Submission to the Second Independent Review of Personal Independence Payment (PIP)

‘Experience of PIP in Northern Ireland’ Research Report 2020
About the All Party Group on Learning Disability (APGLD)¹

Compared to their peers, people with a learning disability experience many health and social inequalities. Without appropriate support and intervention, they are at risk of a range of poorer outcomes. Reflecting the framework of standards set out in the United Nations Convention on the Rights of Persons with a Disability, the APGLD aims to:

- Promote a better understanding of the issues facing people with a learning disability and their families; and
- Influence policy, legislation, and service development to improve the lives of people with a learning disability and their families in Northern Ireland and ensure their full participation in society.

Set up in 2009, the APGLD is comprised of MLAs across political parties, and supported by a number of voluntary and community sector organisations, parents / carers and people with a learning disability.

Acknowledgements

The APGLD would like to sincerely thank all the survey and focus group participants who gave so generously of their time in sharing their personal experiences and insights. Their contribution was significant and invaluable in enabling us to provide a detailed submission to the second Independent Review of PIP. We would also like to thank all members of the Research Advisory Group²; Susan Kehoe who supported development and analysis of the survey; and Danielle McIlroy (QUB) for assistance with qualitative analysis.

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¹ APGLD Members provided at Appendix A.
² Research Advisory Group Members provided at Appendix B.
Executive summary

About the project

Welfare reform is one of the APGLD’s priority issues, and it undertook an inclusive research project on people’s experience of the Personal Independence Payment (PIP) to inform a submission to the second Independent Review of PIP. The study included a policy review; online survey with 492 respondents; and 7 focus groups with 50 participants.

Key findings

1. **Systemic challenges** - Participants highlighted several underpinning issues:
   - PIP is less effective than DLA in achieving an ‘enabling’ approach to independent living.
   - PIP starts on the premise that claimants are potential benefit cheats and the process is designed to ‘catch’ them out.
   - People with a terminal illness or lifelong condition with supportive medical evidence should be screened out of the PIP process.
   - The administration of PIP is time consuming and a waste of public resources.
   - Claimants often require high levels of support from advice agencies and local constituency offices across all stages of the PIP process; more training is needed for Constituency Officers and other organisations supporting individuals to access PIP.
   - The PIP process often leads to unnecessary stress and anxiety which adversely impacts on people’s well-being.

2. **Making a claim**
   - Calling the PIP claim line is mostly straightforward but can be challenging for those with anxiety and/or speech difficulties.
   - The PIP application form can be difficult to complete, with many people finding it repetitive, lengthy, and hard to understand.
   - Most people need support from a family member or independent advice agency to complete their PIP application form, and across the wider process.
   - A successful outcome depends on the use of particular terminology ('buzz words').
   - The application form / process is more tailored towards medical evidence associated with a physical disability.
   - There is a lack of clarity about the supporting evidence needed.
   - GPs are not always best placed to evidence functionality.

3. **Assessment**
   - Many people did not experience the questions, measures, and functional tests used in assessments as wholly relevant to their condition and how their daily life is impacted.
   - Assessors often lack the required level of knowledge and understanding about claimants’ conditions, particularly learning disability, autism, and mental health.
   - Informal observations are unfair and subjective.
   - There is an inconsistency in knowledge and approach amongst assessors.
   - Positive experiences and good practice were evident, and strongly aligned with individual assessors who demonstrated appropriate knowledge, empathy and understanding.
4. Decisions and appeals

- Many people were unclear about how decisions were made, and scoring can appear inconsistent.
- Assessor reports do not always accurately reflect peoples’ situations or what took place during assessment.
- Mandatory Reconsideration is not a meaningful review of decision-making, and acts as a barrier to discourage claimants from progressing to appeal.
- The high success rate at Tribunal suggests the implementation of PIP is flawed; and some people who have chosen not to appeal, often due to stress, may be losing out financially.
- The onus on claimants to acquire and summarise the relevant medical evidence is an additional barrier to the appeals process.
- There are inconsistencies in Tribunal location and approach, with some taking place in courthouses and others in more informal settings.
- Good practice at Tribunals was highlighted, and often associated with the tone set by the Chair, and a belief that evidence would be heard by professionals who were more suitably qualified to make decisions.

**APGLD Recommendations**

1. The Department for Communities should legislate to remove the 6 month life expectancy criterion in the Special Rules for Terminal Illness and introduce a new system based on the clinical judgement of healthcare practitioners.

2. The Department should ensure that people who have a lifelong condition / a condition unlikely to change, with supportive medical evidence, should be screened out of the formal PIP process and receive a rolling award.

3. The Department should ensure that a range of application methods are available for claimants to select the most appropriate method for themselves, including an online form. Staff should also be trained to identify and direct claimants who could benefit from an alternative method of application.

4. The Department should ensure that the application process is more accessible through the provision of easy read claim forms and guidance materials; and that easy read information is available across all stages of the PIP process.

5. The Department should progress the development of accessible materials in consultation with PIP claimants, including people with a learning disability.

6. The Department should provide detailed guidance about the specific types of further evidence required to support a PIP application.

7. The Department should ensure that more appropriate weighting is given across the PIP process to medical and non-medical evidence from the range of supporting health professions; social workers; voluntary and community sector organisations, and family carers.

8. The Department should reduce the number of face to face assessments, which should only be required where it has not been possible to gather all the necessary medical and other supporting evidence.
9. The Department and Capita should ensure that Disability Assessors (DAs) are fully trained in learning disability awareness, and the healthcare needs of people with a learning disability. Enhanced training in partnership with supporting organisations and those who have lived experience should also be undertaken to improve the DA’s understanding of autism and mental ill-health, and other conditions where they may lack the necessary knowledge and experience.

10. The Department should ensure that questions related to suicide and self-harm are not routinely part of the assessment process. If the information is deemed essential it should be sensitively sourced separately by an individual trained in these issues.

11. The Department should ensure that informal and subjective observations by Disability Assessors are not used to assess functional impact and included in PIP assessment reports.

12. The Department should ensure that all PIP assessments are audio recorded as standard practice.

13. The Department should review the Mandatory Reconsideration process as it is rarely successful and presents a barrier to many claimants who drop out at this point when they may be entitled to PIP support.

14. The Department should require all members of Tribunal Panels to be suitably trained on learning disability, autism and mental ill-health so they have a better understanding of individual conditions, impact and support systems. Reasonable adjustments must be implemented to facilitate the best possible environment for claimants at hearings, including proxy representation by someone who knows the claimant best.

15. The Department should ensure that appropriate levels of resources are available to provide comprehensive training on all elements of the PIP process for constituency workers and other local agencies who support claimants.
Introduction

As part of wider welfare reforms, Personal Independence Payment (PIP) was introduced across the UK to replace Disability Living Allowance. PIP is a source of financial support designed to help disabled people and those with long-term conditions manage the extra costs of their condition.

To inform its’ programme of work in 2019 and beyond, the APGLD consulted with a range of stakeholders and subsequently published a paper identifying priority issues for people with a learning disability. PIP was one of the paper’s ten priority areas – with concerns raised regarding how well it was working and to what extent recommendations from the first Independent Review would be implemented.

The APGLD committed to undertaking an inclusive research project to understand more about peoples’ lived experience of the new benefit, with the view to informing the PIP review process and best practice. In addition to those with a learning disability, participation in the research was open to anyone who had accessed PIP.

About this report

This report outlines the main findings from the APGLD research project on people’s experiences of Personal Independence Payments.

Reflecting the Group’s core aim to hear the voice of people directly impacted by policy which affects their lives, illustrative quotes are presented in detail throughout.

We hope the experience of study participants and their suggestions will usefully inform the second Independent Review of PIP being undertaken in Northern Ireland in 2020.

‘Personal Independence Payment is a payment to enable you to live your life to the standard. It’s not a bonus, it’s not a windfall... It’s a tiny amount of money that keeps people managing. But the consequences of losing that are huge.’ (VCSE Support Worker)

Methodology

The desk-based research and fieldwork took place between June-September 2019, and included:

- **Policy review** – an overview of key policy and legislation was completed to provide context and inform development of the project.

- **Online survey** – almost 500 respondents (492) completed an online survey, designed to gauge their experience of the PIP claim, assessment, and appeals process.4

The survey provided opportunities to highlight good practice as well as challenges in the system; and make recommendations to improve the PIP process.

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4 A ‘claimant helper’ completed the survey on behalf of almost one third of respondents (31%).
Focus groups – 50 participants took part in 7 focus groups conducted in Belfast (3), Derry/ Londonderry (2), and Ballymoney (2), and a single 1:1 interview. Participants included:

- Constituency officers / caseworkers (20)
- MLAs / councillors (7)
- Advice workers (6)
- People with experience of PIP / carers (10)
- Voluntary, community & social enterprise (VCSE) sector (4)
- Social workers / health professionals (3)

The groups provided an opportunity for detailed discussion about the PIP process, particularly for those who provide support.

Data was analysed thematically; and supplemented with independent analysis by an academic researcher from Queen’s University, Belfast using a thematic analysis approach facilitated by QSR NVivo.

Survey respondents

Almost two thirds of survey respondents were female. As illustrated at Figure 1, respondents ranged in age between 16 and 65 years, while Figure 2 shows that one fifth of respondents lived in the Belfast City Council area, with the remainder drawn quite evenly across the remaining Councils. The majority were not working (mainly because they were unable or temporarily unable to work due to their health condition / disability), while almost one third were in some form of employment.

Respondents reported a wide range of physical and / or mental health conditions. 3% indicated that they applied for PIP under special rules for terminal illness, of which one third were unsuccessful. While most respondents (62%) said their condition is likely to get worse (43%) or stay the same (19%), many also indicated it is likely to fluctuate in nature (28%). A large number (41%) indicated that additional costs incurred by their health condition / disability was one of the main reasons they applied for PIP.

Figure 1: % Breakdown by age

<table>
<thead>
<tr>
<th>Age Range</th>
<th>16-17</th>
<th>18-25</th>
<th>26-35</th>
<th>36-45</th>
<th>46-55</th>
<th>55-64</th>
<th>65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-17</td>
<td>2%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-25</td>
<td></td>
<td>11%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26-35</td>
<td></td>
<td></td>
<td>18%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36-45</td>
<td></td>
<td></td>
<td></td>
<td>23%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46-55</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>26%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2%</td>
</tr>
<tr>
<td>65+</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>17%</td>
</tr>
</tbody>
</table>

Total survey respondents 492

- 36% male; 64% female
- 49% aged 36-55 years
- 71% urban living; 29% rural living
- 58% not working; 31% working;
  11% retired
- 66% previously on DLA
- 16% have a learning disability
Research Advisory Group

A Research Advisory Group (RAG) comprising organisations and disabled people with lived experience of PIP was established to steer the project and ensure a co-design approach. The RAG considered all ethical aspects of the project, approved and tested the research tools, helped identify participants for focus groups, and was instrumental in promoting the survey.

Policy Review

1.0 What is PIP?

Personal Independence Payment (PIP) is a benefit introduced in Northern Ireland (NI) on 20 June 2016. It replaced Disability Living Allowance (DLA) as the main benefit paid to disabled people of working age (16-24) who have functional restrictions in their ability to complete certain daily living and mobility activities.

PIP is a non-means tested benefit, not subject to tax, which, once someone qualifies, is paid whether they are in or out of work. A fundamental new element of the benefit is the introduction of an assessment which considers an individual’s ability to carry out key daily living and mobility activities. It is still possible to claim DLA for children who are under 16, and for people over 65 to continue to receive DLA.
The purpose of PIP is to help towards some of the extra costs that arise from having a long-term health condition or disability that affects someone’s ability to get around and/or daily living activities. Entitlement is based on the effect a health condition or disability has on someone’s daily life and not on the nature of the condition or disability itself.

