whose details were listed on the form, to find out about how my stroke affects me."

- *Questionnaire Respondent*

"I sat down and thought of all the people I had engaged with about my condition and rang them up and went round each of them to gather further evidence myself. I found it stressful having to go round and get all these things. Putting pressure on people – saying I need these things tomorrow. I was conscious that these people are busy too."

- *Questionnaire Respondent*

"The experience was very difficult and required hours of evidence gathering including having to pay a £50 fee to access medical records."

- *Questionnaire Respondent*

"I have multiple regressive lifelong physical and mental disabilities. I submitted 15+ pages of medical evidence about these from various specialists, occupational therapists, surgeons, GPs, physiotherapists and councillors. My evidence stated that my disease had damaged my bones, muscles, tendons and immune system and that it would never get better as there was no cure; the damage to my body was done and it was likely to continue worsening. I was still only awarded low rate daily living and low rate mobility PIP for two years as they believed my condition "was likely to improve" and almost as soon as my first year on PIP ended, I had to go through the whole process again. It was so frustrating to see all of my medical evidence be dismissed, and to have to unnecessarily go through the PIP process twice in two years. Going through the PIP process is the worst time of my life and I constantly live in fear and anxiety over it."

- *Questionnaire Respondent*

Q13. Have you previously submitted other evidence to the Department for Communities e.g. from previous benefit claims, that you feel was relevant or should have been considered in the claim for PIP? Please briefly explain your answer.

We have no specific evidence on this issue.

Q14. Are there other parts of government (e.g. the NHS, social services) that hold information on claimants that you feel was relevant or should have been considered in their PIP claim?

We have no specific evidence on this issue.

Q15. If you had other evidence available on claimants that you felt would be relevant, would you consider submitting this as part of the PIP claim?

We have no specific evidence on this issue.

Q16. In your experience, when a claimant goes through the appeals system do they submit further evidence at this point?

Appeal statistics referred to previously would suggest that given the high rate of success at appeal that this may be partly due to further evidence being submitted at this stage. The Northern Ireland Audit Office report on Welfare Reform highlighted that 55% of cases heard at appeal were overturned stating that *“this may, in part, be due to additional evidence being made available by claimants.”*³⁰

Q17. Since the first PIP Independent Review, DfC has implemented a number of the suggested recommendations. In your experience, how have these changes altered the experience of people going through the PIP claim process?

In general terms it was felt that there has been little improvement in the process over the last number of years. Information and outreach events have been held however in order to be properly effective claimants need information at the right

³⁰ Welfare Reforms in Northern Ireland, Northern Ireland Audit Office, 17 January 2019
<https://www.niauditoffice.gov.uk/sites/niao/files/media-files/Welfare%20Reform%20Report%202019.pdf>

time. So these types of events are best around the time when a claimant needs to apply for the benefit so timing is crucial and that is difficult to achieve. We believe that there is no substitute for independent advice as it is clear that outcomes are better at all stages when claimants have access to good quality advice. Advice should be freely available to all claimants to properly support them through the PIP process.

With regards to audio recording of assessments we understand there is a pilot around this issue. Audio recording of assessments can be facilitated at assessment centres but for claimants who have an assessment at home the process is more restricted. We believe that audio recording should be provided to all claimants including those that have home visits and that the onus should be on Capita to carry this out.

We firmly agree with the assertion and recommendation by the Work and Pensions Committee ³¹ that: *“Successive evidence-based reviews conducted on behalf of the Department have identified a pervasive culture of mistrust around PIP and ESA processes. This culminates in fear of the face-to-face assessments. This has implications far beyond the minority of claimants who directly experience poor decision making. It can add to claimant anxiety even among those for whom the process works fairly. While that culture prevails, assessors risk being viewed as, at best lacking in competence and at worst, actively deceitful. Addressing this is a vital step in restoring confidence in PIP and ESA. **The case for improving trust through implementing default audio recording of assessments has been strongly made. We recommend the Department implement this measure for both benefits without delay. In the longer term, the Department should look to provide video recording for all assessments.**”*

