# Personal Independence Payment

A Second Independent Review of the Assessment Process

Laid before the Northern Ireland Assembly by the Department for Communities under Article 94 of the Welfare Reform (Northern Ireland) Order 2015 on 11 December 2020



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# Abbreviations

ABBREVIATION	MEANING
AE	Administrative Exercise
AME	Annually Managed Expenditure
AP	Assessment Provider
APGLD	All Party Group on Learning Disability
AR	Award Review
ВМА	British Medical Association
CIR	Condition Insight Report
Covid-19	Coronavirus
CRT	Customer Relations Team
DA	Disability Assessor
DfC	Department for Communities
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
ESA	Employment and Support Allowance
GB	Great Britain
GDPR	General Data Protection Regulations
GP	General Practitioner
НАА	Health Assessment Advisor
НР	Health Professional
HTML	Hypertext Markup Language
НТР	Health Transformation Project
ICE	Independent Case Examiner

ABBREVIATION	MEANING
IT	Information Technology
MLA	Member of the Legislative Assembly
MP	Member of Parliament
MSK	Musculoskeletal
MtC	Make the Call
NI	Northern Ireland
NICVA	Northern Ireland Council for Voluntary Action
NIPSO	Northern Ireland Public Service Ombudsman
PIP	Personal Independence Payment
PIPAG	Personal Independence Payment Assessment Guide
PIPCS	Personal Independence Payment Computer System
PSU	Professional Services Unit
RRF	Rural Residents Forum
SRTI	Special Rules Terminally Ill
UC	Universal Credit
UK	United Kingdom
UNCRPD	United Nations Committee on the Rights of Persons with Disabilities
VRS	Video Relay Service
WAVE	Widows Against Violence Empower
WCA	Work Capability Assessment
WSP	Welfare Supplementary Payment

# Foreword

Personal Independence Payment (PIP) is designed to meet the needs of many of the most vulnerable people in our society and as such should command the confidence and trust of those having to use the benefit. To this end when PIP was implemented in Northern Ireland under the Welfare Reform (Northern Ireland) Order 2015, the Department for Communities committed to carrying out two Reviews of the process of implementation of the benefit.

When my colleague Walter Rader carried out the first Review in 2018 he made fourteen Recommendations to improve the process. While the Department for Communities responded positively to ten of his fourteen Recommendations and have gone some way to putting them into effect, there is still some way to go on implementing them fully.

I can also report that three of the four Recommendations made by Walter in the first Review, which the Department could or did not accept, have been raised again by the broad range of individuals and organisations who have provided evidence to me throughout the second Review.

I want to express my sincere thanks to over 340 claimants, family members, support workers and organisations who invested their time and expertise in submitting evidence to the Review. Many respondents highlighted their personal stories and this provided a valuable insight into their submissions.

The volume of submissions received, and the passion with which the submissions were delivered indicates the importance that is placed on ensuring that this benefit is available to those who most need it. I have to acknowledge that not all of the evidence received during the Call for Evidence could result in a Recommendation nor can all of the comments made be adequately reflected in the Report. I do hope, however, that I have been able to do justice to the input made by all of the contributors.

The findings of the Call for Evidence are laid out in the body of the report and while it was not within my remit to take a view on the political or legal position of the statutory provision, I should point out that the contention around them impacts on much of the evidence. My findings point to the need to improve claimants accessibility to the PIP journey, through the claim process, the type of Assessment carried out and the quality of further evidence used in decision making. They also include Recommendations to broaden the audit process and complaints procedure to increase confidence in the process.

This second Independent Review of PIP again highlights the need for assistance and advocacy in completing the complex PIP application journey. I believe that the Department must carefully consider how to make the best use of both external and internal advisory services to ensure fair treatment for all those undertaking that journey.

I welcomed the opportunity to meet with the President of the Appeal Tribunals and while this Review is not commenting on the working of the Tribunal I found his views and insight very useful in my deliberations.

I cannot complete this foreword without acknowledging the impact of Covid-19 on the process and its likely impact on the implementation of PIP going forward. Many of the practices that have been implemented this year as a result of the pandemic have been commented on in this report, including the suspension of face-to-face Assessments and the implementation of telephony Assessments. Unfortunately the impact of these changes cannot be adequately reflected in the findings of this report as there is little or no statistically viable evidence of their impact at this time. It is my opinion that these changes will continue into the future and it is essential that the Department evaluate and monitor their impact in the longer term.

In conclusion, while these findings and Recommendations are my responsibility alone, I have to convey my thanks to the members of the Independent Scrutiny Group whose input and support was invaluable in providing both critique and assurance as the work of the Review progressed.

And finally, in completing the Review and reaching my conclusions, I am indebted to the hard work and dedication, of my Support Team. In the throes of lockdown they established methods of communication none of us had heard of prior to March 2020, managed my diary, took copious notes, answered all of my questions and remained good humoured throughout the process. The professional approach they adopted is very much appreciated.

matic barry

Marie Cavanagh Independent Reviewer of the Second Independent Review of the PIP Process in NI

# Executive Summary

The Welfare Reform (Northern Ireland) Order 2015 states that the Department for Communities (DfC) (hereafter referred to as "the Department") must lay before the Northern Ireland (NI) Assembly an Independent Review on the operation of Personal Independence Payment (PIP) Assessments within two years of going live and a second Review within four years.

The first Independent Review of PIP was carried out by Walter Rader and his final report was published in June 2018. The first Review made 14 Recommendations of which 10 were accepted or partially accepted and 4 were not accepted by the Department. The Department published an interim response to the first Review in November 2018 and have provided a further progress update at Annex 1.

The second Independent Review of PIP was initially expected to report on its findings in June 2020. However, as a result of the Coronavirus (Covid-19) measures put in place by the NI Assembly, the Reviewer with the support of the Scrutiny Group, asked for the Call for Evidence to be extended from 29 April 2020 to October 2020 with an intention to lay the final report with the NI Assembly in December 2020.

The Department accepted the evidence gathering aspect of the Review had been significantly impacted by Covid-19 restrictions and approved an extension to the Call for Evidence to 16 October 2020, with the final report being laid with the NI Assembly by 11 December 2020.

The Review thanks the Department for granting the extension as it has given people the opportunity to provide more meaningful representation.

# Scope of the Second Review

The Terms of Reference for the second Review are outlined below:

- evaluating the progress made on recommendations arising from the first Review.
- evaluating awareness and experience of the PIP Assessment process for new applications, award reviews and people reporting changes.
- evaluate the process to ensure the most appropriate Assessment type is selected, paper-based reviews, face to face at the Assessment centre or the home.
- evaluation of the effectiveness of the arrangements for ensuring accurate reports are produced.

• evaluate how effectively further evidence is being used to assist the correct claim decision, exploring the balance between how much and the type of evidence we source and what we ask people to provide.

The Department appointed an Independent Scrutiny Group to work alongside the Reviewer and support the Review. Details of the Scrutiny Group members can be found at Annex 2.

## **Overview of findings**

The Review received over 250 responses to an online survey, held 52 meetings with advocacy organisations, Healthcare Professionals, Departmental staff, Capita and Political Parties and received 44 written submissions<sup>1</sup>.

It was positive to hear that some people have seen improvements to the process since the first Review. However, the current process is not a positive experience for everyone, and is still viewed by many with mistrust and suspicion. Evidence gathered during the course of this Review suggests more work needs to be done.

# **Claiming PIP**

Evidence to the Review suggests that the process is often still difficult to navigate. Many respondents have reported that the initial telephone call to make a claim was challenging particularly for those with anxiety or speech difficulties.

Evidence also suggests that some claimants are overwhelmed and stressed at the prospect of completing the PIP2 – "How your disability affects you" form and report they do not understand the questions or they feel the questions do not apply to them.

#### **The Assessment Process**

It is clear from the evidence received by the Review that the Assessment itself causes fear, anxiety, stress and frustration for many claimants.

Concerns have also been raised in relation to the training of the Disability Assessors and the accuracy of the reports produced following the Assessment.

Issues have been reported regarding the Disability Assessor's lack of awareness and knowledge of certain conditions.

<sup>&</sup>lt;sup>1</sup> The submission received from the All Party Group on Learning Disability represented the views of 450+ survey respondents and focus groups with 50 participants.

The Review understands that recording of Assessments commenced in 2019, however, this ceased when face-to-face Assessments were suspended in line with the Covid-19 restrictions.

#### Evidence

The provision of supporting evidence is a key part of the early evidence gathering process as it helps inform the appropriate Assessment type (Paper Based Review or Face-to-Face Assessments now taking the form of Telephone Assessments) and also assists in making accurate entitlement decisions.

The Review understands that sourcing evidence to corroborate a person's functional ability can be challenging. This has been confirmed by claimants and those who support them, advocacy organisations and by Medical Professionals who stated that they cannot provide evidence to support functional impacts and can only provide clinical information.

The Review has also received evidence suggesting there is confusion around what is considered to be appropriate and relevant evidence and who this evidence should be obtained from. The Review is of the opinion that this confusion stems from the fact that PIP is a functional test rather than a medical test.

Additionally, evidence has been received indicating concerns about the lack of consideration given to relevant non-medical evidence.

Where evidence has been provided by claimants and their families there is an overwhelming view that the evidence is disregarded or ignored.

# Special Rules for Terminally Ill (SRTI)

In the first Independent Review, Walter Rader recommended that the 6 months life expectancy criterion for SRTI claims should be removed. The Department, in their interim response to the Recommendations, stated that they could not implement this Recommendation.

This Review has received evidence which continues to support the removal of the "cruel and arbitrary" 6 month rule. The Review has received evidence from a number of advocacy groups, Medical Professionals and Political Parties calling for the definition of terminal illness to be amended.

The Review has heard evidence highlighting the Scottish Government approach to SRTI claims as an example of what can be done on a regional basis with devolved matters.

#### **Decision Making**

The Review has received evidence to suggest that there is a perception that Capita make decisions on entitlement to PIP but this is not the case. In addition there was evidence from the Department's staff who feel that their role diminished when their job title was changed from Decision Maker to Case Manager.

There are also concerns that the process around the setting of review dates is not conducive for those who have lifelong, life limiting or degenerative conditions leading to claimant's receiving short term awards for conditions that are not going to improve.

# **Provision of Statistics**

The Review has heard evidence from a number of organisations that the statistics published by The Department are not as comprehensive as those provided by the Department for Work and Pensions (DWP) and believe that this should be addressed to promote confidence and transparency.

## **Other Considerations**

The Review notes the progress made by the Scottish Government in the development of a new benefit (Adult Disability Payment) which will replace PIP next year. There were many similar issues raised in the public consultation completed by Social Security Scotland to those raised as part of this Review.

In conclusion, the Review acknowledges that not all of the evidence received during the Call for Evidence could result in a recommendation. However, the Review notes all concerns raised and encourages the Department to consider the following with a view to improving the claimant journey, where possible.

- Rural impact
- Safeguarding
- Impact of Covid-19
- Importance of advocacy
- Future of PIP

It is hoped that the planned improvements to PIP alongside the Recommendations of this Review will lead to restoration of trust with fair and more consistent outcomes for individuals ensuring PIP meets its original policy objectives to support and empower disabled people to lead independent and active lives.

#### Recommendations

The 12 Recommendations made by the Review are detailed below and at Annex 4:

#### **Recommendation 1: Communications and Accessibility**

To improve accessibility for those claiming PIP, the Department, in consultation with stakeholders should explore and develop alternative methods of communication and improve existing communication products and information. The Review recommends the following:-

- An easy read version of guidance material and claim form (PIP1 and PIP2);
- Signed guidance material;
- Promoting/publicising the clerical claim form where online access is not available
- The Department should promote the services of and publish the contact details for the Make the Call (MtC) Outreach Team on all PIP literature. This will broaden the service provided by the MtC Outreach Team to assist with the completion of the PIP1 and the PIP2. The Department should utilise this service to make contact with all claimants who make the initial PIP1 claim but do not return the PIP2;
- Staff should be reminded that when a representative, relative or Social Worker contact PIP on behalf of a claimant they should take this as implicit consent; and
- Information on changes to PIP, in particular legislative changes, should be published in an easily accessible central location.

#### **Recommendation 2: Claiming PIP**

- a. The Department should establish a "Task and Finish" group, involving stakeholders and Medical Professionals, to look at the PIP2 and AR1 forms. This group should consider, but not be limited to the following points:
  - Compliance with the legislation in particular PIP Regulation 7 (the majority test), Regulation 4 (the reliability tests), Regulation 2 and Schedule 1 (the need for aids and appliances);
  - Style and format of questions asked; and
  - Guidance to assist completion of the PIP form, ensuring the functional test descriptors and activities are fully explained.

b. The Department should raise awareness about the availability of the two week extension which can be requested for returning the PIP2/AR1 form.

#### **Recommendation 3: Special Rules Terminally Ill (SRTI)**

Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 6 from the first Review that the 6 months life expectancy criterion for terminally ill claimants should be removed and replaced with a system based on clinical judgement similar to that enacted by the Social Security (Scotland) Act 2018. This should include adopting a subsequent 10 year light touch review on awards made where special rules apply.

#### **Recommendation 4: Assessment Type**

- a. The Department should consider the use of new methods of Assessment, embracing the full range of technology available. This should include use of telephony or audio-visual method where available and should also include a range of options from which the claimant can choose in order to best suit their needs.
- b. In the interests of transparency, the Review recommends that the Department's position should be that all Assessments are audio-recorded with the claimant given the option to opt-out.

#### **Recommendation 5: Assessment Process**

To support claimants and Healthcare Professionals to navigate the Assessment process, and to improve the provision of information available and transparency of the process, the Review recommends that the Department take the following steps.

- a. To support Healthcare Professionals and individuals in understanding the information used in the Assessment process, the Department should make available the Condition Insight Reports, detailing the information contained and explaining how this information is used in formulating advice to the Department. These should be published on the Capita website in line with current accessibility requirements.
- b. The Department, in conjunction with Capita, should consider the use of more targeted open questions throughout the Assessment process to ensure a full picture of needs is established as early in the claim as possible and avoid cases passing to appeal stage unnecessarily.

- c. The Department should ensure that evidence provided by the carer/parent/appointee during the Assessment process is fully considered and used to inform the advice provided following the Assessment.
- d. The Department should ensure that evidence is sought from the person who knows the claimant best (medical/non-medical) and all evidence obtained should be weighted, considered and recorded on the Assessment report and Department records.

#### **Recommendation 6: In-House Assessment Providers**

The Department should consider the outcome of the DWP pilot to bring Assessments for both Work Capability Assessment (WCA) and PIP Assessment in-house. The Review recommends that the Department conduct a similar pilot in NI.

#### **Recommendation 7: Further Evidence**

- a. The Department should produce guidance/examples for claimants, advocacy services and Healthcare Professionals of appropriate evidence to support the PIP process and where this evidence should be obtained.
- b. The Department, in conjunction with Capita and relevant Healthcare Professionals, should examine and implement new ways to improve the current poor return rate of GP factual reports.
- c. Proper consideration and recording of evidence when making decisions is essential. All evidence needs to be carefully considered, in relation to the particular circumstances of the individual case, to ensure the correct decision is reached. The Department should ensure the evidence is fully documented and that further evidence, medical or otherwise, has been correctly weighted and documented.

#### **Recommendation 8: Disability Assessor (DA) Training**

Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 11 from the first Review and implements the Recommendation, taking into consideration the following factors:

a. The Department and Capita should ensure enhanced training and support is provided to DA's on conditions, acknowledged by DA's, as outside their normal experience and expertise.

- b. The Department and Capita should consider training for DA's similar to that provided to Departmental Case Managers and ensure that DA's are aware of regulations and their interpretation.
- c. The Department and Capita should provide more empathy skills training given the nature of the DA's role.
- d. The Department should ensure the annual Training Needs Analysis, completed in conjunction with Capita, reflects feedback from the Independent Panels recommended in Recommendation 9 (The Audit Process) and Recommendation 11 (The Complaints Process).

#### **Recommendation 9: The Audit Process**

- a. The Review recommends that the Department bring all auditing functions in-house as this would go some way to improving trust in the auditing process.
- b. The Review recommends that the Department's Health Assessment Advisor (HAA) uses the audit process and observations to identify the conditions/disabilities where DA's require enhanced training. This should be regular, updated and kept under review. The Department's HAA should engage with expert organisations and Medical Professionals to deliver the condition specific awareness/training required.
- c. The Review recommends that the Department appoint an Independent Panel to scrutinise and provide support mechanisms for reviewing the standard of Assessment, quality of reports, outcomes from the audit process and incorporate any learning identified.

#### **Recommendation 10: Decision Making**

- a. The Department should ensure that Case Managers are empowered to carry out their role as Decision Makers and amend descriptor choices, recommended by Capita, if they have evidence to support this.
- b. The Department should ensure that the process for renewing a claim for PIP is the same for all claimants. The current process means that those without a review end date have to complete the new claims process rather than the shortened AR1 form.

- c. The Department should ensure on-going awards are made on all cases where the claimant's condition is lifelong, life-limiting or degenerative. This should include adopting a subsequent 10 year light touch review on awards made.
- d. Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 14 from the first Review and provides a copy of the DA's, including audited versions, to claimants along with their decision letter.

#### **Rcommendation 11: Improvements to the Complaints Process**

- a. The Department and Capita should publish more comprehensive guidance on how the complaints process works. More comprehensive guidance will help allay fears and assure claimants that making a complaint does not impact or influence the final decision.
- b. The Department should establish an Independent Panel to monitor and scrutinise complaints and responses from the Department and Capita. This will remove any mistrust around effective complaint handling.

#### **Recommendation 12: Improvements to published statistical information**

The Review recommends that the Department provide in-depth statistical data in line with DWP published information to promote confidence and transparency.