How many people have claimed PIP?

By the end of February 2020, there were **224,270 PIP claims registered** in Northern Ireland.

Overall, **66% of those who registered were granted an award of PIP** by the end of February 2020.

From 20 June 2016 when PIP was launched until 29 February 2020, there were **145,090 claims in payment**.

**2.0 UK policy objectives and the Northern Ireland context**

The June 2010 Westminster Budget stated that the most urgent task facing the UK was implementing an accelerated plan to reduce the budget deficit. The plan included an initial programme of welfare reform involving changes to benefit rates and entitlements, assessments of need and administration of payments. As part of this, the Government announced that Disability Living Allowance (DLA) would be replaced by PIP, as a component of its major package of welfare reform. A further package of social security changes was announced in 2015 and these are still rolling out.

The 2010 Budget anticipated that these measures would reduce overall UK spending on social security and Tax Credits by £11 billion in 2014-15. The reforms introduced between 2010 and 2015 were expected to realise savings of £17.2 billion across the UK by 2015-16. As the Northern Ireland Audit Office (NIAO) graph below shows, the introduction of PIP accounted for a small share of this cut.

![Figure 3: NIAO estimate of financial savings in 2015-16 from welfare reforms](source: NIAO analysis)

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5 Department for Communities (DfC), Personal Independence Payment (PIP) Statistics (February 2020).
Historically, there has been a high concentration of claimants in receipt of DLA in Northern Ireland. The context is that there is a higher prevalence of disability and illness in comparison with Great Britain. The Department of Health note a 25% higher overall prevalence of mental illness in NI than in England. Approximately 30% of Northern Ireland’s population suffers from mental health problems and many of these cases were directly related to the Troubles.

In November 2009, DLA spend in NI was £13.8 million per week rising to £19 million per week by November 2015. DWP argued that DLA had become “unsustainable” in caseload and cost, that it was “not well understood”, and there was “no process to check that awards remain correct”. The introduction of PIP in NI came at a time when the number of people claiming DLA across the UK was over 3.3 million. In November 2015 around 99,000 of the Northern Ireland DLA working-age caseload had indefinite awards.

The Government Response to the consultation on DLA Reform set out the policy intent for PIP:

“Personal Independence Payment will be a more dynamic benefit that acknowledges that people’s conditions change over time and that our understanding of how disability affects people changes too, so rather than having 70% of people on indefinite awards, as is currently the case with DLA, we will introduce a new fairer, more transparent and objective assessment, and, in most cases, introduce fixed term awards. In doing so we need to take account of the full range of disabilities and treat people as individuals, not labelling them by impairment type, creating a truly personalised benefit that evolves over time.”

The response further indicated:

“Our aim, through the introduction of Personal Independence Payment, is to make the benefit fairer, more straightforward to administer, and for it to be easier and clearer to understand.”

Rollout of PIP began in GB during April 2013. Due to legislative delays PIP was introduced in NI in June 2016. The Northern Ireland (Welfare Reform) Act 2015 provided a power to legislate on certain matters including social security in NI by Order in Council. This conferred power on the Secretary of State, or an NI department, to make further provision regarding these matters by regulations or order. Subsequently the Personal Independence Payment Regulations (Northern Ireland) 2016 were made in May 2016, which introduced PIP from 20 June 2016 for new claims, persons reaching 16 years of age, persons reporting a change of circumstances and those who DLA fixed-term award expires. From December 2016, the Department for Communities (DfC)

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12 Department for Communities, Review of the Personal Independence Payment Assessment Process: Department for Communities’ Interim Response, November 2018, p.4.
14 Ibid. p.4.
began a phased approach to randomly assessing existing DLA claims who had an indefinite award.

2.1 NI welfare reform mitigation package

Following the Stormont House Agreement (Fresh Start Agreement), DfC developed a framework of mitigation schemes to reduce the impact of welfare reform. The Westminster Government did not provide additional funding for these schemes, which are funded from the NI block grant. As part of the Fresh Start Agreement the NI Executive agreed to allocate a total of £585 million from Executive funds over four years to ‘top-up’ the UK welfare arrangements in NI with a review in 2018-19. £94 million was allocated to provide mitigations for those claimants who are worse off following transition from DLA to PIP.15

As Professor Evasion stated in the foreword to the report outlining the mitigation package:

“We have looked at developments elsewhere and are confident that the measures we propose will place Northern Ireland clearly ahead of the rest of the United Kingdom in its efforts to protect vulnerable children and adults - in work and not employed - from hardship.”16

The welfare reform mitigation package has acted as a critical protection to those affected by the social security changes. For those in receipt of ‘mitigations’, these have acted as an important buffer against some of the harsher effects of welfare reform. There are three potential Welfare Supplementary Payments (WSPs) for those who have lost out financially as a result of a PIP decision following the ending of their entitlement to DLA. Only one of these may be awarded at a time:

1. **Pending Appeal WSP:** claimants who do not qualify for PIP after reassessment and appeal the decision will receive a WSP until the Department is notified of the outcome of the appeal;

2. **PIP award is lower than previous DLA award WSP:** claimants who are assessed for PIP and qualify at a reduced rate and whose weekly loss is at least £10 will receive a WSP for up to one year. This payment will be equal to 75% of their loss;

3. **Conflict Related Injury WSP:** claimants who are reassessed for PIP and do not qualify but have received at least four points and can show their disability/illness is as a result of a NI conflict-related injury will receive a WSP for up to one year.

In addition, claimants who lose entitlement to Disability Premiums, Enhanced Disability premiums or Severe Disability Premiums in the reassessment for PIP will receive a WSP for up to one year to cover the loss. Although Carers Allowance has not changed directly, a carer’s entitlement to the allowance may be affected, if the person they look after does not qualify for PIP or is not awarded the qualifying daily living component. If a carer is affected, they will receive a WSP for up to one year to cover their financial loss.

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The table below shows the total expenditure during the 2018/19 financial year on WSPs for PIP claimants and carers:

<table>
<thead>
<tr>
<th>WSP Scheme</th>
<th>Number of claimants who received WSPs</th>
<th>Total amount paid</th>
<th>Average Payment per claimant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pending Appeal WSP</td>
<td>7,880</td>
<td>£15,727,590</td>
<td>£1,996</td>
</tr>
<tr>
<td>Lower PIP award than DLA award WSP</td>
<td>18,820</td>
<td>£14,222,650</td>
<td>£756</td>
</tr>
<tr>
<td>Conflict Related Injury WSP</td>
<td>10</td>
<td>£13,720</td>
<td>£1,372</td>
</tr>
<tr>
<td>Loss of Disability-related Payments</td>
<td>2,460</td>
<td>£4,287,300</td>
<td>£1,743</td>
</tr>
<tr>
<td>Loss of Carer Payments</td>
<td>2,700</td>
<td>£3,483,440</td>
<td>£1,290</td>
</tr>
</tbody>
</table>

It is clearly important that claimants are aware of the availability of WSPs and data suggests that claimants do not have sufficient awareness that if they seek advice and appeal the PIP decision that they will be entitled to supplementary payments. From 2018-2019, 7,880 people received these payments. PIP statistics show that 28,910 people in NI have been assessed as not having entitlement to a PIP award. This indicates that a significant proportion of people, who could have accessed this mitigation, did not and have missed out on the transitional support offered by the welfare reform mitigation.

### 2.2 New Decade, New Approach

In January 2020 the New Decade, New Approach deal included a commitment to ‘extend existing welfare mitigation measures beyond March 2020’ following a review. Following an announcement that protections against the Social Sector Size Criteria would be extended the Minister for Communities stated that she would ‘bring forward regulations on the other strands of the existing welfare mitigations, such as...those transitioning from disability living allowance to the personal independence payment’. Details of this are yet to be released. It is hoped that these regulations will protect up to 26,720 claimants who previously received DLA and who are disadvantaged when assessed for PIP (either because they were not awarded PIP or because they receive less under PIP than DLA). According to the DfC all DLA claimants have now been reassessed for PIP.

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18 This includes Disability Premiums, Enhanced Disability Premiums or Severe Disability Premiums.
19 n13, p 11.
20 n2, p 3.
23 As of May 2020.
3.0 The Operation of PIP in NI

3.1 Application Process

In Northern Ireland, an application for PIP is normally made by contacting the PIP Centre. Initially the claimant will be asked to provide basic details such as their contact details, national insurance number and information used to determine if they satisfy the residence and presence criteria. In exceptional circumstances it may be possible to request a PIP1 form to provide the above information.

After making the application by phone, the claimant will be sent a PIP2 Form: ‘How your disability affects you’. This form will ask the claimant to outline the conditions they have and the treatment and medication they are receiving.

If, however, the claimant is terminally ill and is not expected to live longer than six months, Special Rules may apply and the application process differs. The claimant will contact the PIP Centre in the same way but will be asked additional questions regarding their condition and their ability to get around. If they can provide evidence that they have a life expectancy of six months or less – usually through a DS1500 medical report25 – they will not have to complete the PIP2 form or attend a face-to-face assessment (as is detailed in section 3.2) and will be automatically eligible for the enhanced rate of the daily living component of PIP without satisfying the normal three-month qualifying period. Their application will also be fast-tracked. 26

3.2 Assessment Process

The development of the PIP assessment was informed with input from an advisory group of independent specialists in health, social care and disability. The government and the advisory group considered various options for determining entitlement, including considering the additional cost incurred by individual claimants due to their disability or health issue. However, this approach was deemed to be impractical and expensive and instead the UK government decided to proceed with a functional assessment that would consider a claimant’s ability to carry out day-to-day activities. The new assessment was designed to ‘meet the aims of prioritising support to individuals who face the greatest challenges and expense.’ 27

A key difference between DLA and PIP is that the assessment process for PIP was intended to offer an ‘objective assessment of individual need’ by a health professional. 28 To this end, the UK Government determined that the PIP assessment would be delivered by a third-party provider.

Assessments of PIP in NI are conducted by Capita on behalf of the DfC. In November 2012, Capita was awarded a five-year contract worth £59m to provide the PIP disability assessment service for DfC (this contract was part of a UK wide procurement process). Due to the delay in implementing welfare reform in Northern Ireland, the service was not operational until June 2016. Over the period 2013 – 2016, the contract in NI was worth £2.1m in respect of staffing and accommodation. The contract was subsequently extended to July 2019 (which aligns with DWP...

25 A DS1500 medical report is completed by a GP, consultant or specialist nurse and provides information about a person's condition and their current or future treatment.

26 On average, Special Rules PIP claims are cleared within 2 weeks, compared to thirteen weeks for normal claims.

27 See summary of response to question 3 (para 8-11) in DWP, Government’s Response to the Consultation on DLA Reform (CM, April 2011).

28 DWP, ‘Disability Living Allowance Reform’ (December 2010).
contract expiry dates). At the end of July 2019, Capita announced that it had secured a two-year extension, worth approximately £33m, to its PIP assessment contract with DfC.29

The assessment process is illustrated in the flow chart on page 15. Upon receipt of the returned PIP2 form a Capita Disability Assessor (DA) will review the form, and any enclosed evidence, in order to establish if a face to face assessment is necessary to determine entitlement. Claimants who are terminally ill, and who are not expected to live for more than six months, are fast-tracked and do not have to attend assessments.

In approximately 85% of cases Capita will determine that a face to face assessment is necessary. This assessment will take place either at an assessment centre or in the claimant’s home. The majority of the assessments will involve the DA asking questions and recording responses and observed behaviour. There may also be a short assessment of physical movement.

The DA should then consider all of the available evidence and indicate what descriptors, if any, the claimant would satisfy. The DA will also indicate when the claimant’s condition is likely to change.