³¹ PIP and ESA assessments, House of Commons Work and Pensions Committee, HC 829, February 2018, Page 26, Paragraph 44
<https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/829.pdf>

"It would have helped if they'd contacted me sooner to ask me to join their trial of digital recording of assessments. By the time they did so, I'd already spent a lot of money on analogue recording equipment which didn't even work anyway. Don't get me wrong, I feel lucky that they were doing this trial, and they gave me a copy of the recording afterwards, which I think would be very valuable for all claimants to have, but it would be kinder if they automatically recorded assessments and gave us copies - or, even better, if they allowed us to record ourselves (or not) using our own digital devices. I'm not even sure if they went ahead with rolling out in-house digital recordings after the trial. It would actually have helped a lot of claimants in tribunal situations, which of course gives Capita/the DfC a reason not to do it."

- *Questionnaire Respondent*

"It would have helped me to get a recording of the assessment as my report did not correlate with the assessment."

- *Questionnaire Respondent*

"It would help to have a recording of the assessment as opposed to the assessor writing down my answers which I had put down on the form anyway."

- *Questionnaire Respondent*

Q18. Do you have any further comments regarding the PIP assessment process?

It is clear that there are serious problems with PIP that need to be urgently addressed. The following examples outlined in a report by WRDA on 'Disabled Women and Discrimination'³² highlight examples featured in the media from across the UK on various aspects of the benefit:

- [This woman](#), who is blind, had to sell her belongings in order to live due to the delay in outcome of her PIP appeal.
- [This woman](#), who was sexually assaulted and left incontinent as a result, was humiliated by a PIP assessor and had her disability benefits removed.
- [This woman](#), had to fight to get her PIP support restored, was called a 'lying bitch' by a member of DWP staff.
- [Capita](#), the private company responsible for PIP assessments, had to pay damages to the family of a woman who died after being denied her disability support.
- [This woman](#), who is paralysed, was denied her disability support and stated that the PIP assessment removed all her pride.
- [Capita](#) had to close a PIP claim after initially trying to use a 25-year old report against a woman in which a government contractor called her "aggressive".
- [This woman](#), who suffered brain damage, waiting over two years and still had not received a decision about whether she was entitled to the disability benefit PIP.
- [Legal costs](#), as of June 2019, had rose to £5 million due to the number of PIP applications in Northern Ireland that needed to be reassessed. This is not counting the thousands of cases that are yet to be heard.

Ability to assess mental health issues

Women have reported issues with the ability of the PIP process to assess mental health issues. Many reported that they did not feel the application form properly catered for mental health conditions. Of the women who responded to the questionnaire 70% felt that the PIP assessment was ineffective for assessing mental health issues and only 4% felt it was effective.

³² <https://wrda.net/2019/11/18/disabled-women-and-discrimination-facts-we-need-you-to-know/>

Recommendation:

- **There is a need to review the PIP application form and assessment process to determine how effectively it can measure the impact of mental health conditions on a person's everyday life.**

"The mental health impact was appalling, and in general I have never felt able to be fully honest about my mental health on these forms (my physical conditions are the basis of my claim) because I've heard that mental health-related claims are subject to even worse scrutiny and scepticism."

- *Questionnaire Respondent*

Mandatory Reconsiderations and Access to Justice

If a claimant does not qualify for PIP or disagrees with the Department's decision, they may request a Mandatory Reconsideration (MR). MRs were introduced by the Department in 2016 for claimants who are unhappy with their PIP decision to seek a reconsideration of the outcome before they could appeal. The rationale for MRs was to resolve disputes as early as possible.

A report by the Northern Ireland Audit Office on Welfare Reform reported that out of the 140,000 PIP decisions made between June 2016 and September 2018 that 33,777 (24%) requested a MR. As a percentage of PIP decisions made 4.7% of decisions were changed on MR (6,615) and 9% went on to appeal (12,662).³³ This equates to less than half of those who had requested an MR. The MR process adds an extra level of bureaucracy to the process and for many claimants just extends the PIP appeals process.