# Part 1: Introduction and Background

# **Section 1: Introduction**

- 1.1.1 The Welfare Reform (Northern Ireland) Order 2015 states that the Department must lay before the Assembly an Independent Review on the operation of PIP Assessments within two years of going live and a second Review within four years. PIP was first introduced in June 2016 to replace Disability Living Allowance (DLA) for eligible people who first claimed when they were between the ages of 16 and 64.
- 1.1.2 The Department laid the first Independent Review, conducted by Walter Rader, with the Assembly in June 2018.
- 1.1.3 The first Independent Review focused on the PIP Assessment process from the initial point of contact through to the final outcome decision and made 14 Recommendations. The Department published an interim response to the Recommendations in November 2018. In this response the Department accepted or partially accepted 10 of the Recommendations and did not accept 4 of the Recommendations. The Department has provided a further summary of progress against the accepted and partially accepted Recommendations at Annex 1.
- 1.1.4 The first Reviewer noted that the evidence submitted in NI had similarities with matters identified in Paul Gray's first Review in Great Britain (GB) (2014)<sup>2</sup> and in the Select Committee<sup>3</sup> report (2018) therefore the issues raised were not exclusive to NI. While the first Reviewer acknowledged that constructive practices were already in place he also stated that prompt action was required to build trust and credibility in the process. He further stated that 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.
- 1.1.5 The second Independent Review was expected to be laid with the Assembly by 20 June 2020. This Review of the PIP process aimed to provide a robust examination of the end-to-end operation of the PIP process, examine the progress made with regard to the recommendations made in the first Review and make recommendations for further improvement and change.

<sup>&</sup>lt;sup>2</sup> https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/387981/pip-assessment-firstindependent-Review.pdf

<sup>&</sup>lt;sup>3</sup> https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/82902.htm

- 1.1.6 The Call for Evidence was launched on 4 March 2020 and was designed to gather information from organisations and individuals, relevant to how the PIP Assessment process is operating in NI for new claims, award reviews and changes of circumstances. The evidence was gathered via electronic survey, written responses and meetings. Further detail on the Call for Evidence is outlined in Part 3.
- 1.1.7 As a consequence of the social restrictions imposed to tackle Covid-19 the Department accepted that the evidence gathering aspect of the Review had clearly been significantly impacted by Covid-19 restrictions imposed United Kingdom (UK) wide.
- 1.1.8 In April 2020, the Department's Permanent Secretary accepted and approved the requested extension by the Reviewer. Subsequently the Call for Evidence was extended to 16 October 2020, with the final report to be laid with the NI Assembly by 11 December 2020.

#### Terms of Reference for Second Independent Review.

- 1.1.9 To provide the Department with an independent report evaluating:
  - the progress made on recommendations arising from the first Review;
  - awareness and experience of the PIP Assessment process for new applications, award reviews and people reporting changes;
  - the process to ensure the most appropriate Assessment type is selected, paperbased Reviews, face to face at the Assessment centre or the home;
  - the effectiveness of the arrangements for ensuring accurate reports are produced; and
  - how effectively further evidence is being used to assist the correct claim decision, exploring the balance between how much and the type of evidence we source and what we ask people to provide.

#### **Independent Scrutiny Group**

1.1.10 As with the first PIP Review, the Department also appointed an Independent Scrutiny Group to provide constructive challenge and support to the Reviewer. Details of the Scrutiny Group Members can be found at Annex 2. The Scrutiny Group Terms of Reference were as follows: The Independent Scrutiny Group will be in place to support the Reviewer to:

- Monitor progress of the Review to ensure it remains on plan and within scope of the Terms of Reference;
- Provide advice and support as the Review progresses, discussing and providing guidance as necessary on emerging issues and findings;
- Ensure the final report is underpinned by robust finding and evidence and is presented in a clear and appropriate format; and
- Ensure the Reviewer maintains their independence throughout the Review, acting as a sounding board and providing challenge where necessary.

#### Evidence gathering sources to support the Review

- 1.1.11 The second Review used the following methodology to gather evidence to support the Review:
  - A public Call for Evidence which ran from 4 March to 16 October 2020 and received 263 responses from claimants, their families and individuals involved in supporting people through the process;
  - Meetings with, and submissions from, representative and advocacy organisations including charities and support groups;
  - Observing a number of telephone Assessments;
  - Meetings with a range of Capita operational staff and Senior Management;
  - Meetings with a range of Departmental staff involved in PIP initial contact, Management, Case Managers, and those involved with Mandatory Reconsiderations and Appeals;
  - Analysis of official statistics;
  - Meeting with the President of Appeal Tribunals;
  - Meetings with elected representatives; and
  - Meetings with, and submissions from, professional bodies representing Doctors and other Healthcare Professionals.

#### **Scope of Review**

- 1.1.12 The Reviewer's framework for completion of the Report was the Terms of Reference which allowed for a broader look at PIP, investigation of the quality and consistency of Assessments, accuracy of Assessment reports and gaining an understanding of the claimant experience at all stages of the process.
- 1.1.13 The areas below have been excluded from the scope of the Review however the Department may wish to consider any views or comments expressed by the Reviewer in relation to these:
  - the policy underpinning the introduction of PIP;
  - the descriptors used to assess entitlement to PIP;
  - the operation of the PIP Tribunal; and
  - Commercial arrangements.

# Section 2: Background to PIP

#### Context in which PIP was introduced

- 1.2.1 PIP is a new benefit established under Part 5 of the Welfare Reform (NI) Order 2015 and was introduced in NI on 20 June 2016. PIP replaced DLA for working age claimants and is intended to help people with the extra costs of living with a long-term health condition or disability.
- 1.2.2 The policy intent behind its introduction is set out in the Government's response to its consultation on DLA reform<sup>4</sup> as follows:

"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 Government also said

"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. It is being designed to enable support to be targeted at individuals who require the most assistance to live full, active and independent lives. It is intended to be a simpler, fairer, more objective and more transparent assessment of individual need"

1.2.3 Alongside the policy intent behind the introduction of PIP the Government also highlighted their fiscal goal of achieving a reduction in working age expenditure.

"The Government is committed to ensuring that the new Personal Independence Payment remains affordable and sustainable for the long term. Reducing working-age expenditure by 20 per cent in 2015/16 means reducing working-age expenditure to 2009/10 levels in real terms - £11.8 billion<sup>5</sup>"

<sup>&</sup>lt;sup>4</sup> https://www.gov.uk/government/consultations/disability-living-allowance-reform

<sup>&</sup>lt;sup>5</sup> https://www.gov.uk/government/consultations/disability-living-allowance-reform

The reduction in expenditure was to be achieved by ensuring that priority in the new benefit would go to those individuals who are least able to complete the activities and/or who need the most support to do so.

#### The Assessment

- 1.2.4 Regulation 4 of the Personal Independence Payment Regulations (NI) 2016 states that a person's ability to carry out daily living or mobility activities is to be determined on the basis of an Assessment taking account of relevant medical evidence<sup>6</sup>.
- 1.2.5 PIP is made up of two components, daily living and mobility, paid at one of two rates, standard rate or enhanced rate. The Assessment for entitlement to the two components looks at an individual's ability to carry out a range of key everyday activities that are fundamental to daily life. Ten of these activities relate to entitlement to the daily living component and two to the mobility component.
- 1.2.6 The Assessment for PIP was designed to enable support to be targeted at individuals who require the most assistance to live full, active and independent lives. The Government, in its response to DLA reform, stated:

"The assessment will be a simple, fairer, more objective and more transparent assessment of individual need. It will take account of physical, sensory, mental, intellectual and cognitive impairments, and will focus on an individual's ability to carry out key day-to-day activities. Mobility and the extent to which individuals need care and support in their everyday lives will remain central to this".

- 1.2.7 The Assessment is not a medical examination or medical consultation, it is a functional Assessment designed to gather information about how a condition affects an individual's ability to carry out day-to-day activities. This functional Assessment explores the *impact* of the individual's health condition or disability rather than the *diagnosis* of the health condition or disability.
- 1.2.8 The PIP Assessment is conducted by an experienced Health Professional approved to carry out PIP Assessments by the Departments HAA. The Health Professionals who conduct the Assessments are occupational therapists, nurses (level 1), physiotherapists, paramedics or doctors and they must have the following qualifications and experience:

<sup>&</sup>lt;sup>6</sup> https://www.legislation.gov.uk/nisr/2016/217/regulation/4/made

- they are fully registered with the relevant licensing body (doctors must have a licence to practise);
- They have no sanctions attached to registration unless they relate to disability;
- They have at least 2 years post full registration experience (this refers to either UK registration or equivalent overseas registration for non-UK HPs) or less than 2 years post full registration experience by prior, written agreement with the Authority; and
- They must be cleared by a valid Criminal Records Bureau check.
- 1.2.9 The aim of the Assessment is for the Health Professional to gather sufficient factual information about the functional effects of the individual's condition or disability in order to create a report for the Department's Case Managers to consider when making a decision on entitlement. The Assessment will not be a full physical examination or an attempt to diagnose medical symptoms, it will focus on how life is affected by the challenges faced by an individual as a result of their health condition or disability.
- 1.2.10 When conducting the Assessment, the Health Professional must consider whether the individual can complete the activity reliably, safely, repeatedly within a reasonable time and whether their functional impairment is present on the majority of days. The Health Professional will take account of any aids and appliances that an individual may need to use in order to complete the activity and also where people need support from another person, such as supervision, prompting or assistance.
- 1.2.11 An explanation of the Assessment criteria and point scoring is at Annex 3. If the points given for each activity total between 8 and 11 points this will result in a standard rate award. If the points given for each activity total 12 points or more this will result in an enhanced rate award. Entitlement to the enhanced rate of the mobility component is one of the eligibility criteria for the Motability Scheme<sup>7</sup>.

# **Rollout of PIP in NI**

1.2.12 PIP was introduced in NI on 20 June 2016 for all new claims and those where the award period for DLA had come to an end. The managed reassessment of DLA working age claimants moving to PIP began in December 2016 with claimants selected at random. The managed reassessment process concluded in NI in November 2019 with 135,110 DLA claimants reassessed for PIP.

<sup>&</sup>lt;sup>7</sup> Motability - www.motability.co.uk

- 1.2.13 The reassessment process for children in receipt of DLA who will move to PIP when they reach the age of 16, known as the rising 16's, is ongoing and will continue for years to come. As a consequence of Covid-19 the Department decided to temporarily suspend the reassessment process for this cohort, however the Review understands that the reassessment process has now recommenced.
- 1.2.14 As the managed reassessment process was completed in November 2019 the Department has ceased publishing detailed statistical data on the reassessment outcomes from that date. It is noted that at the time of writing the first report the Reviewer was unable to carry out a robust analysis of the reassessment outcomes data as it was not available and therefore the Reviewer encouraged the second Review to carry out this analysis. The Review will analyse the reassessment outcomes data at Part 2.
- 1.2.15 The tables below provide some high-level information on the following:
  - » PIP claims in payment;
  - » PIP claims in Payment by Level of Award;
  - » PIP claims registered vs PIP claims cleared;
  - » PIP clearance periods; and
  - » Average (median) Clearance Periods
- 1.2.16 This information has been taken from the experimental statistical data published by the Department's Professional Services Unit (PSU) in August 2020 for the period from June 2016 up to May 2020<sup>8</sup>. Notes relating to the data can be found at Annex 5.
- **Note:** All figures are rounded to the nearest 10, and percentages rounded to the nearest 1%, and as a result may not sum to totals.

<sup>&</sup>lt;sup>8</sup> https://www.communities-ni.gov.uk/publications/personal-independence-payment-statistics-may-2020

i. **PIP Claims in Payment** – There were a total of 146,310 claims in payment as of 31 May 2020. Table 1 below shows the split between new claims and reassessments in payment.

Table 1: PIP Claims in Payment as of 31 May 2020

NEW CLAIMS	REASSESSMENT	TOTAL
38,720 (26%)	107,590 (74%)	146,310

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-may-2020 - Data taken from Table 1. Notes related to the data can be found at Annex 5.

ii. **PIP Claims in Payment by Level of Award** – Table 2 below shows the number of claims in payment by the level of award for new claims and reassessments.

AWARDS	NEW CLAIMS		REASSESSMENT		TOTAL CLAIMS IN PAYMENT	
	CLAIMS	%OF CLAIMS	CLAIMS	%OF CLAIMS	CLAIMS	%OF CLAIMS
Enhanced Daily Living & Enhanced Mobility	9,080	23%	47,370	44%	56,450	39%
Enhanced Daily Living & Standard Mobility	2,720	7%	7,380	7%	10,090	7%
Standard Daily Living & Enhanced Mobility	6,770	17%	20,490	19%	27,260	19%
Standard Daily Living & Standard Mobility	6,620	17%	11,550	11%	18,180	12%
Enhanced Daily Living Only	2,480	6%	5,020	5%	7,500	5%
Standard Daily Living Only	9,450	24%	12,920	12%	22,370	15%
Enhanced Mobility Only	740	2%	1,660	2%	2,400	2%
Standard Mobility Only	870	2%	1,210	1%	2,070	1%
TOTAL	38,720	100%	107,590	100%	146,310	100%

Table 2: PIP claims in payment by level of award as of 31 May 2020

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-may-2020 - Data taken from Table 11. Notes related to the data can be found at Annex 5.

The Review notes that 39% of all claims in payment have been awarded the maximum award that can be given i.e. enhanced daily living and enhanced mobility.

iii. **PIP claims registered vs PIP claims cleared** – Table 3 below shows the number of claims registered and cleared (initial outcome decision made).

Table 3: PIP claims registered vs PIP claims cleared as of 31 May 2020

	NEW CLAIMS	REASSESSMENT	TOTAL	
Total claims Registered	88,220 (39%)	140,290 (61%)	228,510	
Total claims cleared	82,390 (38%)	137,050 (62%)	219,440	

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-may-2020 - Data taken from Tables 1 and 2. Notes related to the data can be found at Annex 5.

Of the 228,510 claims registered, 219,440 claims have been cleared and an initial outcome decision made by a Departmental Case Manager.

iv. **PIP Clearance Periods** – Table 4 below shows the length of time it has taken to process a claim i.e. from the date a claim is registered to the date the claim is cleared.

# Table 4: PIP Clearance Periods as of 31 May 2020

	0-4 WKS	5-13 WKS	14-26 WKS	27+ WKS	TOTAL
New claims	2,120 (3%)	46,720 (57%)	32,280 (39%)	1,270 (2%)	82,390
Reassessment	730 (1%)	68,900 (50%)	63,700 (46%)	3,730 (3%)	137,060
Total	2,850 (1%)	115,620 (53%)	95,980 (44%)	5,000 (2%)	219,440

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-may-2020 - Data taken from Table 3a. Notes related to the data can be found at Annex 5.

The data shows that 54% of cases are cleared within a 13-week period and 46% of cases take more than 13 weeks to clear.

v. Average (median) Clearance Periods – Table 5 below shows how long on average it takes to clear a PIP claim from the date it is registered until the date it is cleared by the Departmental Case Manager for cases processed under normal rules and those processed under the SRTI rules.

The table also shows how long on average it takes to clear a PIP claim from the date the claim is referred by the Department to the Assessment Provider (AP) (Capita) to the date it is cleared by the Departmental Case Manager.

	REGISTRATION TO CLEARANCE		ASSESSMENT TO CLEARANCE		
	CLAIMS CLEARED	AVERAGE WEEKS	CLAIMS CLEARED	AVERAGE WEEKS	
Normal Rules	217,100	13	198,470	9	
SRTI	2,340	2	2,200	1	
Total	219,440	13	200,670	9	

#### Table 5: Average (median) Clearance Periods as of 31 May 2020

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-may-2020 - Data taken from Tables 4a and 4b. Notes related to the data can be found at Annex 5.

The data shows that on average it takes 13 weeks for a PIP claim to be processed from date of registration until a decision is made by the Departmental Case Manager.

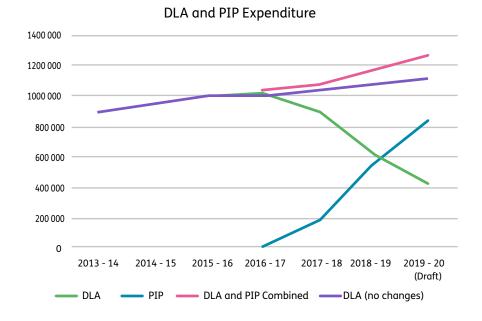
The data also shows that on average it takes 9 weeks for a decision to be made by the Departmental Case Manager once the Assessment has been completed.

# Fiscal

1.2.17 The June 2010 Budget stated that the most urgent task facing the country was to implement an accelerated plan to reduce the budget deficit<sup>9</sup>. Part of the announced spending reductions was £11 billion of welfare reform savings. This was underpinned by a programme which included measures to reform DLA, with expected savings of over £1 billion a year in the projected working-age expenditure by 2014/15.

<sup>&</sup>lt;sup>9</sup> https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/248096/0061.pdf

- 1.2.18 The Northern Ireland Audit Office report on Welfare Reforms in Northern Ireland, published in January 2019<sup>10</sup>, indicates that the savings anticipated from the change to PIP are £1.6 billion to 2024-25.
- 1.2.19 The Review notes that expenditure figures received from the Department's Annually Managed Expenditure (AME) and Business Partnering Branch show that the overall expenditure for both DLA and PIP has exceeded the anticipated spend for DLA had PIP not been introduced in 2016.



## **Chart 1: DLA and PIP Expenditure**

Note: The 2019-20 outturn are draft figures

Data Source: Department for Communities Annually Managed Expenditure (AME) and Business Partnering Branch

- 1.2.20 The graph above shows that the introduction of PIP does not appear to have produced the benefit savings that the policy originally intended and the Review understands that the combined expenditure for DLA and PIP is expected to continue to rise.
- 1.2.21 While it is not possible to know definitively why expenditure will continue to rise the Review would note that legal challenges resulting in changes to legislation would undoubtedly allow more people access to the benefit.