The DA’s report is then passed to a DfC Case Manager who makes the final award decision following consideration of all of the relevant information including the PIP claim form, assessment report and any other supporting evidence from the claimant.30

3.3 Determination & next steps

The claimant is issued with a decision and if they are unhappy with the outcome, they can seek a mandatory reconsideration (MR) within one month. If a claimant is unsatisfied with the outcome of the MR they can appeal against the decision to an independent tribunal within 1 month of the MR notice. It is not possible to appeal against a PIP decision without first requesting a MR.

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29 See https://www.capita.com/news/news/2019/capita-secures-145m-personal-independence-payment-contract-extensions/ The Northern Ireland Audit office is working on a publication that will consider the Department’s management of its contract with Capita and how well the contract has been delivered. The date of publication has not been released.

30 See NI A0 report at n. 3, p. 27.
4.0 Reviews of PIP

The Welfare Reform Act 2012 in Great Britain mandated two Independent Reviews of PIP, both of which were conducted by Paul Gray. The first of these reviews in 2014, taking place against a backdrop of severe delays in the processing of claims, focused on taking an early view on how PIP was performing against the broader policy intent. The second Review was completed in March 2017. Gray noted, in this second Review, that progress against the recommendations in the first Review has been mixed, with the implementation of recommendations either incomplete or slower than the Review had hoped in many areas.31

In the same way, the Welfare Reform (Northern Ireland (NI)) Order 2015 provides the basis for two Independent Reviews of the PIP assessment process, the first within 2 years of the introduction of PIP and the second within 4 years. The first Review was conducted by Walter Rader and was published in June 2018 (Rader Review). DfC issued its interim response to the Rader

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The Rader Review process drew on a variety of sources to gain insight into the PIP assessment process. This included a public call for evidence, meetings with representative organisations, charities and support groups, observations of a number of face-to-face assessments at Capita assessment centres across NI; meetings with Capita operational staff and senior management, meetings with a range of Departmental staff including those involved in PIP initial contact, Case Managers, and those involved with Mandatory Reconsideration and Appeals; an analysis of official statistics; meetings with elected representatives; and meetings with professional bodies representing doctors and health care professionals. Rader noted that respondents’ submissions, and the discussions resulting from meetings across NI, highlight matters of concerns similar to those identified by Paul Gray in the first GB Review.

It was positive to hear of some constructive practices which are already in place. However, the current PIP assessment process is viewed with distrust and suspicion. 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.

[...]

Prompt action is required to build trust and credibility in the process. Openness and transparency should be the hallmarks of an assessment process which aims to focus support to those who most require it because of their diagnosed conditions and restricted functionality.

Walter Rader

The Rader Review issued 14 recommendations. As outlined in Graph 1, the majority of the recommendations were either fully accepted or partially accepted. The subsequent Table summarises the Rader PIP Review recommendations and DfC’s response.

Graph 1: Department for Communities response to the 14 Rader PIP Review recommendations

- Accepted
- Partially accepted
- Not accepted
- Cannot be implemented due to lack of Minister

34 Ibid. p. 5
<table>
<thead>
<tr>
<th>Rader recommendation</th>
<th>Department for Communities (&quot;DfC&quot;) response to recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommendation 1</td>
<td>Accepted</td>
</tr>
<tr>
<td>DfC should coordinate a series of information and outreach events to improve awareness of PIP.</td>
<td>DfC will commence this in January 2019 and will work with thematic support groups and advice sector. DfC has also developed 5 videos to help claimants understand PIP.</td>
</tr>
<tr>
<td>Recommendation 2</td>
<td>Accepted</td>
</tr>
<tr>
<td>DfC should update terminology and simplify and consolidate the terms used.</td>
<td>DfC has begun reviewing terminology. DfC is also tracking developments in GB where DWP has commissioned research to support improvements to the PIP2 questionnaire.</td>
</tr>
<tr>
<td>Recommendation 3</td>
<td>Not accepted</td>
</tr>
<tr>
<td>The use of DLA evidence to support reassessment cases should cease.</td>
<td>DfC maintains its position whereby claimants are offered the option of having their DLA evidence considered as part of their PIP assessment.</td>
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<td>Recommendation 4</td>
<td>Accepted</td>
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<tr>
<td>DfC should review all written material including initial letters and subsequent decision claimants to ensure clarity</td>
<td>DfC accepts the need for clear communications. As above, DfC is tracking DWP’s research and will discuss with stakeholders in NI including the Disability Consultative Forum.</td>
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<td>Recommendation 5</td>
<td>Accepted</td>
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<td>DfC should ensure that claimants with communication needs do not face unnecessary obstacles in applying for PIP. Staff training should be reviewed.</td>
<td>DfC maintains its commitment to improving accessibility and will: shortly implement a Video Relay Service for sign language users; reinforce the various options that are available to claimants with telephony staff; and track any digital developments in DWP with regards to an online claim.</td>
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<td>Recommendation 6</td>
<td>DfC cannot implement</td>
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<td>The 6 months life expectancy criterion to enable special rules to apply should be removed.</td>
<td>DfC does not indicate whether it agrees with this recommendation. It explains that implementing a different approach to the Special Rules would depart from the ‘parity principle’ and would require Ministerial direction; this cannot be implemented at present.</td>
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<td>Recommendation 7</td>
<td>Partially accepted</td>
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<tr>
<td>DfC agree with the relevant professional bodies about obtaining a GP Short Summary Report to support the PIP2 submission. This should be requested for every claim.</td>
<td>In general, DfC’s focus is on a functional rather than a medical history. DfC is monitoring developments in GB where DWP is working with the assessment provider to develop a ‘Function First’ approach. However, DfC accepts that some non-functional clinical information can be relevant and is working with British Medical Association to consider how GP Short Summary Reports could be provided. This will be subject to a cost/benefit analysis and will require Ministerial approval.</td>
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<td>Recommendation 8</td>
<td>Accepted</td>
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<td><strong>DFC</strong> should introduce steps to ensure that Capita are made aware, as early as possible in the process, when additional evidence is received with the PIP2 and advised that it will follow. Capita should be afforded time in the process to await any additional evidence.</td>
<td>In October 2018, DfC implemented a revised process at the Mail Opening Unit to ensure that all information reaches the PIP Computer System more promptly. NB: DfC does not respond to the suggestion that Capita should be afforded more time in such cases.</td>
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<th>Recommendation 9</th>
<th>Partially accepted</th>
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<tr>
<td><strong>DFC</strong> should establish a short term ‘Task and Finish’ group to develop a set of criteria detailing which conditions would be more appropriately addressed through the Paper-Based Review Approach.</td>
<td>DfC recognises that the initial review should identify cases where a Paper-Based Review is more appropriate. However, DfC does not want to place limitations on the evidence gathering process by exempting some claimants from a face-to-face assessment based on their conditions. DfC has worked with Capita to enhance the ‘decision making matrix’ and will discuss at the Disability Consultative Forum in 2019. Further, if the claimant has a progressive condition with no prospects of improvement, DfC has instructed Case Managers to consider making an ongoing award in some situations. Such awards will not have an end date and will be subject to a ‘light touch’ review.</td>
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<th>Recommendation 10</th>
<th>Accepted</th>
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<tr>
<td><strong>DFC</strong> should urgently address issues including the scheduling of assessments and the layout of the assessment room.</td>
<td>DfC has amended the process to give more flexibility for frontline Capita staff to reschedule appointments. The appointment letters have been improved to make it clear that appointments can be rescheduled and now meet the Plain English Crystal standard. DWP is looking at how requests for home assessments are dealt with in GB and DfC is monitoring. DfC has begun discussions with Capita about the lay-out of the assessment room.</td>
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<th>Recommendation 11</th>
<th>Not accepted</th>
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<td><strong>DFC and Capita</strong> should develop enhanced training for Assessors specific to certain groups of conditions. If a claimant can show s/he is affected by one of these conditions s/he should have the opportunity to see an Assessor with enhanced training relevant to their condition, or to have a Paper-Based Review.</td>
<td>DfC maintains that the PIP assessment is a functional rather than a clinical assessment. Whether a health professional is a specialist in a given area, should not impact on their ability to carry out a functional assessment. DfC is satisfied with the formal approval process and the extensive training for Assessors to ensure that they meet DfC’s experience, skills and competence requirements.</td>
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<th>Recommendation 12</th>
<th>Partially accepted</th>
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<tr>
<td><strong>DFC</strong> should introduce audio-visual recording of assessments in both home and assessment centre locations.</td>
<td>DWP intends to pilot video recording of assessments in GB and DfC is tracking developments. DfC will also carry out a pilot of audio recording in NI (but gives no date for this action point).</td>
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Recommendation 13

a) DfC should work with Capita to remove or revise the use of informal observations to support Assessors’ reports. If revised, Assessors should be required to justify the conclusions which they have drawn from their observations.

b) All questions about suicide and self harm should be removed from the assessment.

Accepted (recommendation 13a)

DfC maintains that it will continue to use informal observations as part of the PIP (and ESA) assessment. However, DfC accepts that informal observations must be factual observations and not opinions. DfC Case Managers have been advised to challenge the observations, if they deem them unjustified, to ensure their correct application.

Partially accepted (recommendation 13b)

Capita has completed a review of its processes for observing both the mental and cognitive state of claimants where suicidal intent or self-harm may be relevant. This has resulted in updated guidance to Assessors to ensure that the subjects of suicide and self-harm are only addressed where it is relevant and that this is done in a sensitive and professional manner. The delivery of training on this revised guidance to Assessors commenced on 1 October 2018.

Recommendation 14

A copy of the Assessor’s Report should be made available to claimants along with the decision letter.

Not accepted

DfC is committed to improving communications (see above), it does not accept the need to issue more paperwork (i.e. the Assessor’s report) with the decision letter.

The scope of the Radar Review was limited to the assessment process and therefore did not consider the PIP application process as a whole, wider PIP policy, or underlying principles. The second Independent Review of PIP in NI, whilst also focusing on the assessment process, affords an opportunity to consider how effective the changes, made in the light of Rader, have been as well as the experience of claimants.36

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Results – APGLD survey and focus groups

1. Systemic challenges – underpinning issues

Research participants highlighted several underpinning issues relating to the PIP process:

- PIP is less effective than DLA in achieving an ‘enabling’ approach to independent living.
- PIP starts on the premise that claimants are potential benefit cheats and the process is designed to ‘catch’ them out.
- People with a terminal illness or lifelong condition with supportive medical evidence should be screened out of the PIP process.
- The administration of PIP is time consuming and a waste of public resources.
- Claimants often require high levels of support from advice agencies and local constituency offices across all stages of the PIP process; more training is needed for Constituency Officers and other organisations supporting individuals to access PIP.
- The PIP process often leads to unnecessary stress and anxiety which adversely impacts on people’s well-being.

When discussing key components of PIP, notably the application forms, assessment and appeals, participants across both the survey and focus groups also commented extensively on how they viewed and experienced the collective process. While there was some acknowledgement of improvements in how PIP is being administered, regardless of outcome the process was repeatedly described in negative terms. Given the widely reported challenges and controversy related to the roll-out of welfare reform, the lack of positive commentary about PIP was perhaps to be expected. However, the range and frequent use of negative language such as ‘humiliating’, ‘degrading’, ‘demeaning’, ‘traumatic’ and ‘stressful’ by participants when discussing PIP was a particularly striking aspect of the research.

Participants across the focus groups agreed with the overall aim of PIP to support and empower disabled people to lead independent and active lives. However, there was consensus that PIP has moved away from what was described as a more ‘enabling’ approach under the previous system of Disability Living Allowance (DLA), to one which too often reinforces what people cannot do. Parents / carers can find this aspect of the process particularly challenging.