Recommendation:

- **The Mandatory Reconsideration process should be reviewed to determine whether it is an effective remedy for claimants.**

³³ Welfare Reforms in Northern Ireland, Northern Ireland Audit Office, 17 January 2019
<https://www.niauditoffice.gov.uk/sites/niao/files/media-files/Welfare%20Reform%20Report%202019.pdf>

Access to independent information, advice and advocacy

The benefits of having access to free, independent advice and advocacy at all stages of the PIP process are evident in the success rates for the benefit at application and appeal stages. Given the complexity of the social security system including PIP it is vital that all claimants have access to free, independent advice which is available when they need it. This is not about “playing the system” it is about knowing how to input into the system in the right way to ensure the right result. It is fundamentally unfair that a claimant should suffer any detriment because they did not know or could not get help to navigate this complex system.

Recommendation:

- **Access to free, independent advice should be available to all claimants who wish to avail of it at the point at which they need this help. The Department should provide to all claimants a list of independent organisations who can provide advice and guidance including those organisations linked to specialist conditions along with the PIP claim form. In the interests of transparency, the Department should also inform all claimants that their chances of success are greater if they get help.**

PIP Statistics

The availability of data on all stages of the PIP process which is disaggregated by gender and the full range of Section 75 characteristics would provide clarity and transparency around the process. The regular publishing of PIP data including statistics on Capita performance, mandatory reconsiderations and appeals is important in terms of accountability.

Recommendation:

- **The Department should regularly publish PIP data including statistics on Capita performance, mandatory reconsiderations and appeals disaggregated by gender and other Section 75 characteristics.**

Q19. Please provide any additional evidence or information you think might help inform the review.

We have attempted to provide a range of recommendations to improve the PIP process throughout this response. In this section we summarise the personal impact of the PIP process on the women we spoke to. The women were asked to explain how they felt going through the PIP process. We believe this feedback is key to understanding the real life difficulties with the PIP process. It is only by working to understand and remove the problems that people face during this process that confidence and trust can be restored. It will also help to ensure that potential claimants are not actively deterred from applying for the help they are rightfully entitled to through PIP.

Some of the women reported feelings of fear. Some were afraid of the whole process, reporting they were scared making the application, scared of the outcome, scared of the assessment, scared of losing their award and some reported fear of being punished for becoming more independent.

Many of the women reported feelings of not being believed and of feeling shamed and demeaned going through the process. Stress, anxiety and worry were also common emotions expressed by the women as a result of the process. In addition, some of the women reported feelings of negativity in that the process made them focus on what they could not do.

“The word I would use to describe my PIP application process is ‘scared’. I was scared before the application, scared during the whole process, scared of the outcomes, scared of having more of my PIP taken off me, scared of my renewal, just scared all the time.”

- *Questionnaire Respondent*

“Anxious, very ill, mentally it was a nightmare.”

- *Questionnaire Respondent*

"I am afraid to do well in anything in my life in case they take away my PIP. I am afraid to try and work full time or do anything to get me out of the house as they might take it away. I am afraid always of them punishing me for trying to be more independent, even though it is a personal independence payment. It doesn't make any sense to me, it is like they want us to be stuck at home not able to do anything."

- *Questionnaire Respondent*

"Degraded, embarrassed, felt like I wasn't believed, angry at how I was treated."

- *Questionnaire Respondent*

"I hate these forms. Aside from them being confusing and difficult to fill in they make me focus on the things I can't do and leave me feeling very depressed. The assessment was very stressful and the decision following that first assessment was a cold, clinical statement basically calling me a liar and malingerer. Following my second assessment I was awarded much higher levels for both mobility and personal care even though my condition had only declined slightly which further demonstrates the inconsistency in the whole process."

- *Questionnaire Respondent*

"I found it was terrible for my anxiety, it also wasn't autism aware."

- *Questionnaire Respondent*

"Degrading. It is deliberating as a young woman with serious health conditions. Felt like I was being made fun of."

- *Questionnaire Respondent*

"I felt as if my disability was never taken seriously enough because I was 20 years old."