<sup>&</sup>lt;sup>10</sup> https://www.niauditoffice.gov.uk/sites/niao/files/media-files/Welfare%20Reform%20Report%202019.pdf – Page 26

#### **Legislative Changes since First Review**

1.2.22 Since the first Review there have been no major changes to the PIP legislation that has impacted on how PIP is applied or processed.

## **UK Upper Tribunal Decision**

- 1.2.23 In November 2017 a UK Upper Tribunal<sup>11</sup> ruled on a case, known as the OM Judgement, where the claimant had failed to attend an Assessment and therefore a negative determination was made and the claimant's DLA payments ceased. Aside from issues raised around the appointment process the Tribunal also decided that once a negative determination is overturned DLA should immediately be put back into payment until a PIP Assessment determination is made.
- 1.2.24 This decision resulted in the Department carrying out a scan to identify cases which would have been impacted by this decision. The Department has advised that only a handful of cases were impacted by this decision as the process was changed in November 2017 whereby DLA was put into payment when a negative determination was overturned.
- 1.2.25 In March and September 2017 the Upper Tribunal made two decisions in relation to Overwhelming Psychological Distress<sup>12</sup> and the Interpretation of Safely<sup>13</sup>, known as the MH and RJ Judgements. The Department commenced an Administrative Exercise (AE) in June 2018 to review all PIP claims to check if claimants were entitled to more support as a result of these judgements.
- 1.2.26 As at January 2020 the Department had reviewed 67,380 PIP claims, with 834 arrears payments made. The total amount of additional payments made was around £2.94 million, with the average additional payment around £3,630.

#### Supreme Court Judgement

1.2.27 On 18 July 2019, the Supreme Court considered daily living activity 9 (Engaging with other People face to face)<sup>14</sup>, known as the MM Judgement. The Court held that there was an overlap between 'Social Support' and prompting and when someone who receives prompting from a person meets the definition of a giver of social support (a person trained or experienced in assisting people to engage in social situations) then this could be classed as social support, which would score points of a higher scoring descriptor.

<sup>&</sup>lt;sup>11</sup> https://assets.publishing.service.gov.uk/media/5a324c36e5274a4936ee777c/CPIP\_1567\_2017-00.pdf

<sup>&</sup>lt;sup>12</sup> https://www.gov.uk/administrative-appeals-tribunal-decisions/mh-v-secretary-of-state-for-work-and-pensions-pip-2016-ukut-0531-aac

<sup>&</sup>lt;sup>13</sup> https://assets.publishing.service.gov.uk/media/5a7b1ef1ed915d3ed90624e3/\_2017\_\_AACR\_32ws.pdf

<sup>&</sup>lt;sup>14</sup> https://www.supremecourt.uk/cases/docs/uksc-2017-0215-judgment.pdf

1.2.28 The Review understands that the outcome of this Judgement has been incorporated into PIP processes and guidance from September 2020. The number of cases impacted by this Judgement are not yet known however the Department will be undertaking an exercise to check existing claims and if a PIP award changes as a result of the judgement claimants will receive payments backdated to the effective date in each individual case.

#### **Judicial Review**

- 1.2.29 In July 2020 a PIP claimant, assisted by Law Centre NI, successfully challenged the legal definition of terminal illness at the High Court. The Judge ruled the difference in treatment for terminally ill claimants who cannot reasonably meet the six-month life expectancy rule was discriminatory and granted leave for a judicial review<sup>15</sup>.
- 1.2.30 A further hearing was held in October 2020 however, at the time of writing, the final decision has not yet been published. The Review understands that the claimant received an award of £5,000 for the "upset, distress, annoyance, inconvenience, worry and humiliation" caused as a result of unlawful discrimination<sup>16</sup>.

<sup>&</sup>lt;sup>15</sup> https://www.judiciaryni.uk/judicial-decisions/2020-niqb-53

<sup>&</sup>lt;sup>16</sup> https://irishlegal.com/article/terminally-ill-woman-receives-award-for-distress-and-humiliation-caused-by-terminal-illness-rules

# Part 2: Progress since First Review and Reassessment Outcomes

#### Section 1: Progress since first PIP Review

- 2.1.1 The first Independent Review of PIP, conducted by Walter Rader was published on 28 June 2018. The Department published its interim response on 20 November 2018. The Department accepted or partially accepted 10 of the 14 Recommendations.
- 2.1.2 The Review would firstly like to thank the Department for providing a further progress update on implementation of the Recommendations from the first Review and this can be found at Annex 1.
- 2.1.3 The first PIP Review conducted in 2018, acknowledged the efforts made by the Department in relation to improving communication but found there was a requirement for 'targeted awareness raising campaign which sets out clear messages about the purpose and requirements of the benefit'.
- 2.1.4 The 2018 Review also found a need for increased engagement and communication with PIP claimants to 'demystify the process and address misconceptions'. The first Reviewer recommended 'development of straightforward, clear, information materials, in suitable formats, which describes the PIP assessment process. This would assist claimants, family members and support workers in their understanding of the PIP assessment process and its purpose'.
- 2.1.5 One source of confusion, identified by the first Reviewer related to the range of terminology used to describe various roles within the Assessment process. The Reviewer recommended 'that the Department updates the terminology used to describe roles and functions throughout the PIP Assessment process and simplifies and consolidates the terms used in advice and guidance documents. Particular care should be taken to ensure that the terms, words and titles used do not misrepresent the roles undertaken, or the nature of the PIP Assessment process'.
- 2.1.6 This Review welcomes the steps taken by the Department to raise awareness and improve communication through holding PIP events across Northern Ireland. On a positive note these events were co-delivered by the Department and Capita with the Law Centre and Advice NI delivering a short presentation about the help and services they provide. This Review fully supports and encourages engagement with the community,

voluntary and advice sector and considers this an essential element to ensuring the best outcome for PIP claimants. More detail on benefits of advocacy support can be found in later chapters.

- 2.1.7 Other positive changes include the implementation of a Video Relay Service (VRS) for British and Irish Sign Language users and also the introduction of the facility to record all centre-based PIP Assessments. The Review understands deployment of the service for home Assessments has been 'put on hold' until Covid-19 social distancing restrictions are relaxed and there is a return to face-to-face Assessments.
- 2.1.8 The Review also understands the Department has, from September 2020, introduced a solution to enable claimants to receive and return the PIP2 "How your disability affects you" via a secure email link.
- 2.1.9 These improvements in service have been acknowledged by some Call for Evidence responders.

"We have welcomed the changes made to date and have seen positive changes from the initial review. We do believe the changes implemented have helped claimants during the application process". Choice Housing

"Law Centre NI commends the following changes that have taken place following the previous review:

1. Outreach events 2. Updated / simplified terminology 3. Review written material – letters to claimants / decision letters / materials describing the process 4. Easier access to applications – visual / hearing impairment (apply via telephone) and training for staff re this 5. Agreement w/ pro bodies re GP guidance 6. PIP to await additional evidence as part of PIP 2 process 7. Task and finish group re paper based reviews 8. Scheduling appts and room layout 9. Audio-visual 10. Remove informal observations 11. Remove questions on suicide / self-harm"(sic) Law Centre NI

"We recognise that the Department for Communities have made some progress on the audio recording of assessments and that some communication improvements have been made" Sinn Fein

2.1.10 In relation to those Recommendations not accepted, the evidence submitted to the Review indicated most felt that it was disappointing that the Department did not accept more of the Recommendations from the first Review.

- 2.1.11 Given the substantial supporting evidence gathered during the second Review, the Reviewer recommends the Department revisits Recommendation 6 which concluded that the six months life expectancy criterion for terminally ill claimants should be removed. More detail on the evidence to support implementation of this Recommendation can be found in Part 5, Section 1.
- 2.1.12 Based on the supporting evidence, the Review also recommends the Department revisits Recommendation 11 from the first Review, which relates to the development of enhanced training in specific conditions for Disability Assessor's (DA's). More detail on the evidence to support implementation of this Recommendation can be found in Part 6, Section 2.
- 2.1.13 The Review also considers more work is required to further progress some of the first Review Recommendations which the Department moved to accept or partially accept. Evidence gathered indicates significant support for progressing Recommendation 7 from the first Review, the introduction of a General Practitioner (GP) Short Summary Report to support the PIP2. The Review understands work to develop a GP Short Summary Report has now recommenced with Capita planning to test an electronic format. The Review recommends that completion of this work is expedited, a view shared by some Political representatives, the Royal College of GP's and the British Medical Association (BMA).

'Our members tell us that the form itself is not useful in its current form. It is too long and should be more practical. GPs can answer factual, specific questions and the forms should be redesigned accordingly. Ideally, any redesign of the form would include the ability for it to be filled in online'. BMA

- 2.1.14 The Review also found more work is required on first Review Recommendation 13 which stated 'the Department and Capita should remove all questions about suicide and self-harm from the Assessment. If they deem this information essential, they should source it in an alternative manner'.
- 2.1.15 The case study below, provided by the Green Party, is indicative of the comments received by the Review around this very sensitive issue.

Constituent suffers from manic depression and had attempted suicide prior to applying for PIP. During an at home visit assessment, constituent mentioned the suicide attempts and was asked why they thought they did not go through with it. Further to this assessment and the line of questioning, constituents' mental health deteriorated and they had to seek support. Constituent did not want to make a complaint for fear of being turned down for the PIP payments. 2.1.16 Relatives for Justice called for this issue to be dealt with in a more sensitive way with the Law Centre NI calling for questions on suicide and self-harm to be removed from the Assessment process.

'One Outreach worker reported that a client had a self-inflicted wound on his arm but this was not addressed in the Assessment. Another outreach worker reported that when she tried to explain that the claimant received weekly prescriptions due to overdose, the Assessor said, 'shush.' It does appear that Disability Assessors try to avoid discussions on suicide or self-harm. However, what is imperative is that they seek evidence elsewhere. In this respect if (sic) may be useful if they invite support workers to provide any further information by letter". Victims and Survivors Service

2.1.17 The Reviewer noted that in the Departments update on the implementation of the Recommendations from the first Review the Department accepted that "questions regarding suicide and self-harm should not be asked unless raised by the person at the Assessment or included on the PIP2 questionnaire" (Annex 1). However, in her observation of current telephony assessments she observed that some DA's are still referring to the issue of 'suicide' and 'self-harm' on the basis that the claimant has indicated that they have Mental Health issues in the PIP2 application. It is the Reviewers opinion that this falls outside the Departments intended outcome.

#### Section 2: PIP Reassessment Outcomes

#### Introduction

- 2.2.1 The first Independent Review of PIP, completed by Walter Rader in 2018, noted at the time of writing his report, the Department did not have data specifically around the DLA to PIP reassessment outcomes. Walter Rader noted in Chapter 13 of his report that a robust analysis of the reassessment outcomes was required by the second Review.
- 2.2.2 In NI the reassessment of DLA working age claimants to PIP was completed in November 2019. The Department's PSU published the final statistical data, in relation to reassessment cases for working age claimants, in February 2020<sup>17</sup>.
- 2.2.3 The Review has used the official statistical data published in February 2020 to understand the composition of PIP reassessment cases. It should be noted that reassessments will continue for DLA claimants turning 16.
- 2.2.4 The statistical data used is sourced from the Personal Independent Payment Computer System (PIPCS) and represents all PIP claimants with a postcode in NI. All figures are rounded to the nearest 10 and therefore may not sum to total.

#### **Breakdown of PIP decisions**

- 2.2.5 As at November 2019, there were 141,990 claims in payment, of which 25% were new claims and 75% were reassessment.
- 2.2.6 The table below shows the split between decisions made under Special Rules for Terminally III people (SRTI) and non-SRTI awards. Awards are made under the special rules criterion where the claimant has a progressive condition and is expected to live less than 6 months. The data below shows total claims cleared at the initial decision stage and the percentage of claims awarded, disallowed or withdrawn (these figures do not include decisions made as a result of Mandatory Reconsideration or appeal).

<sup>&</sup>lt;sup>17</sup> https://www.communities-ni.gov.uk/publications/personal-independence-payment-statistics-november-2019

	NON-SRTI	SRTI	TOTAL
Total Claims Awarded	134,340 (98%)	2,060 (2%)	136,390 (65%)
Total Claims Disallowed	70,110 (100%)	20 (0%)	70,120 (34%)
Total claims withdrawn	2,740 (98%)	50 (2%)	2,790 (1%)
Total claims cleared	207,180	2,120	209,300

#### Table 1: Claims cleared and outcomes as at November 2019 for SRTI and non-SRTI

**Note:** The figures in (brackets) in columns 1 and 2 show the % of claims cleared against the total figure in column 3. The figures in (brackets) in column 3 show each of the sub-totals as % of the overall total claims cleared.

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 7. Notes related to the data can be found at Annex 5.

The table above shows the following:

- (i) 65% of all claims cleared were entitled to an award of PIP. Of those 65% of claims cleared, 98% were awarded under the normal rules.
- (ii) 34% of all claims cleared were disallowed PIP and the majority of these claims were assessed under the normal rules.
- (iii) 1% of all claims cleared were withdrawn and again the majority of these were claims made under the normal rules.

2.2.7 The table below shows the split between decisions made for new claims and those made for reassessment claims. The data below shows total claims cleared at the initial decision stage and the percentage of claims awarded, disallowed or withdrawn (these figures do not include decisions made as a result of Mandatory Reconsideration or appeal).

Table 2: Claims cleared and outcomes as at November 2019 for new claims and
reassessment claims

	NEW CLAIMS	REASSESSMENT	TOTAL
Total Claims Awarded	34,290 (25%)	102,100 (75%) (76%)	136,390 (65%)
Total Claims Disallowed	38,210 (54%)	31,910 (46%) (24%)	70,120 (34%)
Total claims withdrawn	1,690 (61%)	1,090 (39%) (1%)	2,790 (1%)
Total claims cleared	74,190	135,110	209,300

**Note:** The figures in brackets in columns 1 and 2 show the % of claims cleared against the total figure in column 3. The second figures in brackets in column 2 show the % of claims cleared against the total figure in row 4.

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 6a. Notes related to the data can be found at Annex 5.

The table above shows the following:

- (i) 65% of all claims cleared were entitled to an award of PIP. Of those 65% of claims cleared 75% were reassessment cases.
- (ii) 34% of all claims cleared were disallowed PIP and the majority of these were new claims (54%).
- (iii) 1% of all claims cleared were withdrawn and again the majority of these were new claims (61%).
- (iv) Of all reassessment cases cleared 76% of cases were awarded PIP

- 2.2.8 The Review notes that, while the number of claims being withdrawn are relatively small over a 41 month period (June 2016 to November 2019), the Department should consider the reasons why claims are being withdrawn, particularly where a claim is made under Special Rules and then withdrawn.
- 2.2.9 The Review received evidence that indicates there is a perception that PIP was introduced to take claimants out of the benefit system. The statistical data shows that while 76% of claimants who transitioned from DLA to PIP received an award of benefit 24% of claimants were disallowed or withdrew their claim for benefit.

#### **Reassessment Outcomes**

2.2.10 As already stated the reassessment of DLA working age claimants moving to PIP was completed in November 2019. The table below shows the outcomes for this cohort and the impact the PIP decision had on the amount that DLA people were previously receiving.

PIP REASSESSMENT OUTCOME	NUMBER	PERCENTAGE
Total	124,540	100%
Award Increased	48,880	39%
Award Unchanged	24,670	20%
Award Decreased of Disallowed	50,140	40%
of which Award Decreased	23,350	19%
Award Disallowed Of which	26,780	22%
Disallowed post referral to the Assessment Provider	23,980	19%
Disallowed pre referral to the Assessment Provider*	2,810	2%
Withdrawn	860	1%

#### **Table 3: Reassessment Outcomes**

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 17. Notes related to the data can be found at Annex 5. The table on the previous page shows the following:

- (i) 39% of claimants received an increased award when they transitioned to PIP. This means that the total monetary value of the PIP award was higher than the total monetary value of the DLA award.
- (ii) 20% of claimants had an award which remained unchanged. This means that the total monetary value of the PIP award was the same as the total monetary value of the DLA award.
- (iii) 19% of claimants saw their award decrease. This means that the total monetary value of the PIP award was less than the total monetary value of the DLA award.
- (iv) 22% of claimants were disallowed PIP 19% of these were disallowed following an assessment and 2% were disallowed before an assessment was carried out.
- (v) 1% of claimants withdrew their claim before a decision could be made on entitlement.
- 2.2.11 The Review notes that while over half (59%) of all claimants who were awarded PIP received the same as or an increase in the total monetary value of the DLA award 19% saw their award decrease and 22% were disallowed entirely.