‘With DLA the focus was on independent living and encouraging people to live and to do and to work but this is a whole shift to something different.’ (Claimant, Focus Group)

‘DLA was always an ability an enabling benefit, and it was to enable people to be independent and now it’s almost turned on its head and it’s about you know it is about proving that you’re not fraudulent and proving even that you’re incapable which is essentially what it’s about.’ (Constituency Officer)

‘Filling out a form with someone, it is like reinforcing everything they can’t do...I had so many carers where maybe I was doing it with the carer because the service user was profound and for them it was almost another sense of grief or loss because you are again going through everything....It is just going over again all of that stuff they can’t do like “my child will never be able to do this and he is an adult.”’ (Social Worker)

‘We’re working a skills-based model but when these people go into these things [PIP process] they have to then work in you know a needs-based model.’ (Constituency Officer)

A common perception amongst claimants and those who support them was that PIP has been designed to ‘catch’ people out as a way for the government to save money. Language such as ‘trap’ and ‘trip up’ were used when describing aspects of the PIP process, extending from the
application form to assessment and later to the appeals process. Many people suggested it was punitive in nature, operating on the premise that everyone is a potential benefits cheat who is planning to exploit the system.

‘They’re asking the question so many times but in different ways to try and catch you out.’ (Claimant, Focus Group)

‘It’s clear for some of those who are assessors they have absolutely no understanding of the issues and they come at this with a view that people who are there are there to cheat the system.’ (Constituency Officer)

‘[It should be made clearer] That we are not here to punish you we are here to help you lead a full life, personal independence that is what the goal is.’ (Constituency Officer)

‘I think going through the PIP process is humiliating for a lot of people...the nature of the interview, the scrutiny that people are under, the fact that they are nervous because they are told [by others] they are going to be made out to be a liar.’ (Constituency Officer)

The issue of why people with significant and lifelong conditions (including learning disability) should be assessed and re-assessed instead of receiving a lifetime award was consistently raised. There was consensus that anyone with a terminal illness or lifelong condition with supportive medical evidence should be screened out of the PIP process.

‘If you are using the word terminal that should be sufficient.’ (MLA)

‘There should be like a common-sense approach with debilitating diseases, they shouldn’t have to prove every three years they still have it.’ (MLA)

‘I’ve had to do two face to face assessments within two years and all of my disabilities are chronic, regressive and have no cure. I don’t understand why people with lifelong disabilities have to do face to face assessments at all.’ (Claimant, Survey)

‘It should be understood that not all claimants should require assessment ...there’s dozens who could be straight through the system without having an assessment.’ (Constituency Officer)

‘I’m not going to change unless there’s a miracle.’ (Claimant, Focus Group)

Criticisms were particularly evident in relation to people with a severe learning disability and their parents / carers being subjected to ongoing reviews.

‘If someone has a severe learning disability you can be pretty damn sure that they are going to meet the criteria for PIP.’ (Social Worker)

‘He’s got Down’s Syndrome, autism and no communication...that is never going to improve, to me that should be a lifelong award, he’s never going to not be Down’s Syndrome, he’s never going to not be autistic, he’s never going to suddenly learn to speak at twenty-five so his dependency is high and will get higher, common sense would tell you that.’ (Parent / Carer)

Compounding the view that many people should not even be part of the process with the significant number of successful appeals led many participants to question whether the administration of PIP was an appropriate use of public funds.

‘It’s a waste of resources too, and manpower...plus, the stress and bother.’ (Claimant, Focus Group)
’...think about the amount of money that’s wasting to reassess a person whose condition is never going to change – the money could be better spent on helping the people who need the help.’ (Parent / Carer)

‘When you get to the stage where it is not getting any better and you need help with practically everything what is the point of reassessment, I think it is a waste.’ (Claimant, Focus Group)

Criticism was noticeably evident with regards how time consuming the PIP process can be. For many it is clearly a lengthy journey from when they first complete the PIP application until they receive an outcome, particularly if they request an appeal.

‘...where a claim is taking 13 or 14 months, that should not be the case, that should not be happening.’ (Constituency Officer)

Several participants commented on the variations in time taken to receive an award and, depending on how long that was, it may not be too long before it must be reviewed again.

‘I think there’s inconsistencies with the length of time for awards and quite often the appeal’s taken eighteen months to be heard they’re getting a two year award which is up in six months so as soon as they get their award letter saying your appeals been granted and you’ve got your award the next week they’re getting a reconsideration or a form out again...even if you do get an award without an appeal they’re sending the letters out for reapplying ten eleven months ahead of the end date which is reducing the lengths of awards...’ (Constituency Officer)

Another striking aspect of the research was the extensive levels of support being provided not just by the advice sector but local constituency offices. This regularly goes beyond assistance with the initial application form and across all stages of the process.

‘Don’t confuse the time solely on forms with the time taken, because the holistic, the emotional support for the applicant and the applicant’s family, there’s a lot more time spent. Every letter that comes through the door is then brought in for us to have a look at ‘is this relevant, should I be adding this on to, do you need to....’ So, it’s a wider package and there’s nowhere else in the community to offer this.’ (MLA)

Time spent with individual claimants usually ranges between 1-1.5 hours to 5 hours, and often beyond for more complex cases, especially where there are mental health considerations.

**Typical support can include:**
- emotional support to the claimant and their families
- completing the PIP form and Mandatory Reconsideration
- reviewing and advising on relevant correspondence from statutory agencies
- assisting with the gathering of medical evidence
- supporting the claimant to make a complaint
- potential attendance at a Tribunal.

‘Each case takes five hours from phone calls backwards and forwards and more. And that is me from helping to fill forms in right through to trying to chase up where the answer is.’ (Constituency Officer)
‘We mainly signpost for forms, so we do Mandatory Reconsiderations and appeals, but I have an appeal this Friday and it's probably a tricky one and probably about twenty hours has went into that.’ (Constituency Officer)

‘The most complicated is the mental health applications because I think then you can become relied on as the point of contact and that can run over a certain amount of hours so they are contacting you at all times about everything.’ (Constituency Officer)

Staff in constituency offices consistently highlighted that they did not always feel qualified or experienced to handle some of the issues that were being presented. For many it had been a steep learning curve and they were interpreting situations and applying knowledge as they went along.

‘And even when it comes to the forms, you know like, we’re not healthcare professionals we’re not doctors. We’re learning so much about all these issues because you have to learn about them because there is no one else there...we’re not trained to be assessment people, you’re just having to self-teach about all these health conditions.’ (Constituency Officer)

‘I think from a constituency perspective again we have our own constraints within our constituency office around the training that we can provide to our staff....a lot of it is kind of working through it ourselves and trying to understand it and interpret it in the best way possible.’ (MLA)

While available training was regarded as being of good quality, there was consensus from constituency officers that they would like more opportunities to avail of it, especially given the level of detail and complexity which cases often entail. While some reported receiving a funding allowance for training, they noted this was per constituency office so did not always meet the demand where there were several staff and the full training budget covered one staff member.

‘The training we did is so detailed, I mean they were excellent trainings, but they were so detailed. The first half hour you felt like you were getting your head around it and then as a level of detail increases and as you are there for three hours if you are not already working in the field then I think it becomes more intimidating.’ (MLA)

‘But any forms of training that comes up, like, our budget has already been spent because I did the universal training as well....so I am the only one that can do any of these things because the budget is gone.’ (Constituency Officer)

Being suitably trained was deemed particularly important given the responsibility that many constituency officers and MLAs felt in ensuring they helped people secure a positive outcome. Alongside advice workers and supporting organisations, they talked extensively about the stress that many claimants experienced but also their own in not ‘letting anyone down.’

‘You know you’re in with someone whose depending on you to work on their behalf, so you don’t want to say the wrong thing because if you say the wrong thing you have it in your head that this whole outcome might change.’ (MLA)

‘Where’s the resilience training for my staff...it doesn’t exist and you know that’s the burdens that we’re facing on a day to day just to get these people through it because you know you’re taking their problems onto your own shoulders and it’s increasing...’ (MLA)

There was overwhelming evidence to suggest claimants are concerned and worried about the PIP process. It was often described by supporting organisations as being a stressful experience which can negatively impact on physical and mental health and exacerbate existing conditions. There was some concern that claimants who are known to services and otherwise managing well end
up seeking support from VCSE and statutory organisations, for example social workers, because of stress associated with the PIP process. Often people find it difficult to discuss the symptoms of their mental illness and are left feeling ‘traumatised’ as a result.

‘And you’ve got service users and carers who are so anxious about this. There is no doubt they are going to get it, it’s just the fact that they have to go through this whole process again.’ (Social Worker)

‘You are putting people through eight to ten months of complete stress and turmoil, exacerbating their conditions. You have clients who come in and by the end of the process their mental health has gone downhill and their conditions are exacerbated.’ (Advice Worker)

Claimants themselves talked about the stress they experienced and the resulting impact on their physical and mental well-being.

‘A normal person under stress can’t eat, can’t sleep, when a person with a disability is under stress their disability heightens – I lose my balance more, I’m more forgetful and I don’t sleep – it’s very serious.’ (Claimant, Focus Group)

‘Cannot put into words the level of stress I felt during the assessment and build up to it. It has set me back in a major way and had major impacts on my physical and mental health.’ (Claimant, Survey)

‘I have been for assessment and renewal, and my GP will confirm this...I have now started to lose my hair again due to stress, and it’s the stress of assessment, stress of waiting, and then the stress of not knowing...’ (Claimant, Focus Group)

In some cases when an application is unsuccessful or going through the appeals process, the levels of stress experienced can have a particularly serious impact on a person’s mental health.

‘…..[a client’s] daughter came to us and said can you help her [mother], she said when she got her zero points she said she closed the door in the room and she was just going to wait to die. She literally had just closed the door on life because it hit her so badly. You know obviously she has now come through the other side of it. It was traumatic.’ (Constituency Officer)

‘Since people’s assessments I have had significant numbers of people who are suicidal and I’m not overegging it. I’m not over exaggerating, people haven’t slept for months because they don’t know what’s going to happen and they don’t know if they will be fit to pay the mortgage at the end of it all and they don’t know if they are going to lose their home.’ (VCSE Support Worker)

People are reluctant to make a complaint about any aspect of the PIP process they are unhappy with, often because they want to avoid further stress or are scared it will affect their award.

‘I always encourage complain, complain, complain but the first thing they say is ‘is this going to affect my claim?’ (Advice worker)

Many research participants expressed scepticism about the official response to complaints about PIP.

‘The complaints procedure, many people are very reluctant to go down that because they feel it may prejudice them their case and I don’t think there is great clarity in how you do that and certainly there is no indication of what changes are made as a result of complaints that are upheld.’ (Constituency Officer)
‘There’s a perceived lack of accountability, both at the assessment stage and at the appeals stage. They didn’t want to acknowledge that someone professionally qualified didn’t actually really do a good job.’ (Parent / Carer)

2. Making a claim

Key issues highlighted by participants when making the initial claim included:

- Calling the PIP claim line is mostly straightforward but can be challenging for those with anxiety and/or speech difficulties.
- The PIP application form can be difficult to complete, with many people finding it repetitive, lengthy, and hard to understand.
- Most people need support from a family member or independent advice agency to complete their PIP application form, and across the wider process.
- A successful outcome depends on the use of particular terminology (‘buzz words’).
- The application form / process is more tailored towards medical evidence associated with a physical disability.
- There is a lack of clarity about the supporting evidence needed.
- GPs are not always best placed to evidence functionality.

There was some acknowledgement that the government has been proactive in trying to improve the process for people making initial contact, and in working with agencies to solve other ongoing issues.