- *Questionnaire Respondent*

“Found the whole process terrifying (extreme fear of being accused of fraud) and worrying (knowing that I would not be able to afford my rent were I not to qualify for PIP, which would ensure my mental health would rapidly deteriorate, even more than usual).”

- *Questionnaire Respondent*

“I felt belittled, disbelieved, gaslighted (I started to doubt my own illness), ignored and like they thought I just a lazy cheat trying to defraud the system.”

- *Questionnaire Respondent*

“Awful. Judged as a lesser person. Increased my depression.”

- *Questionnaire Respondent*

“I feel like I was one of the lucky ones. My condition is quite unheard of and I know people who get zero points. My assessor took my word and doctors reports at face value so I was lucky that I was "believed". I was very nervous though as if you had to prove your illness, but fortunately on the day the assessor was really nice. The decision process was very quick for me, only a few weeks. So I really feel that I was fortunate. I did have a lot of medical evidence though so I think I would've struggled in the absence of this. Getting the award meant I was able to get a mobility car which has been life changing for me. I have just submitted my pip renewal form so I hope that goes smoothly too.”

- *Questionnaire Respondent*

“It's demeaning having to explain to someone what you can't do when you don't look sick.”

- *Questionnaire Respondent*

“Embarrassing I have severe mental health issues and don't like to talk about it. Upsets me for days.”

- *Questionnaire Respondent*

"I felt like a liar, humiliated, depressed, stressed, in pain, brought on stress related symptoms, nervous, irritated, hopeful, desperate."

- *Questionnaire Respondent*

"I felt overwhelmed. I also felt that I was being seen as a fraud. This hit my mental health greatly. Invisible illnesses are hard enough to cope with."

- *Questionnaire Respondent*

"Very stressful. Worse than any interview for a job. I was exhausted after it. I wondered at the end of it if the assessor had read my claim form and evidence."

- *Questionnaire Respondent*

"Very stressful. It was massively worrying that the financial assistance I had from DLA for a life-long condition could suddenly be removed. I was also very worried that anytime I managed to do something nice like travel or go out socially could be used to deny my claim."

- *Questionnaire Respondent*

"Horrible experience - both frustrating and depressing confirming problems experienced. Very anxious waiting for result."

- *Questionnaire Respondent*

"I felt I was begging and claiming something I wasn't entitled to. I had worked full time for 35 years before becoming ill with a life changing debilitating disease."

- *Questionnaire Respondent*

"I found it extremely distressing and difficult. It caused a huge negative impact on my mental well-being."

- *Questionnaire Respondent*

“Awful and stressful. The tone of the letters was aggressive, like they were trying to trip us up. We were put under time pressure to return evidence and paperwork but Capita could take as long as they liked to make a decision - or so it felt like.”

- *Questionnaire Respondent*

“Felt like I was being talked down to and made to feel like I was faking everything.”

- *Questionnaire Respondent*

“It makes me feel like I am begging for this money.”

- *Questionnaire Respondent*

“The whole thing is an exercise in shame, humiliation and trauma.”

- *Questionnaire Respondent*

“I had to ask for an extension on my PIP application process and I became extremely upset every single time I opened those cruel forms. Once I submitted my forms, I sat in fear every single day for what letter would come through my letterbox from the department of communities or from CAPITA. I was given almost no notice about my first assessment, and had a medical procedure the day before and was bedbound. The assessor showed up at my house and tried to get me to get up and do a physical assessment, even though I was under medical instruction to stay in bed and rest for 2-3 days after my procedure. I asked them to come when I was healed from my procedure, and they told me if I delayed my appointment they wouldn't do the assessment and mark me down because of it. After my in-person assessment, I sat in fear every single day for months afraid to look at what post was just put through my letterbox. When my decision letter came from the Department for Communities, I spent a week in bed severely depressed, because they took the support I needed away from me. I have never felt as alone as I did then.”

- *Questionnaire Respondent*

“My DLA support is what allowed me to have a small degree of independence in my life. When I transferred over to PIP, I lost my support and with that, I lost my independence. It has been one of the worst experiences of my life.”

- *Questionnaire Respondent*