# Comparison of DLA and PIP award types

2.2.12 The table below shows a comparison between DLA and PIP by award type for the PIP reassessment outcomes.

# Table 4: Comparison of DLA and PIP entitlement by award type

PIP REASSESSMENT OUTCOME	HIGH CARE HIGH MOBILITY	HIGH CARE LOW MOBILITY	HIGH CARE NIL MOBILITY	MID CARE HIGH MOBILITY	MID CARE LOW MOBILITY	MID CARE NIL MOBILITY
Enhanced Daily Living, Enhanced Mobility	12,030	5,280	110	9,500	10,480	1,170
Enhanced Daily Living, Standard Mobility	290	1,110	20	460	2,570	300
Enhanced Daily Living, Nil Mobility	150	1,280	30	190	2,430	420
Standard Daily Living, Enhanced Mobility	3,580	570	40	7,680	2,430	580
Standard Daily Living, Standard Mobility	990	630	40	2,560	2,530	580
Standard Daily Living, Nil Mobility	520	2,210	70	1,050	5,320	1,010
Nil Daily Living, Enhanced Mobility	100	140	0	340	830	50
Nil Daily Living, Standard Mobility	140	70	0	410	420	50
Disallowed post referral	1,140	2,520	150	2,680	9,830	2,340
Disallowed pre referral *	260	340	20	290	970	200
Withdrawn	110	90	0	140	240	50
Total	19,300	14,240	480	25,290	38,020	6,760

# Table 4 continued:

PIP REASSESSMENT OUTCOME	LOW CARE HIGH MOBILITY	LOW CARE LOW MOBILITY	LOW CARE NIL MOBILITY	NIL CARE HIGH MBILITY	NIL CARE LOW MOBILITY	TOTAL*
Enhanced Daily Living, Enhanced Mobility	1,520	640	790	550	250	42,290
Enhanced Daily Living, Standard Mobility	90	140	230	40	120	5,360
Enhanced Daily Living, Nil Mobility	30	140	230	10	150	5,050
Standard Daily Living, Enhanced Mobility	2,070	270	720	1,030	130	19,110
Standard Daily Living, Standard Mobility	740	210	780	430	170	9,650
Standard Daily Living, Nil Mobility	270	310	920	150	330	12,170
Nil Daily Living, Enhanced Mobility	90	30	20	130	10	1,740
Nil Daily Living, Standard Mobility	120	40	80	130	70	1,530
Disallowed post referral	660	730	2,290	610	1,030	23,980
Disallowed pre referral *	110	80	350	80	140	2,810
Withdrawn	40	20	110	30	40	860
Total	5,730	2,610	6,530	3,170	2,430	124,540

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 16a. Notes related to the data can be found at Annex 5. The table above shows the following:

- Of the 19,300 claimants, who were in receipt of the high rate Mobility and Care components in DLA, 12,030 (62%) received the enhanced rates of Daily Living and Mobility in PIP .
- (ii) Of the 19,300 claimants, who were in receipt of the high rate Mobility and Care components in DLA, 7,160 (37%) received either a lower award or were disallowed. The remaining 110 (1%) withdrew their claim.
- (iii) 34% of PIP claimants (42,290) have been awarded the enhanced rates of daily living and mobility following reassessment.
- 2.2.13 As part of the "Fresh Start, the Stormont Agreement and Implementation Plan" the NI Executive brought forward a series of mitigation measures to support claimants who would suffer financial loss through changes in the welfare system. The mitigation measures were designed to reduce the impact and provide support to individuals as they adapt to these changes. The mitigations were introduced as Welfare Supplementary Payments (WSP).
- 2.2.14 For DLA claimants, who experienced a loss of benefit following a reassessment to PIP, Welfare Supplementary Payments were paid in the following circumstances:
  - Claimants who were assessed for PIP and did not qualify, and subsequently appealed the decision, received Welfare Supplementary Payments equal to the weekly rate of their previous DLA payments until the Department was notified of the outcome of their appeal;
  - Claimants who were assessed for PIP and did qualify, but at a reduced rate and whose weekly loss was £10 or more, received Welfare Supplementary Payments equal to 75% of their loss of benefit for up to one year;
  - Claimants who were assessed for PIP and did not qualify, but received at least four points for either the daily living or mobility components in their PIP assessment and could show that their disability or illness was as a result of a Northern Ireland conflict-related injury may have been entitled to Welfare Supplementary Payments.

- 2.2.15 As well as the above mitigation measures claimants who lost entitlement to Disability Premiums, Enhanced Disability Premiums or Severe Disability Premiums in the reassessment for PIP received a Welfare Supplementary Payment for up to one year to cover the loss.
- 2.2.16 A carer's entitlement to Carers Allowance may have been affected, if the person they looked after did not qualify for PIP, or was not awarded the qualifying daily living component. Carers affected received a Welfare Supplementary Payment for one year to cover their financial loss. This payment stopped if the person being cared for was no longer entitled to a Welfare Supplementary Payment for the loss of DLA.
- 2.2.17 The Review notes that £585m was allocated for the mitigation schemes over a four year period to alleviate hardship for the most vulnerable people in our society. As a result of these mitigation schemes around £38m was paid to DLA claimants transitioning to PIP in 2018/2019<sup>18</sup>.

WELFARE SUPPLEMENTARY PAYMENT SCHEME	NUMBER OF CLAIMANTS WHO RECEIVED WELFARE SUPPLEMENTARY PAYMENTS	TOTAL AMOUNT PAID	
Loss of DLA - Payment during appeal	7,880	15,727,590	
Loss of DLA - Lower award	18,820	14,222,650	
Conflict Related Injury	10	13,720	
Loss of Disability Related Payments	2,460	4,287,300	
Loss of Carers Payments	2,700	3,483,440	
Total	31,870	37,734,700	

#### Table 5: Welfare Supplementary Payment Expenditure 2018/19

**Data Source:** Department for Communities Annual Report 2018/19 on Welfare Supplementary Payments, Discretionary Support, Standards of Advice and Assistance and Sanctions available at https://www.communities-ni.gov.uk/sites/ default/files/publications/communities/dfc-annual-report-welfare-supplementary-payments-2018-2019.pdf.pdf

<sup>&</sup>lt;sup>18</sup> https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-annual-report-welfare-supplementarypayments-2018-2019.pdf

# Level of award

2.2.18 The tables below show the percentage difference between the award levels of the DLA caseload (as at June 2016 pre introduction of PIP) and the award levels of the PIP caseload (as at November 2019).

# Table 6: Percentage breakdown of DLA working Age recipients by component and rate of claim (June 2016)

RATE AND COMPONENT OF CLAIM	NUMBER OF RECIPIENTS	PERCENTAGE OF RECIPIENTS
Higher rate care and higher rate mobility	20,000	16%
Higher rate care and lower rate mobility	14,380	11%
Middle rate care and higher rate mobility	25,240	20%
Middle rate care and lower rate mobility	38,510	30%
Lower rate care and higher rate mobility	5,750	5%
Lower rate care and lower rate mobility	2,550	2%
Higher rate care only	510	0%
Middle rate care only	7,050	6%
Lower rate care only	7,010	6%
Higher rate mobility only	3,250	3%
Lower rate mobility only	2,570	2%
Total	126,810	

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 22a. Notes related to the data can be found at Annex 5.

RATE AND COMPONENT OF CLAIM	NUMBER OF RECIPIENTS	PERCENTAGE OF RECIPIENTS
Enhanced Daily Living & Enhanced Mobility	55,180	39%
Enhanced Daily Living & Standard Mobility	9,310	7%
Standard Daily Living & Enhanced Mobility	26,830	19%
Standard Daily Living & Standard Mobility	17,290	12%
Enhanced Daily Living Only	7,370	5%
Standard Daily Living Only	21,620	15%
Enhanced Mobility Only	2,350	2%
Standard Mobility Only	2,040	1%
Total	141,990	

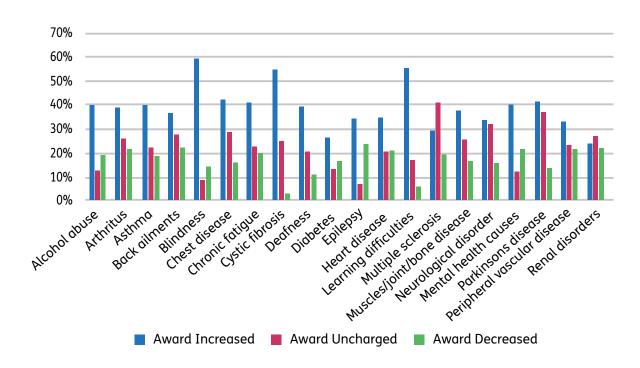
#### Table 7: Percentage breakdown of PIP recipients by level of award (November 2019)

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 22b. Notes related to the data can be found at Annex 5.

The above table shows that 39% of PIP claimants are in receipt of the highest rate of PIP compared to 16% of claimants who received the highest rates of DLA.

#### **Condition breakdown**

- 2.2.19 The Department collects information about claimant's disabilities and conditions. For illustrative and reporting purposes, the table below shows the reassessment outcome for 20, randomly selected, disabilities and conditions at the initial decision stage. The information does not include outcomes made at Mandatory Reconsideration stage or appeal.
- 2.2.20 The table below shows that for the majority of claimants with the disabilities listed their entitlement to PIP was more than they received on DLA.





**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 20. Notes related to the data can be found at Annex 5.

# Age and Gender

2.2.21 The data shows that there was very little difference in the number of women and men reassessed for PIP and very little difference in the outcomes. Table 9 shows the outcomes by gender for reassessed claims were broadly similar.

## Table 9: Outcome by Gender

PIP REASSESSMENT OUTCOME							
GENDER	AWARD INCREASED	RD AWARD AWARD ASED UNCHANGED DECREASED		DISALLOWED POST REFERRAL TO THE ASSESSMENT PROVIDER	DISALLOWED PRE REFERRAL TO THE ASSESSMENT PROVIDER +	WITHDRAWN	TOTAL
Female	39%	20%	19%	18%	2%	1%	64,910
Male	39%	19%	18%	20%	2%	1%	59,640
Total	39%	20%	19%	19%	2%	1%	124,540

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 19. Notes related to the data can be found at Annex 5.

2.2.22 Table 10 provides a breakdown of the reassessment outcomes by age band.

#### Table 10: Outcome by age band

	PIP REASSESSMENT OUTCOME						
AGE BRAND	AWARD INCREASED	AWARD UNCHANGED	AWARD DECREASED	DISALLOWED POST REFERRAL TO THE ASSESSMENT PROVIDER	DISALLOWED PRE REFERRAL TO THE ASSESSMENT PROVIDER +	WITHDRAWN	TOTAL
16-24	34%	15%	13%	31%	5%	1%	9,720
25-34	35%	17%	18%	26%	3%	1%	13,750
35-44	37%	18%	20%	22%	3%	1%	18,500
45-54	40%	20%	20%	18%	2%	1%	33,410
55-64	42%	22%	19%	15%	1%	1%	42,310
65+	40%	24%	19%	14%	2%	1%	6,850
Total	39%	20%	19%	19%	2%	1%	124,540

Data Source: Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 18. Notes related to the data can be found at Annex 5.

# **Mandatory Reconsiderations:**

- 2.2.23 Mandatory Reconsideration is a process the claimant must go through if they are unhappy with a decision. This process allows the Department the opportunity of reviewing the decision and all the evidence to see if the decision can be changed. A claimant must go through this process before they have a right to appeal to the Tribunal.
- 2.2.24 The Review notes that 60,050 Mandatory Reconsiderations were registered as at November 2019 with 38,850 (65%) received against a reassessment decision and 21,210 (35%) received against a new claim decision.
- 2.2.25 The table below shows the outcomes of the Mandatory Reconsiderations carried out by the Department. These figures do not include Mandatory Reconsiderations of claims made under SRTI.

	DECISION NOT REVISED	NEW DECISION – AWARD CHANGED	NEW DECISION – AWARD UNCHANGED	WITHDRAWN CANCELLED	TOTAL
New Claims	330	3,170	15,980	1,050	20,530
Reassessment	320	8,060	28,660	1,420	38,460
Totals	650	11,230	44,640	2,470	58,990

#### **Table 11: Mandatory Reconsideration Outcomes**

**Data Source:** Department for Communities PIP statistics available at https://www.communities-ni.gov.uk/publications/ personal-independence-payment-statistics-november-2019 - Data taken from Table 15b. Notes related to the data can be found at Annex 5.

The table above shows the following:

- (i) A total of 56,520 Mandatory Reconsiderations had been cleared as at November 2019. This total excludes withdrawn/cancelled cases. Of the 56,520 Mandatory Reconsiderations cleared 11,230 (20%) were more advantageous to the claimant. The Review notes that the Minister for Communities, responding to an Assembly Question, indicated that since PIP was introduced in 2016 until August 2020 59% of PIP appeals heard by a Tribunal have been successful <sup>19</sup>.
- (ii) Of the 11,230 decisions where the award was changed 8,060 (72%) were in relation to reassessment cases and 3,170 (28%) were in relation to new claims.
- (iii) Of the 56,520 Mandatory Reconsiderations cleared 45,290 (80%) did not result in a change to the award.

It should be noted that the Department commenced an administrative exercise on 28th June 2018 to review all current PIP claims to check if customers were eligible for more support as a result of two Upper Tier Tribunal judgements in Great Britain. The outcome of this exercise is included in both the new claims and the reassessed DLA reconsiderations categories. As this exercise relates only to the application of these two judgements it resulted in higher rates of 'no change to the award'. Consequently this leads to a higher overall proportion of mandatory reconsiderations resulting in 'no change to the award'.

<sup>&</sup>lt;sup>19</sup> http://aims.niassembly.gov.uk/questions/printquestionsummary.aspx?docid=309144

2.2.26 These figures substantiate the evidence given to the Review that the Mandatory Reconsideration process is not working in the way the policy intended.

"It is extremely rare for a MR to change the DM's decision. I doubt anyone will have respect for the system until the MR decision is removed from the same people making the original decision and are prepared to sign their name. It could just as easily be the same person doing MR on his original decision. There has to be openness for the applicants to have faith in the system". Victims and Survivors Service

"The number of decisions overturned at mandatory Reconsiderations stage is very low. The process remains viewed by many as an administrative hurdle to be endured on the way to appeal. There is also the concern that it discourages some people from proceeding to appeal" Sinn Fein.

2.2.27 The Review notes with interest the recent High Court case brought by an Employment and Support Allowance (ESA) claimant in relation to the Mandatory Reconsideration process<sup>20</sup>. Mr Justice Swift stated that Mandatory Reconsideration was "a disproportionate interference with the right of access to court, so far as it applies to claimants to ESA who, once an appeal is initiated, meet the conditions for payment pending appeal under regulation 30(3) of the ESA Regulations". He went on to say...

"I accept that regulation 3ZA pursues legitimate purposes both in terms of improving the effectiveness of the Secretary of State's administrative decisionmaking, and in promoting efficient use of the resources of the First-tier Tribunal. Even though under regulation 3(4A) of the Decisions and Appeals Regulations it is open to the Secretary of State to revise a decision at any time when an appeal is pending, I accept that there is likely to be practical advantage from a requirement that every appeal be preceded by an opportunity for the Secretary of State to look again at her decision to be satisfied that it is correct. That advantage may well be significant for the Secretary of State: if errors are spotted during the revision process the resources she has at her disposal to respond to appeals will be more efficiently used. I also accept that to the extent that the process interposed by regulation 3ZA between initial decision and right of appeal amounts to interference with a benefits claimant's right of access to court, the interference is small. Where the interference arises, it will comprise no more than a relatively short period of delay. I further recognise that there will also be cases where the requirement

<sup>&</sup>lt;sup>20</sup> https://www.bailii.org/ew/cases/EWHC/Admin/2020/1999.html

imposed by regulation 3ZA works to the advantage of a benefits claimant: when a decision is revised in his favour payment of the benefit concerned will commence or resume much sooner than it would had it been necessary to pursue the matter to a decision by the First-tier Tribunal.

- 2.2.28 The Review acknowledges that this decision was specific to the ESA Pending Appeal Payment during the Mandatory Reconsideration process and does not impact on the legislative requirement for a Mandatory Reconsideration to be carried out.
- 2.2.29 On 18 February 2020, the then Communities Minister, Deirdre Hargey, in response to an Assembly Question, stated that since June 2016 200,000 PIP decisions had been made with approximately 10% of these proceeding to Tribunal. This in effect means that 20,000 PIP claimants had to go through the Mandatory Reconsideration process before they could submit an appeal.
- 2.2.30 The Review notes that statistical data around the clearance time for Mandatory Reconsiderations is not included in the official published statistics. In the interests of transparency the Review would urge the Department to start publishing the clearance times for Mandatory Reconsiderations as part of the statistical data noted at Recommendation 12.
- 2.2.31 The Review understands that the high overturn rate of appeals at the Tribunal is, in the main, as a result of new evidence being submitted. The Review is therefore of the view that the Department should make every effort to obtain evidence from the most appropriate source earlier in the decision making process.

# **Future Data Plans**

- 2.2.32 The Review notes that the statistical information published by the Department are experimental statistics which means that they are new official statistics undergoing evaluation and are published in order to involve users and stakeholders in their development and as a means to build in quality at an early stage.
- 2.2.33 As the Review has received evidence seeking more comprehensive data the Review would encourage the Department to accept Recommendation 12 regarding the provision of statistical information.

# Part 3: The Call for Evidence

#### Section 1: Call for Evidence

- 3.1.1 A Call for Evidence was issued to gather information which would help inform the Reviewer's findings and recommendations. The Call for Evidence was launched on 4 March 2020 and was initially intended to close on 29 April. As a consequence of the restrictions imposed to tackle Covid-19, the Reviewer, with the support of the Scrutiny Group, asked for the Call for Evidence to be extended from 29 April 2020 to October 2020 with a view to laying the final report with the NI Assembly in December 2020.
- 3.1.2 The Department accepted the evidence gathering aspect of the Review had been significantly impacted by Covid-19 restrictions imposed and approved an extension of the Call for Evidence to 16 October 2020.
- 3.1.3 The Call for Evidence was aimed at individuals and organisations who had information which would be relevant to how the PIP Assessment process is working for new claims, Review awards and change in circumstances. Information was gathered in the following ways:
  - An online questionnaire aimed at both individuals and organisations;
  - A series of meetings with organisations; and
  - Submissions from individuals and organisations working on behalf of claimants.

This methodology enabled all those with information relevant to the Review to submit evidence in their preferred format.