‘At the start there were a lot of teething problems was my experience because they had recruited a lot of telephone staff who were inexperienced at dealing with vulnerable people....the Department have fine-tuned it a bit, in conjunction with the community and voluntary sector who have worked closely and relayed what the teething problems are and everybody has worked together to get that going....I know if I raise an issue they will work with you to sort it....’(Advice Worker)

Most survey respondents (86%) knew that they had to call the claim line, with the majority (63%) stating they found the call to be either as expected or easier. However, a quarter of respondents (25%) indicated the initial call was more difficult than they expected. Some are anxious about making phone calls, and there can be difficulties with speaking and / or being understood.

‘As a result of stroke, I can’t speak well, cannot use phone at all, yet initial claim is by phone...’ (Claimant, Survey)

‘I had aphasia, so my voice was difficult to recognise. The switchboard acted on voice recognition which was totally useless for me to get to the right place.’ (Claimant, Survey)
• Three quarters (75%) of survey respondents reported the application form to be more difficult than expected.

Across the survey and focus groups, it was suggested that many people find the form to be lengthy, repetitive and hard to understand in terms of the ‘technical’ language used, particularly those with a learning disability or mental health condition. Many participants reported that both the form and associated correspondence lacked the essential accessibility to meet the range of communication needs.

‘The form is laborious and repetitive.’ (Claimant, Survey)

‘We as an organisation had a number of individuals coming in both about the phone calls and about the forms because the forms are very technical, there’s a lot of technical language used in them so the accessibility was just not there from the outset.’ (VCSE Support Worker)

‘The questions really need to be clarified. For I know, in one question, it was the same thing I wrote down three times...I cannot walk a certain distance without using a crutch. I have to use a crutch for mobility. I cannot walk to the shop without a crutch...its constant repetitiveness in the form.’ (Claimant, Focus Group)

Many research participants thought the process would be easier if there was an option to complete the form online.

‘I just think it would have been a huge help because then you could cut and paste in sections from my reports, from our initial assessments and our comprehensive assessments...’ (Social Worker)

Across the study it was clear that claimants needed a lot of support with application forms. As shown at Figure 3:

• Most survey respondents needed some type of help to complete the application form (81%), and with Mandatory Reconsideration (80%).

• Notably, over one third (37%) could not fill out any of the initial form themselves.

• Almost half (45%) sought help from a friend or relative.

• 56% sought help from advice agency (29%); charity (20%), or constituency office (7%).

Reflected in the focus groups, survey respondents further indicated that a friend, relative or independent advice agency was the most utilised source of support at other stages such as Mandatory Reconsideration and Tribunal (Figure 4). Help was particularly sought from advice agencies, charities, and constituency offices at the Tribunal stage.
‘We tell everybody not to do their own form. It’s too complicated, you have to get someone else to do it. I’ve done about forty or fifty forms for other people.’ (VCSE Support Worker)

Difficulties in completing the application form often relate to a lack of understanding about the PIP activities, descriptors and points. Some people are unclear about the level of information and detail needed and worry about wording things in the ‘wrong’ way. A belief was evident across the survey and focus groups that the use of particular terminology or ‘buzz words’ was essential in securing an award.

‘I have seen people have filled boxes but haven’t touched on any descriptors’ (Constituency Officer).

‘Completing the form is very stressful, as you don’t know what will hinder or help you.’ (Claimant, Survey)

‘I didn’t understand a lot of the questions and I have since discovered that unless you know the ‘buzz’ words to use you’re penalised in the decision-making process.’ (Claimant, Survey)

Wording applications appropriately appears to be one of the main reasons that claimants seek specialist advice with the PIP process. Indeed, advice agencies / constituency officers consistently reported they had become practiced in framing information in ways more likely to maximise success, with many working off templates and using the same key words and phrasing.

‘I learnt the hard way because the first time I did not do that and did not use their terminology, people were not getting the points. So, I changed the terminology to say exactly whatever they said, and people got the points.’ (Social Worker)

‘We would find key words like repeatedly, debilitating, ah, most of the week, on the worst day, it affects me mostly. Whatever way you want to frame it, we find that basically using that terminology for any question and then framing it around a particular scenario...’ (Constituency Officer)

‘It kind of proves that it is very mechanical...it is a very uncaring kind of process. The fact that you have to say certain key words for them in order to say ‘ah right, they must be actually unwell’.....you are essentially saying a different thing in a different way it is essentially rejected.’ (Constituency Officer)
“...sometimes they [claimants] don’t like the language that you may need to use in order to get them into the box. So, you have to be very sensitive in and around that...” (Advice Worker)

A common issue highlighted in the survey and focus groups was that the application form and overall process has a ‘one size fits all’ approach in being more tailored towards medical evidence associated with a physical disability, and less suitable for conditions such as learning disability and autism.

‘A person with learning disabilities has absolutely no need to attend a doctor on a monthly basis, a weekly basis or anything else and that’s not taken into consideration whatsoever.’ (Parent / Carer)

‘I feel they give an awful lot of emphasis to what medication you’re on. A lot of people with learning disabilities may not be on any medication...I mean somebody with autism for example may not be on, you know their therapy is routine, structure and help but they’re still needing a lot of support for that but just because it doesn’t come out of a bottle doesn’t belittle their need you know.’ (Constituency Officer)

The form can also be challenging for claimants with mental ill-health and fluctuating or ‘invisible’ conditions.37

‘There was too much emphasis on physical restrictions. As I have ME there was not enough allowance given for the mental fatigue that comes with my condition.’ (Claimant, Survey)

‘...and fibromyalgia, mental health issues, MS, scoliosis... anything where there’s a lack of specialism and understanding about the transient nature of conditions.’ (VCSE Support Worker)

Many issues around the type, quality and weighting of supporting evidence were raised in the survey and focus groups. Sourcing and then applying the appropriate evidence often appeared to be incredibly complex and time consuming and was one of the key reasons that claimants requested support.

Almost half (49%) of survey respondents reported that they were unclear about the type of supporting evidence needed alongside their application.

‘There were no guidelines, so I didn’t understand why they were asking me the questions. They asked for medical evidence, but I have a learning disability. I’m not sick’ (Claimant, Survey)

‘We were unsure what medical evidence was best to provide because with my son, right back to primary school, he’d had you know, the children’s psychological services, through into CAMHS, and into adolescence you know, mental health services... or was just the most recent stuff relevant? (Parent/Carer, Focus Group)

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37 Invisible disability, or hidden disability, is an umbrella term that captures a whole spectrum of hidden disabilities or challenges that are primarily neurological in nature and not immediately apparent. Typical examples include fibromyalgia, chronic pain, chronic fatigue syndrome or ME, and many types of mental illness such as depression and anxiety disorders.
The successful completion of an application form in one appointment with a constituency office or advice agency very much depends on individuals being in possession of all the necessary evidence.

‘We would book someone in for ninety minutes to get a PIP2 form completed. And again ninety minutes provided you have already told that person ‘when you are coming, I want you to bring as much supporting evidence as you can with you.’ We would also draw up a template and ask if you have had any investigations or you have had any tests in the last year or you have had any healthcare professionals involved. We are giving them a wee bit of homework to do before they come and fill in the form.’ (Advice worker).

However, even when evidence is brought to appointments set up to complete application forms it is not always straightforward. Some organisations reported frustration at the quality of supporting evidence being supplied by GPs and other medical professionals, suggesting it is often too vague and needs to have more specific detail and clarity about an individual’s condition and capabilities.

‘...we are put in this position whereby we’re not getting evidence from doctors that clearly states what’s wrong with the person...yes constituency offices can help with PIP forms and can help people that are entitled to PIP but what we need is doctors letters to say that this person actually has this condition and they can’t do a, b and c that fits in with the criteria for PIP and that I think would be extremely helpful.’ (Constituency Officer)

‘Consultants also don’t know the descriptors so even if they try to write a bespoke letter it’s not, it’s not dealing with the functionality aspect at all.’ (Constituency Officer)

A key theme emerging from the focus groups relating to poor quality evidence was that GPs are not always best placed to evidence functionality. Many participants believed that GPs do not have enough expertise or knowledge with regards learning disability or certain medical conditions to assess a person’s daily capabilities, which can also vary day to day as conditions fluctuate.

‘Our GP would ask me what’s the day to day like because they don’t know, he’s not at the doctor continually for medical things so his record would not show his behaviour problems, his frustrations, his lack of being able to cope with noise...’ (Parent / Carer)

‘The problem is it didn’t show nitty gritty, day to day problems I have.... GPs know very little about MS.’ (Claimant, Focus Group)

‘GPs don’t have the evidence in relation to functionality...because it’s not part of a medical condition so they don’t have a record, they don’t know what somebody can do in their own home.’ (Constituency Officer)

It was also suggested that other professionals / keyworkers can have a better picture about an individual’s health needs and capabilities than GPs so their supporting evidence should be given more weight.

‘...it’s not just the GP but the social workers, the psychiatric nurses, community nursing staff and the organisations that provide the physical and mental support and emotional support for the individuals, there needs to be some weight in there.’ (VCSE Support Worker)

‘We always advise people to go and get a letter from your OT team, your back-up team you know what I mean, your school, whatever that case may be because your GP records will never, ever describe your functionality on a day to day basis, it’s not medical.’ (Constituency Officer)
Linking into one of the key underpinning issues that too many people who should not be are going through the PIP process, there was consensus that evidence from qualified GPs and other health professionals should be sufficient.

‘Sometimes I just think can you not trust the health professionals... It should suffice for me to send a letter and say, “This man has a severe learning disability, autism and epilepsy and he has no speech and needs support with all of his daily living and mobility issues.”’ (Social Worker)

“We met with the GPs over this and they said it was very time consuming, because they had to go into old medical records and basically, they should have been able to write I think this person is eligible. That should be it, not challenging it.’ (MLA)

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The survey results also revealed a lack of clarity about the finer points of the PIP process:
- **56%** of survey respondents were unaware they could request a two-week extension.
- Almost two-thirds **(64%)** were unaware of how long it would take for a final decision to be made.
- Over half were unaware of the option to request a home assessment.
- **52%** did not understand they could request a more detailed explanation of the decision and a full copy
- **59%** reported not having knowledge or experience of supplementary payments.

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### 3. Assessment

Key issues highlighted by participants about the PIP assessment process included:

- Many people did not experience the questions, measures, and functional tests used in assessments as wholly relevant to their condition and how their daily life is impacted.
- Assessors often lack the required level of knowledge and understanding about claimants’ conditions, particularly learning disability, autism, and mental health.
- Informal observations are unfair and subjective.
- There is an inconsistency in knowledge and approach amongst assessors.
- Positive experiences and good practice were evident, and strongly aligned with individual assessors who demonstrated appropriate knowledge, empathy and understanding.

Whereas people were assessed via an application form and supporting evidence under DLA, a face-to-face assessment is required for PIP. These assessments are intended to be functional rather than medical, in that they consider the impact an individual’s health condition or impairment has on their everyday life. The assessment process drew the most commentary across both the survey and focus groups, with key areas of discussion including the nature of the assessment and the role of the assessor.

“For me, the difficulties start when the assessment takes place, that’s when people really come unstuck in the process...” (Constituency Officer)

‘People do find assessment in the main if not intimidating, then definitely disconcerting. You know because, unfortunately in these situations too many people feel that this is a test and they feel they have to justify their illness to someone.’ (MLA)
‘You’re a bag of nerves, you’re talking about how to clean your ass, they ask you things that are very personal and very intimate and you’re shocked by it. You could be knocked off by it…’ (Claimant, Focus Group)

- The majority of survey respondents were assessed either at home (45%) or in an assessment centre (45%).
- 10% reported they had qualified for PIP via a paper-based review.
- Survey respondents were generally happy with the convenience and accessibility of the assessment.
- The main reasons claimants brought somebody with them was ‘to provide moral support or company’; ‘to support my needs associated with my disability/health condition’; and ‘to help with the information I needed to answer questions.’