3.1.4 The Review also had access to research completed by the All Party Group on Learning Disability (APGLD). This APGLD research, completed in September 2019, was supported by an online questionnaire with 492 responses noted. Several focus group sessions incorporating 50 participants were also carried out including constituency workers, Members of the Legislative Assembly (MLA's), Advice Sector staff, Healthcare Professionals and those involved in providing care to PIP claimants. The APGLD, with the support of Mencap NI and Law Centre NI, carried out this survey as part of a research study to find out about the experience of individuals claiming PIP, to understand what works, to learn about the challenges faced and make recommendations to Government. This project was carried out in partnership with Action Mental Health, Compass Advocacy Network, Disability Action, Marie Curie, Multiple Sclerosis Society, Parkinsons UK, Ulster University and PIP claimants with personal experience.

# Publicising the Second Review Call for Evidence

3.1.5 The following methods were used to publicise the Second Review Call for Evidence:

METHOD	DETAIL
Press Release	The Call for Evidence was launched by press release in March 2020. It was sent to over 550 recipients including media, Political Parties and stakeholder organisations
Social Media	The Department used Twitter to promote the Review on several occasions. In addition, the Department posted details of the Review on Facebook, including links to information about the Review and how to submit evidence.
Reviewer Interviews	The Reviewer undertook an interview with 'On Your Behalf' (Radio Ulster/Radio Foyle) in which she discussed the Review and encouraged individuals and groups to submit evidence.
Leaflets and flyers	In addition, the Call for Evidence was advertised in the 35 local benefit offices and the 9 Capita Assessment Centres by way of posters and leaflets. These were also planned for distribution to 100 libraries but this was impacted by the closure of the Library Network due to Covid-19 with a short message being developed for display on screens in the libraries instead.
Letters to MLA's and Wider Advice Sector Organisations	Letters advising of the Call for Evidence were issued to MLAs, Health Organisations and advice sector organisations.

METHOD	DETAIL
Northern Ireland Council for Voluntary Action (NICVA) and Advice NI newsletter British Deaf Association Facebook	An article publicising the Review was placed in both NICVA and Advice NI newsletters alongside a feature on British Deaf Association Facebook page to encourage engagement with the Review.

#### **Information Gathering - Questionnaire**

- 3.1.6 The Call for Evidence questionnaire was made available on the Departmental website with a link to the online version for completion. Signed videos in both British Sign Language and Irish Sign Language were also made available on the Departmental website. The questionnaire was also made available in Easy Read and word versions which could be submitted by email or post.
- 3.1.7 The questionnaire was in two parts. Part 1 was aimed at individual claimants, their family members or representatives and Part 2 was aimed at organisations or individuals, with experience of the PIP Assessment process.
- 3.1.8 The survey was structured in line with similar questionnaires used to gather evidence in the first Review in NI and the two Reviews carried out by Paul Gray on behalf of DWP in GB. This allowed the Reviewer to identify comparisons with previous findings. The questions were designed to draw evidence in line with the Terms of Reference for the Review.
- 3.1.9 It should be noted that the data gathered was influenced by voluntary response bias, so those respondents who chose to respond did not necessarily reflect the entire claimant population. Specifically **Voluntary response bias** occurs when sample members are self-selected volunteers, as in voluntary samples.
- 3.1.10 It should be noted that the Reviewer makes no claim that every view expressed can be substantiated. The views expressed by respondents are the reality for those individuals and organisations. Throughout this Report quotes from respondents are used to illustrate issues and develop recommendations.

#### Responses to the Call for Evidence – Questionnaire

- 3.1.11 In total 307 responses were received as a result of the Call for Evidence. Respondents to the survey accounted for 263 all of which were submitted online. A further 44 responses were received electronically or in hard copy.
- 3.1.12 Of the 307 responses, 252 were received from individuals (who had completed questionnaire Part 1) and 11 were submitted by organisations (completing Part 2). Of those completing Part 1 around one in four was a friend, carer or family member acting on behalf of someone claiming PIP.
- 3.1.13 Out of the 11 responses to Part 2, 27% reported being in the Advice Sector, 27% from a Charity, with the remaining in 'Other' or 'Prefer not to say'.
- 3.1.14 The Review notes that 4 people who responded to Part 2 of the questionnaire as individuals indicated that they were associated with or worked for organisations. The Review takes the view that those respondents were individuals and not representing the views of organisations.
- 3.1.15 In addition to the 263 online responses, 44 organisations, Political Parties, representatives and individuals provided the Review with written submissions in a format other than the questionnaire.
- 3.1.16 All responses have been classified as evidence of experiences and have been considered as such when drawing up the recommendations.
- 3.1.17 The Reviewer notes that similar themes were found in the responses to the Call for Evidence to those found in the first Review, those found in the responses to the online questionnaire issued by the APGLD and to those found by Paul Gray when completing the Second Review of PIP on behalf of DWP in 2017. This commonality reinforces the opinion taken by the Second Reviewer of the findings and recommendations she has made.

#### Analysis of Responses – Questionnaire

3.1.18 Part 1 of the survey consisted of 19 open and matrix style questions with the first 4 relating to responder type. Part 2 of the survey consisted of 19 open and matrix style questions with the first 3 questions related to respondent specific details such as, who they were and/or the organisation represented.

- 3.1.19 Opening questions were designed to capture information on category of responder 'Are you responding as someone who has claimed PIP for yourself?' to 'From where did you/ the person claiming PIP receive support to submit your/their claim? These were followed up with matrix style questions such as 'Overall how satisfied were you with the claim process?' requiring a rating response from very satisfied to very dissatisfied. This provided the Review with quantative data on levels of satisfaction and provided assurance on the validity of qualitative responses.
- 3.1.20 The opening questions were generally followed by open-ended follow-up questions such as "Could anything have improved your face to face Assessment with Capita, if so, please tell us about this." The open-ended responses have been analysed to identify key themes in each response and into further sub-themes enabling the Review to identify a series of key themes recurring throughout the responses.
- 3.1.21 Past and current PIP claimants were asked questions to establish their experiences in making a claim, having an Assessment and receiving the final decision alongside seeking their views on exchange of information across the Department and in the wider Health Service. Organisations with experience of the PIP process or of representing claimants were asked for their views, on access to and consideration of, further medical evidence, data sharing and any progress noted since the first Review.

#### **Evidence Gathering – Meetings**

- 3.1.22 Meetings were scheduled with a wide variety of key stakeholders involved in both the delivery of PIP and those who support claimants through the process. The Reviewer also responded to individual meeting requests from the wider community, voluntary and advice sector.
- 3.1.23 The Reviewer was keen to ensure a wide range of these individuals/organisations were represented and paid particular attention to ensuring a spread of rural/urban representation.
- 3.1.24 In addition, a series of meetings were scheduled between the Reviewer and those with particular interest or direct involvement in the PIP Assessment process. This included several groups of Departmental staff representing the various stages of the PIP Assessment process, in order to gain an understanding of the end to end process. To complement this, the Reviewer also met with staff working with the Assessment Provider, Capita, again with the aim of understanding the element of the Assessment process delivered by the external contractor.

- 3.1.25 Due to the impact of Covid-19 and the social restrictions imposed as a result, the Reviewer facilitated the majority of these meetings virtually. Some were completed faceto-face in line with the NI Executive guidance on social distancing. The Reviewer notes the restrictions in this regard and thanks all participants for engaging with the Review under these difficult circumstances.
- 3.1.26 A total of 22 face-to-face or virtual meetings with both the Advice Sector and Voluntary and Community organisations took place. 6 meetings took place with representatives from Political Parties. 8 meetings took place with representatives of professional bodies.
- 3.1.27 The Review Support Team, appointed by the Department, provided secretariat cover at the majority of meetings, except when the Reviewer completed observations of telephony based Assessments.

#### **Evidence Gathering – Observations of Assessments**

3.1.28 No face-to-face observations were able to take place due to the measures put in place by the Minister to protect the most vulnerable claiming PIP. The Reviewer undertook 8 observations of telephony based Assessments with the agreement of Capita and the claimants involved. The Reviewer also observed 6 telephony interactions of claimants with Departmental Staff regarding Claim Registration and requests for Mandatory Reconsideration.

#### Analysis of Evidence - Written Submissions and Meetings

3.1.29 The findings from each meeting and written submissions were subject to an analysis of main themes and sub-themes. The evidence gathered from all sources was considered by the Reviewer informing all findings and recommendations. Quotes taken from the Call for Evidence have been included in the Report to demonstrate the position taken by the Reviewer.

#### Comparison of findings – First Review

- 3.1.30 The overall findings of evidence gathered from all sources between the First and Second Reviews are broadly similar. The Call for Evidence methodology for the Second Review, while in line with the first Review, included new means of gathering evidence due to restrictions imposed as a result of the Covid-19 response.
- 3.1.31 The Reviewer made use of virtual meetings to gather evidence rather than face-to-face meetings. Observations of Assessments were only available via telephone and although there were fewer responses to the online survey, the Review had access to commissioned research completed by the APGLD.

Overall the Reviewer noted that similar themes emerged in the second Review as had done so during the first Review specifically:

- Claimant experience was negative due to a stressful and overly long process;
- Poor accuracy of reports provided by the DA;
- Lack of expertise of DA of full range of conditions presented;
- Conduct of DA lack of empathy and professionalism;
- Access to and weighting of further evidence sourced; and
- Removing the 6 month rule on SRTI cases
- 3.1.32 The Reviewer also acknowledged new themes emerging:
  - More work needed on Recommendations made in the Rader Review;
  - Increased awareness raising in relation to support and advocacy services including the MtC Outreach team within the Department;
  - More transparency needed in audit process and Assessment process;
  - Process for renewing a PIP claim when a review date has not been set;
  - Impacts of Covid-19; and
  - Empowerment of Case Managers.

#### Summary

3.1.33 The Review's findings are similarly underpinned by the findings from research from the APGLD which was commissioned to provide recommendations to Government and to feed into the Second Review.

#### Conclusion

3.1.34 The Reviewer concludes that there is a direct comparison between the issues reported during the First Review and the Second with the latter further supported by findings of the research commissioned by the APGLD.

#### Section 2: Detailed analysis - Call for Evidence Survey Responses

- 3.2.1 In part 1 of the Call for Evidence survey aimed at individuals, responses fell into the categories of:
  - Claimant experience;
  - Further evidence; and
  - Data sharing

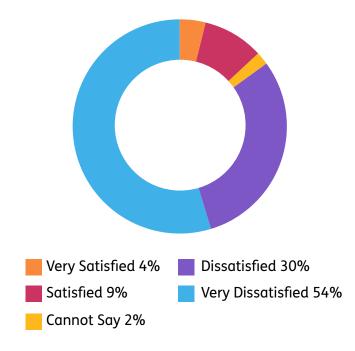
In part 2 of the Call for Evidence survey aimed at organisations and individuals working as part of an organisation, responses fell into the categories above and:

• Progress since last Review

#### Part 1 and Part 2 - Claimant Experience

3.2.2 The vast majority of claimants reported a significant degree of dissatisfaction with the Assessment process. 84% were either dissatisfied or very dissatisfied.

#### Chart 1 – Claimant satisfaction with the PIP process



- 3.2.3 Most common reasons for this were:
  - Inaccurate reporting of the Assessment
  - Length of time taken for the claim, dispute and appeal process
  - Overall a stressful and anxious experience
  - Further evidence was not considered
  - Lack of awareness/training of conditions such as mental health by the DA's
- 3.2.4 When asked what could have improved this experience many felt that the DA having more experience or training in their condition would help alongside displaying more empathy and understanding.

"People who actually understand the conditions they are dealing with. The person had never heard of 3 of my conditions and therefore no idea how they affect me on a daily basis." PIP Claimant (PIR108)

3.2.5 Many were critical of the DA rushing through the process and reported feelings of not being believed. There was a belief that audio recording of the Assessment would address this by helping the claimant feel the DA was taking sufficient time to listen to and understand them and not use this time to type up the report.

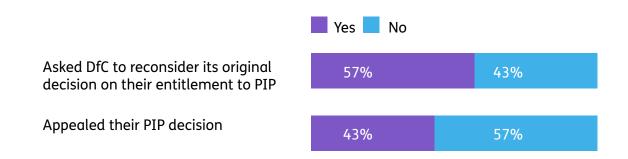
"Meeting with someone who has read your file, knows about your condition(s) and does not make assumptions based on a one-off meeting." PIP Claimant (PIR103)

3.2.6 Research carried out by the APGLD also corroborated these findings as 73% felt that the questions asked and functional tests were not relevant to their condition.

# "I found it to be lengthy and not really getting to the heart of what my day to day life is like" PIP Claimant (PIR013)

3.2.7 Chart 2 below indicates the volume of responders who opted to have a Mandatory Reconsideration of their initial outcome decision. Most reported that this was a negative experience with many feeling that further medical evidence produced was not considered with the original decision being "rubber-stamped". "MR was pointless and from the response did not take into account any additional or previous information. Once again stressful, takes too long and is completely impersonal." PIP Claimant (PIR172)

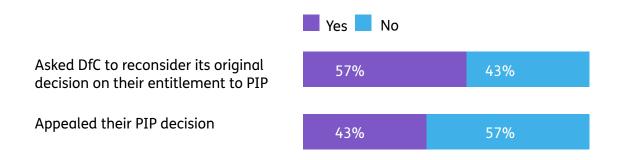
# Chart 2 - Did you ask the Department for Communities to reconsider its original decision on your entitlement to PIP?



3.2.8 Chart 3 highlights the volume of responders who then proceeded to Tribunal. The Reviewer notes that these numbers are significantly reduced. However, it should be pointed out that many of those who progressed to the Tribunal stage reported that they finally felt listened to despite the appeals process being overly long, protracted and very stressful.

"The appeal process was the only part of this PIP assessment that I felt they listened" PIP Claimant (PIR215)

# Chart 3 - Did you appeal your PIP decision?



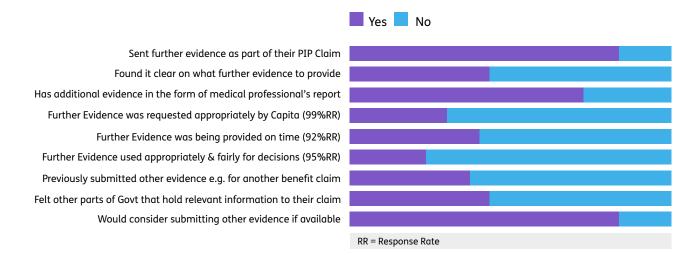
3.2.9 Most claimants who responded have had similar Work Capability Assessments (WCA) for ESA or have been assessed by Occupational Health. However, the majority of responders reported the PIP Assessment to be more stressful than other similar Assessments.

3.2.10 On a positive note, those claimants who attracted an award of PIP did feel the award of PIP provided financial independence and led to them being able to remain in work or seek employment. Conversely those who failed to attract an award of PIP felt disadvantaged by this and therefore unable to return to or seek employment.

"PIP means a great deal to me. Especially the fact I was entitled to a blue badge because of getting the enhanced mobility. It has made things much easier when leaving my home as I can park in more suitable places and closer to where I am trying to reach. I'm more confident now going out on my own." PIP Claimant (PIR298)

#### Further evidence – individuals (part 1)

3.2.11 Chart 4 indicates that most claimants chose to provide further medical evidence throughout the process, both at initial claim stage and at Mandatory Reconsideration stage.



#### Chart 4 - Further Evidence

3.2.12 Although a large percentage chose to provide medical evidence (83%), the vast majority were not clear as to what constituted good medical evidence. Reasons for this were lack of clarity on who should provide the evidence, where to obtain the evidence and concerns about accessing the information due to potential cost and/or burdening an already under pressure health service.

"There is a brief guideline on what should be included but not anything with detail" PIP Claimant (PIR499) "Due to my GP being under increased pressure, he will not/ has no time to write any additional evidence." PIP Claimant (PIR563)

- 3.2.13 Many believed that Capita would automatically approach their GP or Healthcare Professional to request additional medical evidence as details of Healthcare Professionals involved in supporting claimants are requested in the claim form. Capita had only approached other Healthcare Professionals in 39% of cases referred.
- 3.2.14 Several responders indicated they felt that their application would not be considered properly if they did not submit medical evidence. They took the view that the provision of further evidence was mandatory and an expectation rather than an addition.

# "Basically I submitted all mine to prove I wasn't lying in any way about my condition because I always feel I have to prove my disability" PIP Claimant (PIR586)

- 3.2.15 There was also evidence from respondents that there is an over reliance on the evidence from Healthcare Professionals and that this is given more credibility than evidence provided by those providing care or family members who are better placed to comment on daily functional restrictions.
- 3.2.16 Conversely the majority of those who chose not to submit further medical evidence did so as they felt it would not be considered or they believed the Department/Capita would request this.

# Further Evidence – organisations (part 2)

3.2.17 Evidence from the Advice Sector reported similar issues where evidence presented had not been fully considered at both initial claim and Mandatory Reconsideration stage. They report that those claimants who had not sought advocacy were likely to have been disadvantaged with regard to sourcing further medical evidence.

"...they often feel that just being able to talk about their illness is enough; often these individuals suffer low mental health and find it hard to understand the process or don't know what to do next or how to proceed; in cases of lower capacity or intelligence there is a total lack of understanding on how to go about this process and they are reliant on others to help and they don't always get the right support" Anonymous (PIR2082)

- 3.2.18 The majority of Voluntary and Community Sector organisations believe that the high rate of decisions overturned at Tribunal stage supports the assumption that reliable and well sourced further medical evidence is essential to fair, balanced and accurate decisions.
- 3.2.19 There is a concern that many are unable to access further medical evidence due to delays in seeing their GP or consultant. This has been caused by pressures in the health care system and is exacerbated by the Covid-19 response.
- 3.2.20 The Reviewer noted that in responses from Voluntary and Community Sector organisations, claimants express feelings of hopelessness when they get to appeal stage. Many claimants indicated that they were charged by GP's for requesting medical records and also faced delays in receiving notes that had to be redacted in line with General Data Protection Regulations (GDPR) requirements.

"Yes they provide GP records if requested but they provide full records and do not trawl through them to provide only evidence to support their appeal. Also because GP records are now computerised there is scant information on them. A full report (typed) from a GP / other health practitioner/ social worker who is known to the customer should be requested" Anonymous (PIR2704)

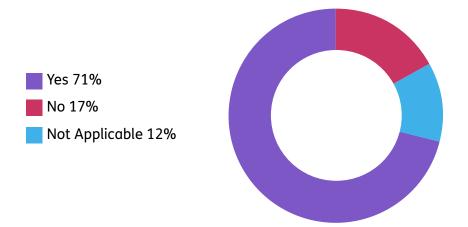
3.2.21 The Reviewer noted that responses to the online questionnaire indicate that there is support for the onus to be placed on Capita and/or the Department to secure medical evidence as this is often placing an added burden on the advice sector who report difficulty in establishing the best source of this evidence in their client's best interests.

#### **Data Sharing**

3.2.22 The Reviewer noted that in Figure 4 most responders to the online questionnaire were in favour of a data sharing approach being taken across the Department and the wider health service. 71% agreed they were comfortable with this approach. This is caveated with the stipulation that all regulatory requirements were met with regard to GDPR.

#### Figure 4 - Data sharing

Comfortable with the Department sharing information between different benefit systems or with other parts of Government to support their PIP claim



3.2.23 Those who were not in favour of data sharing were concerned about access to and wide ranging use of this information for other purposes.

"Providing this was made clear, what exactly would be shared, with whom, by whom, how it would be stored, ultimately disposed of and consent given" PIP Claimant (PIR820)

"If it was done securely and appropriately, it would help to strengthen your case without you having to do all the work to get the information." PIP Claimant (PIR806)

- 3.2.24 Organisations representative of and working on behalf of claimants were asked if they had noted any progress since the last Review. The Reviewer noted that the majority of responses indicated that more needs to be done by the Department as little difference was noted in relation to the implementation of the Recommendations from the Rader report in 2018.
- 3.2.25 There was widespread support for the full implementation of Recommendation 6 regarding the removal of the 6 month rule in cases of terminal illness. The recent High Court judgement regarding the SRTI rule has also further supported this position of scrapping the 6 month rule<sup>21</sup>. On 22 October 2020, Mr Justice McAlinden ruled in the claimant's favour awarding damages of £5,000. He said Mrs Cox endured "upset, distress, annoyance, inconvenience, worry and humiliation… directly as a result of the difference in treatment"<sup>22</sup>.

"The cruel and arbitrary six month rule for Special Rules claims should be scrapped, and replaced with a system based on clinical judgement like that introduced by the Social Security (Scotland) Act 2018. The maximum three-year duration of Special Rules PIP awards should be removed, with a light-touch Review at 10 years only." Craig Harrison Policy and Public Affairs Manager Marie Curie Northern Ireland

- 3.2.26 There was a similar call to revisit Recommendation 11 in the Rader Review regarding training and expertise of the DA's and Recommendation 14 regarding the automatic issue of a copy of the Assessment report alongside the outcome notification.
- 3.2.27 Some improvements were noted regarding the provision of VRS for the Deaf community and of audio recording in Assessment Centres. The Reviewer notes the progress made and the plans to continue the roll-out of audio recording for home Assessments, although this is currently interrupted by the Covid-19 response. The voluntary sector also note improvements made in ensuring written material issued by Capita and the Department are clear, concise and free from jargon.

<sup>&</sup>lt;sup>21</sup> https://www.judiciaryni.uk/judicial-decisions/2020-niqb-53

<sup>&</sup>lt;sup>22</sup> https://irishlegal.com/article/terminally-ill-woman-receives-award-for-distress-and-humiliation-caused-by-terminal-illness-rules

#### Conclusion

- 3.2.28 Responses to the Call for Evidence were largely negative in nature regarding the claimant experience of the Assessment process with the predominant sentiment expressed being one of a stressful, long and arduous journey for the majority of claimants.
- 3.2.29 The Reviewer noted that there were examples of positive experiences where claimants noted empathic and professional Assessments carried out by Capita, efficient and good customer service provided by the PIP Centre and confirmation of the positive financial support provided by an award of PIP and its impact on remaining in work.
- 3.2.30 The Reviewer noted that overall feedback at meetings and from written submissions indicate that more work needs to be done on the Recommendations arising from the first Review.

# Part 4: Communication, Accessibility and Claiming PIP

# Section 1: Communication and Accessibility

#### Introduction

- 4.1.1 It is accepted that different kinds of impairment can present different challenges. This was acknowledged in the first Independent PIP Review, carried out by Walter Rader, who recommended that the Department provide suitable and accessible options for those with particular needs to allow them to apply for PIP where telephone or hand written completion of forms was not suitable.
- 4.1.2 The Department, in their response to this recommendation, acknowledged that they are committed to ensuring there are suitable accessible options for claimants and will continue to take on board the requirements of those with particular needs.
- 4.1.3 The Review acknowledges that the Department's preferred method for making the initial claim (PIP1) is via telephone and the Review also acknowledges and welcomes the introduction of VRS since the first Review.
- 4.1.4 More recently the Review has been informed that the Department has introduced a solution which will enable claimants to receive and return the PIP2 "How your disability affects you" via a secure email link. The introduction of this process is welcomed by the Review.
- 4.1.5 In the longer term, the Review understands that, an online digital solution for claiming PIP is currently being developed by DWP which NI claimants will also benefit from and this additional method will go some way to addressing Recommendation 5 from the first Review. The Department indicated in their response to the first Review that they will be tracking developments in relation to the digital solution.
- 4.1.6 The Accessibility Regulations 2018, which came into effect in September 2018, means that Public Sector organisations have a legal duty to make sure their websites and mobile applications meet accessibility standards so that people with additional needs can access services and information .

The Review understands that the Department is taking steps to ensure that online publications comply with these regulations and this development is welcome.

- 4.1.7 DWP and the Office for Disability Issues have published guidance entitled "Using a range of communication channels to reach disabled people"<sup>23</sup>. This guidance acknowledges that some of the frequently used channels to communicate information may be out of reach or inaccessible to some disabled people. Using a range of communications will help to maximise the number of people the Department can reach and communicating in accessible formats ensures that information is available to everyone.
- 4.1.8 According to the Literacy Trust, 'One in six people in the UK struggle to read and write.' Gov.UK has produced guidance on "How to write well for audiences"<sup>24</sup> which explains why communications should be pitched for a 9 year old reading age. Knowing how people read means communications can be quickly and easily understood.

#### Findings from the Call for Evidence

- 4.1.9 As well as responses from claimants to the online survey the Review received a number of submissions from and held meetings with individuals, organisations, Healthcare Professionals and Political representatives. A number of concerns still remain around the accessibility of PIP products throughout the PIP process.
- 4.1.10 Whilst the Review acknowledges that the Department has introduced new measures since the first Review was carried out, the findings from the Call for Evidence suggest that more work needs to be done to ensure all PIP products are accessible to everyone.
- 4.1.11 Some of the comments received from claimants include the following:

"Make the application process accessible via the internet" PIP Claimant (PIR969)

"First post form 1 ask to ring pip but my mum rang them they want me to speak to pip mum yell they she Deaf how do you expect my daughter to ring you she can't hear" (sic). Case Study from Handsthattalk

The above comment was made by a member of the Deaf community who had asked her mother to contact PIP to make a claim on her behalf however PIP staff asked to speak to the claimant directly. Assuming that the mother would have known the claimant's personal details implicit consent should have applied here.

<sup>&</sup>lt;sup>23</sup> https://www.gov.uk/government/publications/inclusive-communication/using-a-range-of-communication-channels-to-reachdisabled-people

<sup>&</sup>lt;sup>24</sup> https://www.gov.uk/guidance/content-design/writing-for-gov-uk

4.1.12 A number of organisations and Political Parties have also expressed concerns about the lack of alternative formats for making a claim for PIP.

"Despite the wide spectrum of health conditions, there are a limited number of formats in which to give and receive information. The requirement to complete 'Part 1' of the form on the phone can take up to 20 minutes. It can be difficult and off putting for some people and appears to be an unnecessary step in the process". Sinn Fein

"We are also concerned over the accessibility of the PIP form and lack of different versions available in Northern Ireland. This had been brought to our attention when a request for an easy read form was submitted, and the person was issued with a form in larger font size, with no other differences on the format and layout of the form. They were not made aware that no easy-read version exists". The Green Party

- 4.1.13 The APGLD carried out an online survey in 2019 which was completed by 492 respondents. The purpose of the survey was to gauge people's experience of the PIP claim process, Assessment and appeals process and the findings from this survey have been presented to the Review.
- 4.1.14 One of the key issues identified in the APGLD survey was that calling the PIP claim line was challenging for those with anxiety and/or speech difficulties. While 63% of the respondents felt the call was as they expected or was easier than they expected, 25% of respondents felt the call was more difficult than they expected. Responses from those who found the call difficult include:

"As a result of stroke, I can't speak well, cannot use phone at all, yet initial claim is by phone..."

"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"

4.1.15 The Review understands that the Department introduced measures to safeguard vulnerable claimants going through the reassessment process when PIP was introduced. These measures involved the MtC Outreach team contacting claimants who did not respond to the invitation to claim PIP. As the reassessment process has now been completed this action would appear to have ceased.

- 4.1.16 Departmental statistics as at May 2020 show that 12,370 (14%) of new claims registered were disallowed as a result of people failing to return the PIP2 and 3,530 (3%) of reassessment cases were disallowed as a result of people failing to return the PIP2. These figures may not reflect the true picture if some of the claimants impacted by these decisions came back through the system either by making a new claim or if the Department accepted "good reason" for not returning the PIP2. The actual number of claimants impacted is not known however the Review considers these figures to be a cause for concern.
- 4.1.17 Anecdotal evidence, for people failing to return the PIP2, would suggest the reasons for this is because people don't understand the questions or they feel the questions do not apply to them however this is indicative of the responses received during the Call for Evidence from claimants who have gone on and applied for the benefit.

"The application form for PIP can be very overwhelming for claimants who suffer from learning, mental or physical disabilities". PIP Claimant (PIP056)

"The claiming process, in particular the claim forms are unnecessarily long and may be confusing to some. For someone who is claiming due to mental ill-health, many of the questions were not appropriate". PIP Claimant (PIP1182)

4.1.18 PIP is a benefit that is intended to help people with the extra costs of living with a longterm health condition or disability and the Review has concerns that some of these people are falling through the net. The Review is of the opinion that the safeguarding measures referred to in paragraph 4.1.15 above should be reintroduced.

#### **Recommendation 1: Communications and Accessibility**

To improve accessibility for those claiming PIP, the Department, in consultation with stakeholders should explore and develop alternative methods of communication and improve existing communication products and information. The Review recommends the following:

- An easy read version of guidance material and claim form (PIP1 and PIP2);
- Signed guidance material;
- Promoting/publicising the clerical claim form where online access is not available
- The Department should promote the services of and publish the contact details for the Make the Call (MtC) Outreach Team on all PIP literature. This will broaden the service provided by the MtC Outreach Team to assist with the completion of the PIP1 and the PIP2. The Department should utilise this service to make contact with all claimants who make the initial PIP1 claim but do not return the PIP2;
- Staff should be reminded that when a representative, relative or Social Worker contact PIP on behalf of a claimant they should take this as implicit consent; and
- Information on changes to PIP, in particular legislative changes, should be published in an easily accessible central location.

# **Section 2: Claiming PIP**

# Introduction

- 4.2.1 Making a claim for PIP is a two stage process. Initially the claimant contacts the PIP Centre using the telephone claim number. At this point the form (PIP1) containing basic eligibility details is completed. This information is captured electronically and constitutes the first part of the claim.
- 4.2.2 Following the call, and assuming the basic eligibility conditions have been met, a PIP2 form is issued. This form is designed to determine 'How your disability affects you'. When the claimant completes this form it is forwarded to the Assessment Provider. The claimant has four weeks to complete and return the PIP2 form.
- 4.2.3 The Review has heard concerns about both stages of the process. Claimants report difficulties in both making the initial claim using the telephony route and in completing the long PIP2 form within the four week's allowed.
- 4.2.4 Feedback from the Advice Sector indicates those with both physical and mental health conditions report problems making the initial call. Claimants with mental health or learning disabilities find it difficult to communicate by telephone and/or reply to questions in quick succession. Members of the Deaf community have also identified problems communicating with the Department throughout the entire claim journey.
- 4.2.5 Claimants reported challenges in returning the PIP2 form in the specified 4 weeks. The two main areas of concern were the ability to access assistance with the completion of the forms and problems getting supportive medical evidence to corroborate their statement of needs within the timeframe allowed.

# **Overall themes from Call for Evidence**

- 4.2.6 Feedback indicated general dissatisfaction regarding the application process with the majority of responders feeling the forms are too long, too difficult to complete and designed to reflect a 'one size fits all' approach. As societal understanding of the impact of living with an illness or disability grows, there is a growing body of thought that this should be reflected in the application process.
- 4.2.7 There is also significant concern that the application process has become so complex that some form of advocacy is a must.

#### **Claimant experience**

4.2.8 Responses to the online questionnaire indicate that claimants find the claim forms repetitive and time consuming to complete.

"The forms are difficult to navigate & very repetitive" PIP Claimant (PIR1194)

"The claiming process, in particular the claim forms, are unnecessarily long and may be confusing to some. For someone who is claiming due to mental ill-health, many of the questions were not appropriate" PIP Claimant (PIR1182)

4.2.9 Some responders acknowledged the restrictive nature of one claim form for all conditions, as the form did not lend itself to tease out the complexities of those with a variety of conditions.

"I feel there should be two separate processes/forms, one for people with physical difficulties and one for people with mental health difficulties." PIP claimant (PIR341)

4.2.10 The Review also received responses indicating that the lack of understanding of the functional nature of the Assessment process led to relevant details not being provided in the PIP2 form.

#### Submissions to the Review

- 4.2.11 Submissions to the Review indicated similar themes to those found in both responses to the online questionnaire and the stakeholder meetings held. Most responders indicated that the claim form is cumbersome and presents challenges for all in accurately recording the nature of their needs.
- 4.2.12 These challenges are further added to by the difficulty that claimants face in accessing the advice and support services they need to complete the PIP2 form, within the four weeks allowed. Many claimants are unaware they can request an extension to this four week period.
- 4.2.13 Given the disconnect between the lived experience felt by the claimant and the narrow frame the questions take in the PIP2 form, the voluntary sector have called on the Department to look again at the claim form and reconfigure the questions to enable a more reflective response to the various conditions experienced.

"Critically review and improve the structure of the PIP2 form so that it matches the PIP descriptors; in other words we contend that it should reflect 'highest' to 'lowest' in terms of the points available within each descriptor". Advice NI

4.2.14 Advice NI has also called on the Department to align the questions posed in the PIP2 form with the regulations, thus creating more transparency in the process and defining exactly what information claimants are expected to provide.

"The PIP form should be updated to more accurately reflect the Regulations and case law". Advice NI

# **Evidence from organisations**

- 4.2.15 Feedback from stakeholder meetings followed a similar thread to those found in submissions. There is overall support for enhancing the existing telephony claims with online digital routes to reflect the advances made in technology.
- 4.2.16 DWP Minister Justin Tomlinson agreed when, in response to a Parliamentary question tabled on 28 August 2020, he mentioned a new online digital channel 'PIP Apply' which is due to be introduced by the end of the year <sup>25</sup>.
- 4.2.17 Organisations also highlighted to the Review, issues with the reports produced by the DA's specifically with regard to interpretation of the legislation.

"The claim form could be improved to better reflect the PIP descriptors, particularly in view of new case law and the requirements under Regulation 4 (i.e. it is the ability to undertake the descriptors safely, repeatedly, to an acceptable standard and within a reasonable time). Although this criterion is mentioned in the guidance notes, we found that many clients did not read these. Integrating these regulations for each question in the form would offer greater clarity." WAVE trauma – PIR529

- 4.2.18 Relatives for Justice pointed out that the absence of a text box, offering claimants an opportunity to detail someone who could evidence their needs, prevented the inclusion of a valid and useful source of corroborative evidence.
- 4.2.19 Representatives from the main Political Parties called for more work to be done to improve accessibility for all, including simplifying language and converting forms to Easy Read.

<sup>&</sup>lt;sup>25</sup> https://questions-statements.parliament.uk/written-questions/detail/2020-08-28/82607

4.2.20 Representatives from the Healthcare community called for more engagement with Healthcare Professionals, to ensure their feedback is factored into any amendments made to the application process to improve accessibility for the claimants and the Healthcare Professional.

#### What is good and works well

- 4.2.21 The Deaf community indicated some progress has been made since the first Review with the introduction of VRS in the Department and more recently in Capita. This has ensured better access for claimants who are deaf or hard of hearing.
- 4.2.22 The Department has moved recently to ensure all products are compliant with the Accessibility Regulations which came into effect on 23 September 2018<sup>26</sup>. The Review acknowledges this work will improve access for all, but especially for those who are blind, and those requiring access to Easy Read versions of products.
- 4.2.23 The provision of information to help individuals better understand what is expected to happen throughout the PIP Assessment has been welcomed by the Review, but there is an acknowledgement that this is still confusing to most. Whilst the videos on NI Direct are a move in the right direction there is still a body of evidence to suggest this has not gone far enough.