**Experience of the assessment**

Most **survey respondents** were not positive about the suitability of assessment tests and questions, or the assessor’s knowledge about their condition:

- 73% disagreed or strongly disagreed that measurements and functional tests were relevant and appropriate.
- 65% disagreed or strongly disagreed that questions were relevant and appropriate to their condition.
- 62% disagreed or strongly disagreed the questions allowed them to explain the impact of their condition on daily life.
- 66% disagreed or strongly disagreed that the assessor understood their condition.
- 46% disagreed or strongly disagreed that the assessor understood their application form and had all the supporting evidence.
- 53% disagreed or strongly disagreed that the assessor listened to them.

Feedback was more positive in terms of the assessor explaining the assessment and how claimants felt they were treated in the assessment:

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38 Very few positive or even neutral responses.
The significant levels of dissatisfaction with the assessment process were strongly mirrored in the focus groups regarding the nature of the assessment, and particularly with the role and experience of assessors. **Key issues** included:

- **Assessors lack the required level of knowledge and understanding about claimants’ conditions**: Participants were generally of the view that assessors do not understand all the different disabilities and health conditions which they encounter in their role, with mental health regularly highlighted.

  ‘These assessors are not trained in any particular field, particularly I would say in mental health, they don’t even begin to understand what the issues are, but you can also apply that to the deaf community.’ (MLA)

  ‘When asked if the assessor was aware of my condition – xxx disease- she stated she’d never heard of it but had a ‘quick google’ at the weekend! The assessor declined to accept information I had brought with me about my condition printed from the official xxx websites….the assessor could not possibly make correct judgements and observations without having good awareness about my condition, prognosis and how it effects daily living.’ (Claimant, Survey)

Assessors were often described as being ‘nice’ or ‘pleasant’, but perhaps a bit out of their depth when faced with a condition with which they were not familiar.

  ‘I do think the lady we had on that particular day did the best she could do to understand my situation, she was very respectful …. I felt she backed off in some of the areas where she really didn’t have the knowledge, questions I thought she probably would ask she didn’t.’ (Parent / Carer)

Advice agencies and supporting organisations often found it difficult to understand how an assessor could make appropriate observations and fair judgements without some professional background in the area.

  ‘Like I had a lady today in tears, her daughter is autistic and the person who assessed her was a physiotherapist so the person who assessed her has no understanding of autism or mental health in general.’ (Advice Worker)

  ‘I mean you are having people with complex mental and intellectual problems being treated by people who are trained in physiotherapy, you know it is a medical professional but they have no insight whatsoever into the practical affects that these conditions have on people.’ (VCSE Support Worker)
Concerns were further expressed in the focus groups, and reflected in the survey, that assessors with limited or no knowledge of a claimant’s condition may not give due consideration to supporting medical evidence.

‘How can my daughter’s oncologist, physio, ophthalmologist, and neurosurgeon all think she’s disabled and entitled to PIP, yet a government contractor think they know better?’ (Claimant, Survey)

‘...I feel a nurse practitioner is not qualified enough to overrule a doctor or consultant’s expert opinion.’ (Claimant, Survey)

A common criticism was that assessors’ lack of knowledge meant they were unable to fully appreciate the fluctuating nature of many disabilities and health conditions. It was widely held that more focus should be placed on a claimant’s ‘worst day’ to gain a realistic picture of the challenges faced.

‘I think everybody’s disability is different and it can affect them differently on different days.’ (Claimant, Focus Group)

‘I tell them to describe their worst day. That’s the only way that is going to get you were you need to be you know...’ (VCSE Support Worker)

There was broad consensus across the focus groups that claimants should be assigned assessors with relevant knowledge and experience in their disability or health condition. Some frustration was expressed that this view was not accepted by the government contractor.

‘We have had this conversation for numerous years with Capita. They say it is not about your condition it is about your functionality. It does matter what your condition is... but they say so you don’t have to be qualified in mental health, you don’t have to be qualified in cancer palliative care treatment.’ (Advice Worker)

- **Assessors lack understanding about learning disability and autism**: Learning disability was frequently highlighted as an area where assessors lacked knowledge and understanding, including that it is a **lifelong** condition. Many support workers expressed surprise at encountering professionals who appeared not to be fully aware of even the most basic facts about learning disability.

‘I think that assessors don’t have an understanding of learning disability and I think they send the wrong professionals out to the wrong people.’ (Constituency Officer)

‘Once you get a diagnosis of a learning disability it’s a proper diagnosis which I don’t think they really seem to take into account, you know you’ve an IQ under 70 and significant issues with social functioning and they just need to understand that, that’s going to be there for life, it’s not going to go away, they’re not going to get cured of it.’ (Constituency Officer)

A lack of understanding about learning disability extended beyond the assessment and to other professionals across the wider PIP process.

‘It’s not just the people doing the assessment who don’t have the understanding of learning disability, people on the appeals panels don’t know either you know, so the whole process doesn’t understand the specific needs of that.’ (Constituency Officer)

‘xxx has Down’s Syndrome...the person I talked to said we have to check to see if his condition is still the same. Now you just think about that, the level of ignorance and stupidity and just well - I says unless there has been a miracle.’ (Constituency Officer)
Knowledge of learning disability and autism was considered especially important in ensuring that the approach taken in assessment was an appropriate one in order to gain an accurate picture of an individual’s capabilities. One example often given was the need to understand that they may often reply to questions in the affirmative to ‘please’ people.

‘If you’re interviewing a person with a learning disability and they are responding ‘yes’ to everything, the assessor should break down the questions, and dig deeper and go to the companion – not to undermine the voice of the individual but making sure it’s correct and they’re being realistic.’ (Social Worker)

‘Assessor was not familiar with autism and how it affects my daughter’s life and how she sees and thinks about things and that she just wanted to please her with giving her the ‘right’ answer...’ (Claimant, Survey)

• ‘Informal’ observations are unfair and subjective: Most advice agencies and constituency officers raised concerns that observations based on a claimant’s demeanour and appearance were being recorded as part of the assessment, usually without the individual’s knowledge. These included making eye contact, smiling, and being well presented, all common examples highlighted as being used to reduce the number of points awarded.

‘You can provide as much specialist reports, doctors’ reports but if they go in there and make eye contact with the Capita assessor and look clean and tidy, then that is their award out the window.’ (Advice Worker)

‘These guys are sitting here, and on the forms, they are actually writing her hair was combed and she looked well. You know, she smiled...’ (Constituency Officer)

Many also cited a claimant being able to travel independently to an assessment as another observing factor which negatively impacted on the points received.

‘Their attitude is, if you can sit through a 45 minute assessment or a 30 minute assessment on your own, when you don’t have any choice, and you have no one to go with you, they are saying you can access the building, you can make the journey down, you can engage with the assessor, zero points. It’s disgusting.’ (Advice Worker)

Participants were generally of the view that assessors failed to appreciate and understand that the way people present at assessment may not reflect how they are on most days.

‘People are incredibly resilient...they try to function, and they do go out on their own and that sort of thing. But if you are resilient and you have human qualities that everyone should admire that actually works against you which is sad.’ (VCSE Support Worker)

‘...but these people have made a particular effort to be that way for that day and it’s not every day and it’s not normal, if you went to their door the next day they could be in their pyjamas.’ (Constituency Officer)

Most participants viewed these types of observations as unnecessary and questioned their relevance in the process.

‘Customer was able to maintain good eye contact; customer was wearing a suit. What has that got to do with anything?’ (Constituency Officer)

‘Initial general observations, put in at start of the decision, well dressed, seemed well nourished...these general observations tend to have nothing to do with the disability they’re assessing.’ (VCSE Support Worker)
Notably, several participants reported that the use of what they perceived to be biased observations by assessors had resulted in them advising claimants to consider how they travelled to, dressed, and appeared at their assessment. They were uncomfortable taking this approach, believing it contradicted their own ethos as well as that of PIP to promote independence.

‘I think it is really bad that we have to encourage people with disabilities to dress untidy, to put your head down, to don’t speak, don’t engage, don’t do this so they can get a benefit.’ (Constituency Officer)

‘...don’t maintain eye contact, don’t bring a handbag, don’t get the bus you know even if you can and if there is no other way of getting somewhere, don’t be getting the bus. That’s ridiculous, we’re telling someone with a disability not to do things.’ (Constituency Officer)

Notably, criticisms of assessments by supporting organisations were often associated with the privatised nature of the process and what was perceived to be an uncaring and business-like approach. Many participants also questioned how effectively this part of the system was reviewed.

‘Like they are literally trying their best but there is no vocational approach, it is very clinical it is very uncaring. It’s privatised which is the main problem....It’s privatised, so you know, there’s no caring in it, there’s no caring element to it there’s nothing, it you either hit this mark, that mark and that mark or else forget about it, you just walk out of it. There’s no movement or care to it all, it’s very clinical, very machine like, it’s not a nice system...’ (Constituency Officer)

‘I would like it back in the public domain, so the people who are doing the assessments have a duty of care towards you...healthcare and other education professionals you know so you can have a more joined up approach to this.’ (VCSE Support Worker)

‘The actual awarding of the contract is not the issue; the issue is how the performance of the contract is reviewed’ (Parent / Carer).

• **Good practice in assessments was reported:** While there was much criticism of the assessment process, some positive experiences, and good practice were highlighted.

‘I had a very straightforward process. Had it at home, the girl who came to see me had a good understanding, she came in and did ask the questions and explained she was going to help to type everything in and some of the questions would be repeats from the form. I found her very good and she gave me a fair hearing.’ (Claimant, Focus Group)

Based on extensive experience supporting claimants, most supporting organisations believed that good practice in relation to assessments very much depends on the individual assessor and their approach. Some are widely regarded as being more professional, knowledgeable, understanding, and empathetic than others.

‘It’s depending on the assessor to be fair and some of them are better than others.’ (VCSE Support Worker)

‘We’ve had some reasonable experiences with the assessors, but they are so unpredictable.’ (Constituency Officer)

‘When we’re going out with a client to do one we’re always hoping it’s this one girl because she’s so understanding....absolutely no training in learning disability but is so good...like she’s so good she’s so empathetic, she really understands.’ (Constituency Officer)
Experience of interaction with supporters of claimants during assessment was mixed, with some assessors encouraging them to contribute and others seemingly not. It was generally viewed as better practice when the claimant’s supporter was permitted to engage in the process, but that this needed to be clear, and consistently applied.

‘Any assessments I’ve been to the people doing the assessments have been more than good, I’ve been allowed to say whatever I’ve needed to say in order to back up anybody that had forgotten anything and I was never pushed or told sorry this isn’t your place.’ (VCSE Support Worker)

‘The assessors should be encouraged to speak to the advocate and allow them to interact where it’s necessary in terms of answering the questions or to support the person to speak. That should be made clear. That’s not interfering with the regulations, it’s simply saying good practice around the role of the companion.’ (VCSE Support Worker)

To further support good practice, some participants believed that audio recording should have been a feature of assessments from the outset of PIP being introduced.

‘I do firmly believe that the Capita medical assessments would be very different if they were being recorded.’ (Advice Worker)

4. Decisions and appeals

Key issues highlighted by research participants about decision and appeals included:

- Many people were unclear about the basis on which decisions were made, and scoring can appear inconsistent.
- Assessor reports do not always accurately reflect peoples’ situations or what had taken place during assessment.
- Mandatory Reconsideration is not a meaningful review of decision-making, and acts as a barrier to discourage claimants from progressing to appeal.
- The high success rate at Tribunal suggests the implementation of PIP is flawed; and some people who have chosen not to appeal, often due to stress, may be losing out financially.
- The onus on claimants to acquire and summarise the relevant medical evidence is an additional barrier to the appeals process.
- There are inconsistencies in Tribunal location and approach, with some taking place in courthouses and others in more informal settings.
- Good practice at Tribunals was highlighted, and often associated with the tone set by the Chair, and a belief that evidence would be heard by professionals who were more suitably qualified to make decisions.
While most survey respondents achieved a satisfactory outcome, many participants in the survey and focus groups expressed dissatisfaction with the process. These included with the assessment outcome and the basis on which decisions were made; the purpose of Mandatory Reconsideration (MR); and the number of successful appeals following Tribunal:

- **Assessment scoring can appear inconsistent:** Many support workers reported frustration in understanding the scoring process, especially when claimants with similar health conditions and situations were awarded widely different points, or claimants with serious conditions received zero points.