## All Party Group research

- 4.2.24 The submission from the APGLD, commissioned to feed into the Review, also calls for improvements to claiming PIP.
- 4.2.25 The Review notes the suggestions in relation to a digital claim route, more accessible products, clearer guidance notes and the request to simplify the claim form.
- 4.2.26 The Review notes the concerns raised that the questions asked should be reframed to reflect all conditions. This exercise should be completed in consultation with disabled people and their advocates.
- 4.2.27 This will ensure that individuals are given the best possible opportunity of completing the form correctly and providing the information required. Claimants, and those who support them, would benefit from a more tailored set of questions, in the claim form, which

<sup>&</sup>lt;sup>26</sup> https://www.gov.uk/guidance/accessibility-requirements-for-public-sector-websites-and-apps

would expect to draw out the important information set out in the legislation. This would ensure relevant information is available at the earliest stage possible in the process and could directly influence whether a face-to-face Assessment is required.

4.2.28 Given the comments received about accessing additional supportive evidence in a timely manner, the following Recommendation will reduce some of the concerns expressed to the Review. Increasing awareness of the 2 week extension to the time allocated to returning key information is key to ensuring full transparency.

#### **Recommendation 2: Claiming PIP**

- a. The Department should establish a "Task and Finish" group, involving stakeholders and Medical Professionals, to look at the PIP2 and AR1 forms. This group should consider, but not be limited to the following points:
  - Compliance with the legislation in particular PIP Regulation 7 (the majority test), Regulation 4 (the reliability tests), Regulation 2 and Schedule 1 (the need for aids and appliances);
  - Style and format of questions asked; and
  - Guidance to assist completion of the PIP form, ensuring the functional test descriptors and activities are fully explained.
- b. The Department should raise awareness about the availability of the two week extension which can be requested for returning the PIP2/AR1 form.

# Part 5: The Assessment Process

# Section 1: Special Rules Terminally Ill (SRTI)

- 5.1.1 Claims to PIP can be made under the 'Special Rules for Terminal Illness' (SRTI) criteria where the claimant identifies as having an illness or condition which reduces their life expectancy.
- 5.1.2 The legal definition of terminal illness used to determine eligibility for a SRTI claim is: "a progressive disease and death in consequence of that disease can reasonably be expected within six months."
- 5.1.3 This definition of terminal illness was introduced by the UK Parliament in 1990 and applies in Northern Ireland, England, and Wales and for non-devolved benefits in Scotland.
- 5.1.4 Individuals claiming under the Special Rules criteria are advised to obtain a DS1500 report from their GP, consultant or specialist nurse. All claims under the Special Rules are flagged and sent to the DA to be determined and returned to the Department within 2 working days. There are currently, in NI, 2,260 PIP awards under the Special Rules at May 2020 with an average claim clearance time of 2 weeks<sup>27</sup>.
- 5.1.5 Successful claims made under the Special Rules are therefore spared the longer wait for a decision than those made under 'normal rules' clearance times which is 13 weeks on average.

## **Current process**

- 5.1.6 The Review notes the concerns raised about the unequal treatment afforded many who have a progressive and life limiting condition but who fail to qualify under the Special Rules.
- 5.1.7 It should be noted that those individuals who qualify under Special Rules do not need to satisfy the three month qualifying condition, do not need to complete the PIP2 and qualify automatically for the highest rate of daily living for a period of three years.

<sup>&</sup>lt;sup>27</sup> https://www.communities-ni.gov.uk/publications/personal-independence-payment-statistics-may-2020

- 5.1.8 The All Party Parliamentary Group for Terminal Illness confirms "This "six-month rule" was introduced into law in 1990 to exempt terminally ill people from the six-month qualifying period for the Attendance Allowance it was not initially intended to be a wider definition of terminal illness and the timescale has no clinical meaning in most cases"<sup>28</sup>.
- 5.1.9 The issue of terminal illness is an extremely sensitive one and the "six month rule" wrongly assumes that life expectancy can be accurately predicted. This is challenging for the clinicians involved in establishing whether or not the Special Rules apply and is backed up by many studies on this issue<sup>29</sup>.
- 5.1.10 Walter Rader, during the First Independent Review of the PIP Process 2018, made a Recommendation that the "six month rule" should be removed and replaced with the clinical judgement of a medical practitioner<sup>30</sup>.
- 5.1.11 The Department did not accept this Recommendation at the time and stated the following:

"The Department could not progress this recommendation at the time as under the statutory framework provided for in the Northern Ireland Act 1998 social security law in Northern Ireland is maintained in parity with provision brought forward by DWP, unless the Executive and Assembly determine otherwise. More recently the Department has been fully involved in the current DWP Review of special rules criteria".

5.1.12 DWP launched a review of the definition of terminal illness in July 2019<sup>31</sup> and DWP Minister Justin Tomlinson announced on 29 June 2020 that changes 'were coming soon'. The Review has recently been advised by the Department that they have been involved in the DWP review and they are awaiting a final outcome from DWP. The Departments update on this issue can be found at Annex 1, Recommendation 6.

<sup>&</sup>lt;sup>28</sup> https://www.mariecurie.org.uk/globalassets/media/documents/policy/appg/all-party-parliamentary-group-for-terminal-illnessreport-2019.pdf - Page 10, APG for terminal illness

<sup>&</sup>lt;sup>29</sup> https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0161407

<sup>&</sup>lt;sup>30</sup> https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-independent-review-pip-assessment-process-june-2018.pdf – P9- Recommendation 6

<sup>&</sup>lt;sup>31</sup> https://www.gov.uk/government/news/terminally-ill-benefit-claimants-deserve-a-fresh-and-honest-evaluation-of-the-way-thesystem-supports-them

## **Scottish Model**

- 5.1.13 Much has been made of the Scottish model which has attempted to address this inequality of treatment. As PIP is a devolved benefit under the Scottish Social Security system, the Scottish Government has moved to replace the current system with a new definition where, for the purposes of claiming benefit, a clinical judgement is made on the individual's life expectancy.
- 5.1.14 Under the definition in the Social Security (Scotland) Act 2018: "an individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if... it is the clinical judgement of a registered medical practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual's death."<sup>32</sup>
- 5.1.15 The All Party Parliamentary Group for Terminal Illness stated:

"This approach better reflects the clinical reality of terminal illness and advances in prognostication over the last three decades – however, it will create a "two tier" benefits system in Scotland and inconsistency across the UK as only Personal Independence Payments and Attendance Allowance are devolved"<sup>33</sup>.

ESA and UC claimants are disadvantaged by this change of approach as these benefits are not devolved.

## **Recent Court Judgement**

- 5.1.16 The issue has received widespread support from the Voluntary and Community sector in NI with a PIP claimant, Lorraine Cox who was supported by Law Centre NI, recently being given leave for a judicial review of the 'six month rule".
- 5.1.17 On 22 October 2020, Mr Justice McAlinden ruled in the claimant's favour awarding damages of £5,000<sup>34</sup>. He said Mrs Cox endured "upset, distress, annoyance, inconvenience, worry and humiliation" caused as a result of unlawful discrimination."

<sup>&</sup>lt;sup>32</sup> https://www.gov.scot/policies/social-security/terminal-illness/#:~:text=The%20Social%20Security%20%28Scotland%29%20 Act%202018%20sets%20out,terminal%2C%20for%20the%20purpose%20of%20accessing%20disability%20assistance

<sup>&</sup>lt;sup>33</sup> https://www.mariecurie.org.uk/globalassets/media/documents/policy/appg/all-party-parliamentary-group-for-terminal-illness-report-2019.pdf

<sup>&</sup>lt;sup>34</sup> https://irishlegal.com/article/terminally-ill-woman-receives-award-for-distress-and-humiliation-caused-by-terminal-illness-rules

5.1.18 The Review understands the Department is currently considering the ruling and its impact. Minister Carál Ní Chuilín met with representatives from the voluntary and community sector on 17 September to discuss the issue.<sup>35</sup>

#### Assembly motion

- 5.1.19 The Review notes the motion brought by Kellie Armstrong MLA and Paula Bradley MLA where the Assembly voted to pass the motion to remove the 'six month rule'.
- 5.1.20 Although the motion is not binding on the Department, the Review understands the Minister also indicated her support for the motion and stating that the Department has been 'proactive on the review'.<sup>36</sup>

#### **Claimant Experience**

5.1.21 The majority of feedback received from the Call for Evidence on this issue originated from the Voluntary and Community sector, which supports individuals through their PIP journey where a progressive or life limiting condition is involved. There were, however, some comments made by claimants in the online questionnaire indicating dissatisfaction with their overall experience of claiming PIP.

"Getting diagnosed with stage 3 cancer, 18 weeks of chemo and sickness, surgery, weeks of radiotherapy and now permanent nerve damage and joint pain was bad enough. But to fill in a form and then get stressed about the face to face assessment caused more anxiety I didn't need" PIP Claimant (PIR2002)

"The whole process takes too long having MND, confirmed by a qualified medical consultant, should fast track the decision. No one gets better from MND." PIP Claimant (PIR1985)

#### **Evidence from organisations**

- 5.1.22 The Review notes that there was widespread support within the Voluntary and Community sector for the abolition of the 'six month rule' and the implementation of Recommendation 6 from the First Independent Review of PIP.
- 5.1.23 The Review also received evidence from six of the Political Parties similarly calling for the removal of the 'six month rule'.

<sup>&</sup>lt;sup>35</sup> https://twitter.com/CommunitiesNI/status/1306542171630243840

<sup>&</sup>lt;sup>36</sup> http://aims.niassembly.gov.uk/officialreport/report.aspx?&eveDate=2020/10/06&docID=310172#2981858

- 5.1.24 Organisations that specifically work with those individuals with terminal, life limiting or progressive conditions have unilaterally called for the Recommendation from the first Review to be accepted.
- 5.1.25 Marie Curie, Motor Neurone Disease Association, Law Centre NI and Advice NI have all called for this work to be progressed.

"The cruel and arbitrary six month rule for Special Rules claims should be scrapped, and replaced with a system based on clinical judgement like that introduced by the Social Security (Scotland) Act 2018. The maximum three-year duration of Special Rules PIP awards should be removed, with a light-touch review at 10 years only" Marie Curie PIR504

"First, the definition of terminal illness where it is specified there must be a reasonable expectation of death within six months is still in use. Second, awards made under the Special Rules are still usually limited to three years maximum duration. As a complex and unpredictable terminal illness, it is impossible to give someone living with MND an exact prognosis, which means that some are still not able to benefit from accessing the Special Rules even though they are living with a terminal condition" Motor Neurone Disease Association PIR518

- 5.1.26 Similarly, there was support in the representations made to the Review by the medical community. The Royal College of GP's confirmed that "It is difficult for GP's to diagnose whether someone has 6 months or less to live, the Department should trust GP's judgement whether someone is terminally ill". They also confirmed "someone could have palliative care for 10 years but could die at anytime".
- 5.1.27 The Royal College of Occupational Therapists confirm

"Claimants receiving palliative care. The issue of special circumstances for claimants with a terminal illness is extremely difficult. Many claimants have a terminal diagnosis, but their prognosis is beyond 6 months and clinical staff are not comfortable filling out the DS1500 stating that they have 6 months to live. Being forced to give a prognosis for a benefit application is very difficult for all concerned. The psychological impact of the PIP assessment process, when someone has a life-limiting illness, is also hard. Claimants report that when they describe their problems to the assessor, they do not feel the assessor comprehends the sheer impact of the condition; it is very difficult to describe to a stranger the impact of a devastating illness on an individual's life". 5.1.28 Given the substantial body of evidence gathered from a wide range of individuals, organisations, Healthcare Professionals and political parties, the Review calls on the Department to accept the Recommendation 6 from the first Review.

## **Recommendation 3: Special Rules Terminally Ill (SRTI)**

Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 6 from the first Review that the 6 months life expectancy criterion for terminally ill claimants should be removed and replaced with a system based on clinical judgement similar to that enacted by the Social Security (Scotland) Act 2018. This should include adopting a subsequent 10 year light touch review on awards made where special rules apply.

# Section 2: Assessment type

## Introduction

- 5.2.1. Once the claimant has successfully made their claim by either post or telephone, the PIP2 is issued to the claimant to be returned to the AP. On receipt the AP will conduct an initial review of the case to establish if:
  - Further evidence is needed
  - The claim can be assessed on the basis of the paper evidence provided; or
  - If a face-to-face consultation is required
- 5.2.2 Following on from Recommendation 9 of the Rader Review, the Department, in conjunction with Capita, introduced a decision making matrix to support Capita Assessors in determining the most appropriate type of Assessment for each individual. A comprehensive review of this was carried out and changes made to the matrix were discussed at the Disability Consultative Forum.
- 5.2.3 In the majority of cases a face-to-face Assessment is deemed necessary to accurately assess the claimant's functional ability. The Assessment can be held at either an Assessment Centre or in the claimant's home.
- 5.2.4 In light of the current world health crisis caused by the Covid-19 pandemic, in March 2020 the Department moved quickly to suspend all face-to-face Assessments for disability benefits including PIP for an initial period of three months.<sup>37</sup> On 7 July 2020 Minister Carál Ní Chuilín announced that these measures would be kept under review.

## **Current Assessment process**

- 5.2.5 On 16th March 2020 the then DfC Minister, Deirdre Hargey, announced measures to protect the most vulnerable by suspending PIP face-to-face Assessments. The Minister further confirmed the use of telephony as a means of conducting the Assessment process<sup>38</sup>.
- 5.2.6 The Review notes that Capita moved quickly to introduce telephony Assessments as a temporary contingency solution given the need to protect claimants who could be considered in the vulnerable group due to their health condition or disability.

<sup>&</sup>lt;sup>37</sup> https://www.communities-ni.gov.uk/news/minister-introduces-further-measures-protect-most-vulnerable

<sup>&</sup>lt;sup>38</sup> https://www.communities-ni.gov.uk/news/minister-announces-measures-protect-most-vulnerable-ensure-delivery-social-securityservices

- 5.2.7 A DWP Committee report published on 22 June 2020 detailed the efforts made by both the AP's and DWP to address the current restrictions imposed by the pandemic and acknowledges the fact that telephony Assessments are not recorded<sup>39</sup>.
- 5.2.8 The Reviewer understands the Department is currently undertaking an exercise to review options which best support the recording of these Assessments in the short term.
- 5.2.9 It is also worth noting that DWP Minister Therese Coffey confirmed that Assessment Provider ATOS has begun audio recording of PIP Assessments from 21 September 2020 and Capita are expected to follow suit.<sup>40</sup>
- 5.2.10 Given the current health crisis shows no sign of abating, the Reviewer is of the opinion that the use of telephony Assessments is likely to be a feature in the short to medium term. The Reviewer would therefore urge the Department to ensure that audio recording is progressed promptly.
- 5.2.11 The Review has received feedback indicating a mixed response to the introduction of telephony Assessments. This appears to be linked to the health condition or disability faced by the claimant.
- 5.2.12 Early indications are that those with mental health conditions prefer the use of telephony to conventional means of Assessment whilst those with a physical disability prefer the face-to-face method.
- 5.2.13 The Reviewer undertook audio observation of eight telephony Assessments in conjunction with the DA in Capita. The observations were across a range of claimants from both rural and urban backgrounds and across a number of different DA's.
- 5.2.14 Consent was given by the claimant for the Reviewer to join these Assessments and the subsequent reports were shared with the Review to ensure sight of the full end to end process.

<sup>&</sup>lt;sup>39</sup> https://committees.parliament.uk/publications/1558/documents/14743/default/ Para 143/144 DWP Committee report

<sup>&</sup>lt;sup>40</sup> https://committees.parliament.uk/oralevidence/963/default/ Answer to question 225

#### **Reviewer's Observations of Assessments**

- 5.2.15 With the arrival of Covid-19 and the implementation of the restrictions, the Department halted all face-to-face Assessments and implemented telephony Assessments. The Reviewer observed eight telephony Assessments over a period of two weeks in mid-August/mid-September 2020.
- 5.2.16 During the observed Assessments the DA set the scene for the process, explained that they would be typing notes throughout the Assessment to capture all of the information being given by the claimant. Claimants were asked if they had anyone accompanying them and were asked if they were ready to proceed.
- 5.2.17 Some claimants indicated that they were nervous and apprehensive of the process and some indicated that their companion would do most of the talking. Where this occurred the Reviewer observed that the DA's directed all questions to the claimant, although they did interact with the companion when they answered questions proffering relevant information regarding the claimant's condition.
- 5.2.18 Of the eight Assessments observed three claimants were accompanied by a partner or friend, and on five occasions claimants were unaccompanied. The Reviewer noted that in two of the Reports, the Reviewer was identified as in attendance with the claimant, which was an error and not what she would have expected to see. Interestingly, in none of the Assessments observed was an advocate present. Whilst the observed Assessments followed a similar pattern, the process varied in length from 45 minutes to 85 minutes.
- 5.2.19 As a result of the eight observed Assessments the Reviewer formed the opinion that some of the claimants found the telephony Assessment easier to deal with. Some claimants would have preferred a face-to-face Assessment as they wanted the DA to see how they were affected by their condition, 'if you were here you could see how I am fixed'. The Reviewer was also struck by the similarities of the difficulties faced by claimants in the first Review, where the observations were made at Centre based face-to-face Assessments. There were indications of stress, anxiety and concern at having to go through the process of Assessment. The three claimants who were accompanied did defer to their partner or friend to support them in the presentation of their conditions, but the five unaccompanied claimants were not, in the opinion of the Reviewer, adequately supported in their Assessment.

5.2.20 The Reviewer acknowledges the challenges involved in producing a report covering a claimant's daily functionality drawn from a relatively short interview. This is further exacerbated by the fact that the interviews are now taking place over the telephone and are not recorded.