  ‘I think there’s no balance between the award lengths people are getting, some people it’s a year or two years or indefinitely....There’s people I’ve supported and some get 2 years some get 5 and I don’t know how they measure that.’ (VCSE Support Worker)

- **Assessor reports do not always accurately reflect peoples’ situations or what had taken place during assessment:** This was one of the most common concerns raised by claimants and support workers, including the absence of relevant details/evidence and assessors adopting a cut and paste approach to producing reports.

  ‘The biggest complaints that we have about assessments is that they are never a true reflection of what actually occurred.’ (Advice Worker)

  ‘Everything I said or is on my PIP form they wrote the opposite for. Literally everything. The most insulting was that she said my mood was fine. Whilst I was sitting there shaking sweating unable to look her in the face could hardly find my words and she said in the write up that my mood was fine no sign of any mental disorder and that I looked her in the eyes the entire time.’ (Claimant, Survey)

  ‘The same assessors churning out the same reports... it is those people that you’re coming across again and again and you think, you know this isn’t right.’ (Constituency Officer)

- **Mandatory Reconsideration has no discernible purpose:** Claimants who disagree with the outcome of their PIP assessment can ask for the decision to be reviewed through MR. There was broad consensus across the study that MR is not a meaningful review of decision-making, and
instead serves as a barrier to discourage claimants from progressing to appeal. There appeared to be little expectation from supporting agencies that anyone would succeed at this stage, with participants stating that they were always looking ahead to the appeal and often advising their clients to do the same.

‘I think they are just rubber stamping. Unless you can provide substantially more supporting evidence it isn’t going to be overturned.’ (Advice Worker)

‘Success rate at MR, and I would say that we are a first-class service even though I say it myself, is about 5%. 70% at appeal...they put in that middle tier to cut out appeals.’ (Advice Worker)

‘I don’t know anyone who has actually done a successful Mandatory Reconsideration, it’s always gone to appeal... so, it’s nearly pointless having that, you’d be better to just go straight to appeal, cause the Mandatory Reconsideration has no benefit to anyone.’ (VCSE Support Worker)

‘What you do is you tell the client in advance this isn’t going to change, we don’t even say it’s highly unlikely, we say they will fail Mandatory Reconsideration.... it’s just an extra hoop, don’t worry about it, we need to focus on the appeal.’ (VCSE Support Worker)

- The high success rate at Tribunal suggests the implementation of PIP is flawed: Those claimants who are not satisfied with the decision made at MR can submit an appeal through a Tribunal service. The significant numbers of successful appeals at Tribunal stage is concerning given there will be people who have chosen not to appeal, often due to stress, who may be losing out financially.

‘People are frightened... or because of how difficult it is or the stress they’ve been under and they don’t even appeal.’ (Claimant, Focus Group)

‘I think that the fact that so many are overturned in appeal exposes how bad the actual system is working that Capita are absolutely failing people...You shouldn’t be having that high level of you know of awards going to people appealing through the Tribunal.’ (Constituency Officer)

‘It concerns me the number of successes we have when we go to appeal so that would suggest to me that the original process was wrong in some way....’ (MLA)

‘So, from zero points, mandatory reconsideration, appeal panel says no, got set aside, then go to the next one with the right support and the right evidence presented in the right way and he gets everything and he doesn’t even have to walk into the room...[this] basically shows me that the front end process simply isn’t working right.’ (Parent / Carer)

Despite the high success rate, supporting agencies are often reluctant about advising clients to appeal in case an initial award is reduced or removed entirely.

‘I was advised not to go to Tribunal in case she lost it totally. And that was her only source of income...I don’t think she would have coped if she’d gone again.’ (Parent/Carer)

‘When you go to appeal everything is up for grabs it’s not just the period of the review, they could end up losing their entitlement...’ (VCSE Support Worker)

- The onus on claimants to acquire and summarise the relevant medical evidence is an additional barrier to the appeals process: This was the subject of much discussion by supporting organisations across the focus groups, with the main issues usefully illustrated in the following quotes:
‘Clients are now expected to obtain their own medical records, read through them, understand them, locate the information that is most pertinent to their case, and also perform some sort of data redaction exercise. We would say that the onus is too much on clients, particularly those with mental health difficulties, those who are not familiar with medical terms and maybe lack the capacity of understanding that would find it quite difficult as well. Those are all issues that are now barriers to a lot of people taking part in the Tribunal process.’ (Advice worker)

‘You’ve got the issue with getting the evidence even for appeals with the whole GDPR process now the onus is on the claimant to get the evidence and take it with them…you’ve also got the situation where a lot of these claimants maybe don’t fully understand themselves of their own situation and it becomes quite scary for them and they’re trying to read information that’s in a language that they don’t understand.’ (Constituency Officer)

‘How is a vulnerable claimant or customer is as they put it, awful term, a human being, a vulnerable human being is now being told to go to your doctor, get your notes printed out, redact them or you will be in trouble.’ (Constituency Officer)

- **There are inconsistencies in Tribunal location and approach:** Some Tribunals take place in community settings or hotels which are more relaxed and informal for claimants, while others are experienced in the more adversarial environment of a courthouse. Attending court and presenting evidence for a PIP Tribunal can be overwhelming for some claimants, with connotations that they have done something wrong or even ‘criminal’.

‘It makes them feel like a criminal and takes away their human dignity.’ (Constituency Officer)

“‘My son’s first appeal Tribunal…it was very traumatic for him actually getting up there in front of the Tribunal and I was actually myself quite shocked because my son had suddenly gone from being a claimant to an appellant within a courtroom framework.’ (Parent / Carer)

‘For many people going for assessment it’s traumatic enough without having to cope with all the drama of the courthouse…you’re associating people with a perception that everyone who goes is a criminal and that is wrong.’ (MLA)

‘I actually feel like a criminal myself. I do feel really under pressure saying don’t look up. I actually had one recently, where the girl was talking and she was smiling and I was practically kicking her under the table, don’t smile kind of thing. And I think what the heck am I doing really….just because you are disabled doesn’t mean to say that you can’t actually be happy and wash yourself every day.’ (Constituency Officer)

However, some support workers preferred the ‘professional’ environment of the courthouse compared to the lack of privacy often afforded in other settings.

‘I prefer the courthouses…it is a bit more professional, you get a consultation room and you are in a setting which is more controlled. Other locations, there is a hotel…but you are still in the lobby with whoever else happens to be there. There could be crowds of people, there could be functions taking place. I have been there when there has been a wedding taking place in the middle of the Tribunals, a funeral as well…It’s hard to keep someone concentrating in the middle of this going on, especially when they might have mental health difficulties when they are surrounded by people as well. I just don’t like it in terms of privacy.’ (Advice Worker)

‘One I had recently was in a community centre and we were sitting waiting in a photocopying room for 45 minutes waiting for the appeal to take place which isn’t ideal at all. There are
people going in and going out whilst I was trying to talk to the client. There was also their GP notes and records, not even sitting on the table, on a box of photocopying paper.’ (Advice Worker)

The degree of formality in approach during the Tribunal itself was a recurring theme and characterised to what extent the experience was a positive one. As with assessments, some supporters were able to speak on behalf of the claimant while others were not; and much depended on the tone set by the Chair.

‘...they had three name plates and they didn’t even introduce themselves – to me it was a very clear signal don’t speak until you’re asked.’ (MLA)

‘The legal chair conducted it like he was conducting a court hearing... conducted it very formally.’ (Parent / Carer)

‘There is variance amongst the chairs on the Tribunal panels because there is one.... she’s amazing, she starts off every Tribunal with ‘I can see that you’ve got problems. We’re going to try and help you, we’re constrained with this legislation but I’ve got a few questions to ask you and if you don’t mind we’ll see if we can get you over the line’ whereas [with others] it’s much more difficult. We go in there having to prove from the word go and they don’t come across as impartial.’ (Constituency Officer)

Variations were also reported in what panels expected with regards the provision of medical evidence.

‘And certainly panels, in my experience, panels approach that in very different ways. My Tribunal this morning, they were content with a couple of pages. This appeal had been adjourned before because the medically qualified member had insisted on more medical evidence. So, the amount of evidence, even if you have had a look at it beforehand, it really is up to the panel and panels can be very different in what they consider. That is very confusing for clients.’ (Advice Worker)

- **Good practice in Tribunals was reported:** While there was some criticism of the Tribunals, there was also much positive feedback. The high chance of a successful outcome at Tribunal engendered confidence in this part of the process and was often associated with a view that evidence would be heard by professionals who were more suitably qualified to make decisions.

‘I would tell people, don’t worry if you go to an appeal, there are people there who are qualified, a doctor...you’ve more chance there at an appeal than you have with a civil servant who hasn’t a clue what you’re talking about. Don’t be afraid of an appeal, go for it.’ (VCSE Support Worker)

‘I’ve had some very good experiences with some really good appeal Tribunal panels where the GP has been an absolute champion or the solicitor.’ (Constituency Officer)

The use of reasonable adjustments played a key role in ensuring the experience of claimants and their supporters was a positive one.

‘I had quite a negative experience of a Tribunal and recently had a very positive experience of a Tribunal with another client who was very nervous...we went and the Clerk came out and asked me to come in and they asked me a few questions and they says we understand your client is very nervous and I says she’s passed herself she hasn’t slept last night, this process is very traumatic for her and they says well would you mind if we ask your experience, if we could ask you a few questions and then we would make a decision and I just went through the form literally about three or four points and just explained about her learning disability
and they awarded her and they brought her in just to accept it and she was just so relieved so that was a real positive. For me someone whose got a severe learning disability that might be the way to do it to reduce the anxiety for them going in.’ (Constituency Officer)

**Ideas to improve the PIP process**

A key part of the project was providing participants with an opportunity to put forward their ideas and solutions to improve the PIP process, with the following common themes identified:

**Applications**

- Improve the application process by simplifying the PIP form and reframing the questions in consultation with PIP claimants.
- Consider separate forms for people with physical disabilities and those with a learning disability and / or mental health condition.
- Provide the option of completing the PIP form online.
- Provide easy read guidance notes with the application and across all stages of the PIP process.

**Assessments**

- Assessors should be fully trained in learning disability awareness, and the healthcare needs of people with a learning disability.
- Assessors should be better trained to conduct assessment with claimants who have mental health conditions and a history of suicide attempts / self-harm, specifically to avoid the use of inappropriate or insensitive questions.
- To better understand the functional limitations of specific disabilities and health conditions, the assessors’ background and skills should be more closely aligned with claimants’ individual needs.
- The use of personal and inappropriate observations to judge functional impact should not form part of an assessment, and claimants should be made more aware of their use.

**Tribunals**

- Tribunal panels should be trained on learning disability and the use of reasonable adjustments.

**Supporting organisations**

- More training is needed for Constituency Officers and other organisations supporting individuals to access PIP.

**These suggestions to improve the PIP process formed the basis of the following recommendations from the APGLD to the Second Independent Review of PIP.**
Recommendations

1. The Department for Communities should legislate to remove the 6 month life expectancy criterion in the Special Rules for Terminal Illness and introduce a new system based on the clinical judgement of healthcare practitioners.

2. The Department should ensure that people who have a lifelong condition / a condition unlikely to change, with supportive medical evidence, should be screened out of the formal PIP process and receive a rolling award.

3. The Department should ensure that a range of application methods are available for claimants to select the most appropriate method for themselves, including an online form. Staff should also be trained to identify and direct claimants who could benefit from an alternative method of application.

4. The Department should ensure that the application process is more accessible through the provision of easy read claim forms and guidance materials; and that easy read information is available across all stages of the PIP process.

5. The Department should progress the development of accessible materials in consultation with PIP claimants, including people with a learning disability.

6. The Department should provide detailed guidance about the specific types of further evidence required to support a PIP application.

7. The Department should ensure that more appropriate weighting is given across the PIP process to medical and non-medical evidence from the range of supporting health professions; social workers; voluntary and community sector organisations, and family carers.

8. The Department should reduce the number of face to face assessments, which should only be required where it has not been possible to gather all the necessary medical and other supporting evidence.

9. The Department and Capita should ensure that Disability Assessors (DAs) are fully trained in learning disability awareness, and the healthcare needs of people with a learning disability. Enhanced training in partnership with supporting organisations and those who have lived experience should also be undertaken to improve the DA’s understanding of autism and mental ill-health, and other conditions where they may lack the necessary knowledge and experience.

10. The Department should ensure that questions related to suicide and self-harm are not routinely part of the assessment process. If the information is deemed essential it should be sensitively sourced separately by an individual trained in these issues.

11. The Department should ensure that informal and subjective observations by Disability Assessors are not used to assess functional impact and included in PIP assessment reports.
12. The Department should ensure that all PIP assessments are audio recorded as standard practice.

13. The Department should review the Mandatory Reconsideration process as it is rarely successful and presents a barrier to many claimants who drop out at this point when they may be entitled to PIP support.

14. The Department should require all members of Tribunal Panels to be suitably trained on learning disability, autism and mental ill-health so they have a better understanding of individual conditions, impact and support systems. Reasonable adjustments must be implemented to facilitate the best possible environment for claimants at hearings, including proxy representation by someone who knows the claimant best.

15. The Department should ensure that appropriate levels of resources are available to provide comprehensive training on all elements of the PIP process for constituency workers and other local agencies who support claimants.
Appendices

Appendix A: All Party Group on Learning Disability

MLA Members

- Chris Lyttle (Alliance Party), Chairperson
- Colm Gildernew (Sinn Fein), Vice-Chairperson
- Pat Catney (Social Democratic and Labour Party)
- Robbie Butler (Ulster Unionist Party)
- Kellie Armstrong (Alliance Party)
- Roy Beggs (Ulster Unionist Party)
- Paula Bradshaw (Alliance Party)
- Pam Cameron (Democratic Unionist Party)
- Mark Durkan (Social Democratic and Labour Party)
- Harry Harvey (Democratic Unionist Party)
- Gordon Lyons (Democratic Unionist Party)
- Nichola Mallon (Social Democratic and Labour Party)
- Patsy McGlone (Social Democratic and Labour Party)
- Colin McGrath (Social Democratic and Labour Party)
- Karen Mullan (Sinn Féin)
- Christopher Stalford (Democratic Unionist Party)
- Rachel Woods (Green Party)

APGLD Planning Group

Mencap NI (Secretariat); CAN; Families involved Northern Ireland (FiNI); ARC; Positive Futures; Triangle; Caring Breaks; Orchardville; NOW Group

Appendix B: Research Advisory Group

- Fiona Cole & Mary Anne Webb (Mencap NI)
- Susan Kehoe (Mencap NI Consultant)
- Anna Hughes; Megan Millar; and Ciara Fitzpatrick (Law Centre NI)
- Janet Schofield & Ursula Campbell (CAN)
- Craig Harrison (Marie Curie)
- Gillian Carr; ‘C’ (Claintont) & Carol Scullion (Action Mental Health)
- Stewart Finn (MS Society)
- Caroline McEvoy (Parkinson’s NI)
- Jason Olsen (Ulster University)
- Patrick Malone (Disability Action)
Appendix C: Case Studies

1. CASE STUDY – Action Mental Health

XXX has a diagnosed mental health condition. He has PTSD and experiences ‘anxiety and obsessive thoughts’ along with severe depression. XXX had been in employment for 5 years when he took his first ‘breakdown’ but still managed to carry on a relatively normal life and continued to work with help of medication. Since then he has had 6 more ‘breakdowns’ with each one making it more and more difficult to function with day to day activities.

XXX first applied for state support in December 2017 when he found that holding down a job was proving too difficult, and financially he could not support a family and pay a mortgage. His wife (who had just given birth) did not return to work as XXX could not look after a baby in his condition. He was awarded the standard rate of PIP and put into the ESA Support Group after going through an assessment for each.

Twelve months later the ESA payment was reduced after being taken out of the Support Group, which he appealed and subsequently won. Six months after that his PIP payment stopped after a review held within his home. XXX said his PIP payment stopped abruptly and he was not notified.

During the assessment XXX felt that the assessor did not fully understand Mental Health. He felt he was being ‘scrutinised’ on his appearance despite his disability being invisible. XXX felt this was unfair. XXX said ‘many people, especially men, can present as fine when out in the community and go home and take off the mask and even, unfortunately, take their own lives. This is a silent killer with invisible symptoms that cannot be determined with a 30 minute assessment.’ XXX felt he was stereotyped. If he had been unshaven and unkempt, looking at the floor while talking, he may have been awarded PIP, due to this kind of appearance being in your favour. This is a flawed system. XXX felt he was punished for being honest and presenting as he felt that day. “Mental Health can change minute to minute, day to day – depending on what triggers are happening at that time. This was not taken in to account during the assessment”.

XXX said he found the whole process ‘intimidating’. He said he felt like his ‘life was being assessed – not his illness’. He felt like a ‘fraud’ and a ‘liar’, like he was doing something wrong by asking for help. XXX said he found the experience ‘humiliating and traumatic’. “You have to re-live your mental trauma every time an assessor is in front of you, with your life, in their hands.” There’s no understanding of how difficult that is to do, and it takes time to get over. Having to discuss, in each assessment, everything that has led you to that point is very difficult, and it puts all those bad thoughts and memories back in your mind. It also makes you doubt yourself and feel like you are not as bad as you actually are, even though he knew that every time he tried to work and try to function in society he had another traumatic breakdown. The PIP process should be able to read a person’s case history rather than them having to relive it every time they are re-assessed.

XXX felt the system is not fit for purpose especially regarding mental health. XXX shared the same information the first time he was assessed as he did the second time (where he was subsequently awarded 0 points). XXX felt it can depend on who you get on the day and that it is a lottery to determine the outcome.

XXX said the questions he was asked do not enable the assessor to understand a person’s Mental Health. ‘They asked if I could cook a simple meal and wash myself or how I travel. This does not
help ascertain the extent of my mental ill health’. ‘I may, sometimes, do all of these things reasonably well to survive and at other times with great personal stress and anxiety. Then at times I cannot do them at all.’

XXX said the only positive thing he could say about the PIP experience is that an assessor came to his house which helped him to manage his anxiety better as he could do the interview in familiar surroundings. Other than this the whole experience was ‘terrible’ and futile.

XXX feels that Capita staff should only interview people with a Mental Health Diagnosis if they are professionally qualified in mental health. If Capita staff were appropriately trained and the questions were fit for purpose and relevant, then this would prevent government money being wasted by having to appeal and attend tribunal, only to get awarded PIP in the end anyway. It would reduce stress and anxiety for the claimant and it would support their recovery, as a constant worry about the next PIP assessment does not support people to stay well.

XXX felt the whole process was like a trial, with a jury would deciding his case based on his response that day, regardless of the actual affect poor mental health can have on a person over their entire lifetime.

XXX also feels that a claimant is forced to seek help, even if they are emotionally unable to do so, as no one is currently in place to offer this help and it is up to the individual to beg for assistance, only to be turned down more often than not.

He is currently waiting for a tribunal to overturn the PIP decision in August 2019.

2. CASE STUDY – Law Centre NI

XXX has a physical disability due to damage to his right hand and suffers with mental health problems. XXX had been on DLA and was assessed for PIP in 2016. His PIP claim was initially rejected. He put in a complaint to DfC concerning the evidence used to assess his claim. A reference was made to evidence given by a social worker which XXX knew could not be true as the social worker in question no longer worked at the hospital. He received a response from the PIP Centre Support Team who had clarified with Capita that actually it was the community psychiatric nurse. The nurse denied being spoken to and there was no record of anyone on the hospital database having given any information about XXX to Capita. Citizens Advice intervened on XXX’s behalf. The problem was rectified and XXX was awarded 12 points for daily living giving him entitlement to the standard rate.

In 2018 XXX was told that his PIP award would be reviewed and that he had to attend a face to face assessment in an assessment centre. Before the assessment XXX was notified by DfC that because no PI P2 form had been received his PIP payment had been stopped. XXX was able to provide proof of postage which led to the dispute being resolved and his payment reinstated.

XXX’s wife dropped him off to his assessment. He reported feeling dizzy from stress being going in. The assessor asked him whether he had completed a PIP2 form which he knew had been received because of the earlier disagreement. The assessment continued despite the assessor not having sight of the PIP2. DfC later accepted that XXX’s form was not available to the assessor due to an error.

The assessor was a midwife and XXX felt that she did not have any understanding of his mental health problems. There were few questions asked about his mental health and the focus of the assessment was on his hand which is a more minor problem. He also noted that she did not make
an attempt to build any rapport. Instead XXX felt under pressure to give answers to fit predetermined and superficial questions.

XXX scored no points and was not awarded PIP. He disputed the assessor’s report from the outset as he states it was riddled with inaccuracies. The assessor stated on her report that XXX had not completed the PIP2. Another striking comment in the assessor’s report was that XXX engages on a daily basis with family members but, with the exception of his wife, XXX has no close family and no extended family with whom he regularly interacts with.

XXX sought a Mandatory Reconsideration which resulted in no change to his award. There was little by way of explanation in the MR report except references to a medical report having been received from XXX’s GP. XXX did not see a copy of this report until the tribunal stage. The MR report said ‘he (the GP) was unable to provide any information on how your conditions impacted on your ability to carry out the activities for daily living and mobility.’

XXX contacted his GP who said he had not filled in any form and was instead informed that a female doctor at the surgery completed the forms for PIP. The reference to ‘he’ in the MR report was therefore inaccurate. The other doctor, having never met XXX, filled in his prescription but answered ‘not known’ to the majority of questions about XXX’s capabilities. The purpose of this was to enable XXX to explain his difficulties himself at the assessment. XXX’s GP looked at the report and said there was nothing in the form to uphold or take away his PIP claims but the MR referred specifically to the report in denying XXX’s claim.

XXX got in contact with his local MLA who wrote to DfC to complain on his behalf. Eventually DfC replied to say that “the appeal service is the most appropriate way to deal with your concern.” The same complaint was also sent to Capita and XXX received the standard response. The assessor was interviewed by her line manager and cannot remember the assessment but if XXX has any evidence to support his complaint to send it in and Capita would be happy to look at his case again. He then escalated the complaint only to receive a reply stating that there was robust information to support the assessor’s report and DfC’s decision.

In December 2018 XXX received a supplementary advice note which awarded him 7 points but did not give him entitlement to the standard rate. The note uses numerous acronyms which are not explained anywhere. This was in contrast to a letter received by XXX in January 2017 in which DfC stated that the use of acronyms ‘was not standard practice and they should not be used.

XXX appealed the decision. He attended the tribunal alone and was before the panel for less than fifteen minutes. The LQM advised XXX that the DfC had no further comments to make on the case, no presenting officer was present and the panel awarded XXX 9 points for daily living giving him entitlement to the standard rate.

Upon advice from Law Centre NI, XXX has filed a complaint with the Independent Case Examiner.