"The Commission believes that there needs to be further clarity on what claimants can do to ensure that their assessments are being recorded through audio-visual recording if they wish and what process is entailed to facilitate this as well as ensuring they are fully aware that they can opt-out if they are not comfortable with the assessment being recorded". Commission for Victims and Survivors - PIR506

#### **Future picture**

- 5.2.21 The Review understands the future use of telephony Assessments is currently one of many options being explored under the umbrella of the Health Transformation Project (HTP) here in NI.
- 5.2.22 The Department confirms the HTP is monitoring findings from the recent DWP trials of the introduction of audio-visual Assessments as part of the parity approach taken.

"For PIP, we are also trying to test doing video assessments for around 500 customers, so we can understand whether that improves the healthcare professional's capacity to ensure a positive experience for the customer and be able to get more evidence to support a recommendation on a functional assessment, so we are pushing on video, with audio for telephony" John Paul Marks Director General, Work and Health Services, Department for Work and Pensions speaking at DWP Committee on 30 September 2020

- 5.2.23 Feedback provided by DWP indicates no notable uptake of the use of audio-visual Assessments which is in line with the uptake of audio recording of Assessments here in NI. However, the Review recommends the Department follow progress here closely with a view to introducing full audio-visual recording in NI.
- 5.2.24 A recent study of 3,000 PIP claimants, carried out by a benefits information service provider in GB (Benefits and Work), cements the anecdotal findings of the Review to date which suggests there is a mixed response to telephony Assessments, dependant on the condition or disability faced.

- 5.2.25 Those with mental health conditions preferred the use of telephony Assessments by 60% to 40% to face-to-face Assessments. This changed where the claimant's main disabling condition was a physical one. Conversely, there was a small majority of claimants with a physical health condition in favour of face-to-face. The indications were telephony 48%, face-to-face 52%.
- 5.2.26 For claimants with both a physical health and a mental health condition, the results were a clear majority for telephone Assessments. The results were: telephone 57%, face-to-face 43%<sup>41</sup>.
- 5.2.27 DWP recognise the need to improve trust and transparency in the Assessment process and are currently examining balancing the need to audio record Assessments against requirements for data storage<sup>42</sup>.
- 5.2.28 All of this work has been accelerated by the need to move online due to the current health crisis and the social distancing restrictions caused by Covid-19<sup>43</sup>.
- 5.2.29 The Reviewer notes the existence of emerging anecdotal information on the use of telephony Assessments as opposed to a solid evidence base. This is due to the lack of data on the outcomes and overall claimant experience of this method of Assessment.
- 5.2.30 It is understood the Department will undertake a survey of those who have experienced a telephony Assessment, for both PIP and ESA, and will factor the findings into any consideration of incorporating telephony as a more permanent method of Assessment in the future.

## **Claimant Experience**

- 5.2.31 Claimants have reported initial concerns they have been unable to add advocate support to the call. This is a concern for the Review, especially where the importance of advocacy is understood to be vital for many claimants.
- 5.2.32 The Review confirms the need to ensure where advocacy is requested, that the Department, in conjunction with Capita, are not disadvantaging claimants where technical issues present. This is especially important when considering reasons a call was unsuccessful as this could result in the claim being turned down.

<sup>&</sup>lt;sup>41</sup> https://www.benefitsandwork.co.uk/news/4262-pain-humiliation-and-failed-claims-caused-by-being-forced-into-wrong-pip-assessment

<sup>&</sup>lt;sup>42</sup> https://committees.parliament.uk/publications/1558/documents/14743/default/ - Para 145

<sup>&</sup>lt;sup>43</sup> https://committees.parliament.uk/oralevidence/963/default/ - Question 225

5.2.33 There is also evidence to suggest some individuals preferred the face-to-face Assessment when describing exacerbation of physical conditions.

"Assessment done over the phone, HOW can a decision be made on the strength of a phone call? Do you have any idea of the pressure this is inflicting on good, decent people who are due a benefit?" PIP Claimant PIR1716

"It was a telephone assessment so happy enough" PIP Claimant (PIR1711)

"I wish I could have been assessed face to face but due to COVID the assessor couldn't see my pain." PIP Claimant (PIR1709)

## **Evidence from organisations**

- 5.2.34 Representatives from advocacy organisations broadly welcomed the use of telephony based Assessments. Some have raised concerns including the need to ensure that the quality of the final outcomes are monitored to ensure fair and balanced decisions are made using all available evidence.
- 5.2.35 Feedback from the Departmental Quality Assurance team indicates a growing number of queries being submitted to them following telephony Assessments. This has increased the number of requests for their advice on particular claims.
- 5.2.36 Some of the advantages to using telephony Assessments have been identified by advocacy organisations representing those with mental health conditions. East Belfast SOS indicated that many clients reported more positive experiences as a result of a telephony based Assessment, as this lessened feelings of anxiousness as claimants were more comfortable in their own homes.
- 5.2.37 There are also noted disadvantages to the use of telephony Assessments. Feedback from the Ulster Unionist Party indicated one constituent had found his fluency in discussing his condition had been used against him in his final outcome decision. This would indicate the use of 'informal observations' in another way.
- 5.2.38 Feedback from a volunteer, working with the Rural Residents' Forum, also highlighted the importance of the Department monitoring trends in outcome decisions following telephony Assessments. This was due to a recent higher than usual number of individuals, who were supported in their application, being disallowed.

- 5.2.39 When the situation allows face-to-face Assessments to resume, the Review urges the Department and Capita to ensure the claimant should have choice in selecting their preferred method of Assessment.
- 5.2.40 The Review acknowledges the constraints faced by those in rural areas who do not have sufficient broadband connection to facilitate a full range of communication options.
- 5.2.41 The Review notes that the charity MIND in GB is encouraging their members to lobby their Member of Parliament (MP) to ensure that the use of telephony Assessments is extended beyond a short term contingency method. The charity argues that telephony should be one of the options available to individuals requiring a PIP Assessment. This is especially for those with mental health issues.<sup>44</sup>
- 5.2.42 Full roll-out of the recording of the Assessment by telephony or face-to-face, on an opt-out basis, will deliver trust in the accuracy of advice provided to the Department by way of reports produced. This would also remove the need for the contentious informal observations and would save time for the DA. It would negate the need to type notes throughout the Assessment and would enable them to concentrate on more bespoke questions to better assess functional restrictions.
- 5.2.43 Overall this could lead to fairer decision making and fewer appeals.

"If all face to face assessments were recorded by the DfC and those recordings made available to all parties (preferably in a commonly assessable digital format) the accuracy of the assessments would be far improved and all parties can easily draw attention to inaccuracies and misunderstandings the entire process would involve less work on both sides re: appeals and stress of undergoing the claim" PIP Claimant (PIR2072)

"Ensure the assessment is recorded or videoed, the assessor that came to my house lied about everything when I asked for copy she was in my house 10 minutes claiming she was in for 45" PIP Claimant (PIR2062)

"A video interview would have meant that I could have answered the questions fully and from a comfortable position at home. I had to park quite a distance away from the assessment centre as it was located in a busy city centre in the middle of the day". PIP Claimant (PIR1658)

<sup>&</sup>lt;sup>44</sup> https://action.mind.org.uk/we-cant-go-back-tell-your-mp?utm\_source=Campaigner%20Email&amp;utm\_ medium=Email&utm\_campaign=Welfare%20-%20assessments

#### **Recommendation 4: Assessment Type**

- a. The Department should consider the use of new methods of Assessment, embracing the full range of technology available. This should include use of telephony or audio-visual method where available and should also include a range of options from which the claimant can choose in order to best suit their needs.
- b. In the interests of transparency, the Review recommends that the Department's position should be that all Assessments are audio-recorded with the claimant given the option to opt-out.

# Section 3: Assessment process

#### Information on what to expect

- 5.3.1 The Review acknowledges the attempts made by both the Department and Capita to improve access to useful and accessible material to help guide claimants through the Assessment process. However, the Review notes that evidence indicates that the information being provided is still insufficient and does not meet the needs of claimants, their advocates and Healthcare Professionals.
- 5.3.2 Claimants report confusion and uncertainty as to the exact nature of supportive evidence required to accompany their claim. Healthcare Professionals similarly report issues in clarifying those areas where confirmation of functional needs is required.

## **Capita library**

- 5.3.3 Capita reported to the Review that DA's are supported in their Assessment by use of an extensive library of information to support the provision of accurate and robust advice to the Department.
- 5.3.4 This includes access to clinical and non-clinical decision making materials, access to coaches, e-learning and online resources such as Condition Insight Reports (CIR).
- 5.3.5 CIR's are designed to highlight the impact on people of various mental or physical health conditions. The CIR resource has been developed in conjunction with key stakeholders such as MS Society, Parkinsons NI, Action Mental Health and Positive Life.
- 5.3.6 These reports contain key information to help DA's best understand the lived experience of individuals with particular conditions. They were designed to help DA's frame their understanding of the conditions faced and how the condition may affect the individual's day to day life.
- 5.3.7 Capita confirmed to the Review that CIRs were designed in response to early comments made about the understanding being displayed by DA's. Subsequently, their development now forms part of Capita's ongoing collaboration with stakeholder groups.

## **Claimant Experience**

5.3.8 Claimants reported many issues where lack of understanding of the real impact of their condition led to inaccuracies in their Assessment report.

"Again it's kind of put on the individual to guess what might be useful and why and all in the context of "they are trying to catch me out" PIP Claimant (PIR2231)

"It is very difficult for a consultant to be asked to give more evidence if he already has confirmed the diagnosis" PIP Claimant (PIR2209)

# **Evidence from Organisations**

- 5.3.9 Most of the organisations involved in supporting PIP claimants reported that the information provided to claimants regarding the Assessment was unclear. Both Healthcare Professionals and claimant advocates indicate that the information required, regarding activities and descriptors, was inadequate and led to evidence being missed or unreported.
- 5.3.10 Most of the organisations responding to the Review indicated that clear guidance should be developed to help claimants understand the information being gathered to justify the descriptors on the claim form and to understand what they should provide as part of the application process. Healthcare Professionals also indicated that clear information should be provided to them, when they are being asked to submit evidence in support of an application.

"Clear and accessible guidance is needed to help claimants understand what evidence they should provide as part of a PIP application. Organisations who provided evidence to the Work and Pensions Committee Inquiry into PIP and ESA, explained that difficulties in obtaining useful expert evidence arises from confusion about what PIP assessments seek to measure. In this context, we believe that the Department provide guidance (as part of the PIP1 form) that details what is considered "good evidence" for a PIP claim. This should provide illustrative examples and case studies of good and poor quality evidence, which where possible are directly related to descriptors and different conditions. .....It would also be helpful if the Department worked with professional bodies, and directly with the medical profession, to increase awareness about the type of evidence that they should provide in response to contractor and claimant requests". Law Centre NI

- 5.3.11 The Review notes the impact of the current Covid-19 pandemic on the Healthcare system and the pressures faced by Healthcare Professionals on a day to day basis. However, representations made by the organisations representing Healthcare Professionals state that they are happy to work with the Department and Capita to improve the experience for their patients.
- 5.3.12 The Review notes that the evidence gathered indicated that more transparency and a clearer indication of what is needed to support an application for PIP, earlier in the process, would improve the claimant experience and prevent cases proceeding to an Appeal Tribunal unnecessarily.

#### Importance of evidence gathering on Assessment process

- 5.3.13 The PIP Assessment Guide (PIPAG)<sup>45</sup> confirms that on receipt of a referral from the Department, the DA should conduct an initial review of the case file to determine whether:
  - Further evidence is needed
  - The claim can be assessed on the basis of the paper evidence held at this point (a 'paper-based review') or
  - A face-to-face consultation will be required
- 5.3.14 The AP should seek additional evidence from professionals involved in supporting claimants where they feel this would help inform their choice. The DA should contact the most appropriate person involved in the claimant's care. In some cases this might be a support worker, care giver or therapist rather than the GP. The DA should await the return of any further evidence requested before deciding whether a face-to-face Assessment is needed.
- 5.3.15 Where the DA is content the evidence gathered is sufficient to warrant a Paper Based Review, the advice is provided to the Department with justification for all descriptors recorded. However, the PIPAG confirms that it is expected that the majority of cases will need to move to face-to-face Assessment.
- 5.3.16 Where the case progresses to a face-to-face Assessment the PIPAG also confirms that the DA is directed to employ the following approach.

<sup>&</sup>lt;sup>45</sup> https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/918328/pip-assessmentguide-part-1-assessment-process.pdf - Para 1.3.6

Different types of questions should be used where appropriate:

- Open questions which need more than a "yes" or "no" answer (for example, "Tell me about...", "What do you do when...", "How do you...") encourage the claimant to describe how their health condition or impairment affects them
- Closed questions which need a specific answer (for example, "Can you...", "How often...") are needed when establishing a fact, such as how often medication is being taken
- Clarifying questions invite the claimant to explain further some aspect of what they have said (for example, "Let me make sure I've understood this correctly...")
- Extending questions allow the HP to develop the story the claimant is giving (for example, "So what happens after...").

# **Current approach - Assessments**

- 5.3.17 The Review has heard evidence that there is an inconsistency in approach taken by DA's. This can lead to inconsistent outcomes as some DA's are better than others in establishing the true picture of needs experienced by PIP claimants.
- 5.3.18 Representations have been made that reports produced by the DA's are overly structured and very formulaic. There have also been reports of huge inaccuracies in the report produced when compared to the individual claimant's version of events.
- 5.3.19 The Review understands that there is a lack of exploratory questioning throughout the Assessment process. It is at the face-to-face Assessment stage that this is most apparent. It is also apparent that this impacts on the accuracy of the report produced.
- 5.3.20 Reports of the short time taken to conduct the face-to-face Assessments also indicate time pressures being placed on DA's to produce their report at pace. Many claimants report the DA spending the majority of the time typing up during the face-to-face Assessment. DA's should be given adequate time after the Assessment and consider the use of digital recordings rather than typing up notes during the Assessment.
- 5.3.21 It is also the opinion of the Reviewer that inaccuracy in reports is linked to the lack of awareness of the challenges faced by claimants across the range of conditions that DA's are assessing.

#### **Claimant Experience**

- 5.3.22 The Review has received feedback from claimants as to a lack of probing questions being asked to fully establish the impact of their condition, often reporting assumptions being made. This includes the use of 'informal observations'.
- 5.3.23 The case study from Widows Against Violence Empower (WAVE) Trauma Centre below best illustrates this:

"Case 4300920: the DA awarded client 0 points for moving around although she was assessed at home and did not stand up at any time, in receipt of DLA HR mob since 2002 (indefinite award), client's oral evidence of poor mobility due to permanent spinal cord condition overlooked. Incorrect assumption made that since client no longer attended Orthopaedics (because there was nothing more that could be done) that there had been an improvement in her condition. The DA came to her own opinion that the claimant's surgery had been successful and that back pain was not consistent with the surgery received. Client got OT assessment funded by VSS which supported her need for aids and provided her with mobility scooter, on this basis Appeal Tribunal awarded her points for moving around (which led to enhanced award for Mobility)" PIR529

"The questions were quite hard to understand and didn't allow me to give answers relating to my case" PIP Claimant (PIR1590)

"Can you lift a fork, walk a metre ... the questions are almost designed to try and catch you out; so one may say can you lift a fork ...then few questions later a pen. Really horrendously worded questions. Questions need to be based on what medical conditions are; the limitations these cause from your own medical records and medications people are on ...because certain drugs and mixing them for various illnesses means it would not be safe to work." PIP Claimant (PIR073)

"Could have asked a different range of questions suited to anyone who has a disability. The questions asked does not give a true picture of the claimant". PIP Claimant (PIR1227)

"Assessments are rushed and questions are leading which evoke the desired answer by the assessor to the detriment of the claimant". PIP Claimant (PIR1225)

"I just sent everything I don't remember there being any 'DON'T send this type of evidence". PIP Claimant (PIR1366)

- 5.3.24 Claimants report feelings of being tested against their statement of needs as recorded in the PIP2 form.
- 5.3.25 The Review noted that levels of illiteracy are not considered when taking evidence at the face-to-face Assessment. One example provided to the Review suggested a claimant was deemed able to plan a journey unaided as they could use a mobile phone. What was overlooked in this case was the fact the phone had only preloaded numbers held.

#### **Evidence from organisations**

- 5.3.26 The Review heard evidence suggesting that the narrow field of questioning employed by DA's led to inaccurate reports and dissatisfied claimants, who often have to pursue their claim to Tribunal. Claimants often report that a more balanced approach is taken at tribunal where panel members take the time to examine the existing evidence and consider new evidence presented.
- 5.3.27 Women's Regional Consortium reported

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

They also reported that the questions in the assessment were repetitive and they felt frustrated that these questions had already been answered on the application form" PIR521.

5.3.28 The Review notes that there is significant concern that certain groups such as those with mental health conditions, autism or those with a learning disability are often either reluctant to divulge the real issues they face or are unaware of the true nature of support needed. This is where the evidence of the care giver or parent becomes essential.

"The questioning by the Assessors is also not necessarily suitable for those with a learning disability or autism. Very basic questions are asked – for example in relation to their ability to dress / wash themselves, their ability to eat/drink, but they do not ask about other difficulties which they experience socially (e.g. their vulnerability with other (sic), their sensory issues, their difficulties with public transport, appointments, or friendships) People with learning disabilities and autism may also suffer because of their ability to understand other people's motives, and therefore be more susceptible to influence; as such they may not engage with the assessment process as well as others.

There is also a flaw with the system in that it relies heavily on self-assessment and face to face assessment. Many individuals, particularly those with mental health problems, may not be a forthcoming with the true impact of their condition due to the social stigma attached". Fermanagh and Omagh District Council PIR522

5.3.29 Organisations such as the Royal College of Occupational Therapists, whose members are both DA's and Healthcare Professionals involved in supporting PIP claimants, report issues establishing the true nature and impact of pain and also on the time pressures faced by DA's.

"Claimants with fatigue and pain; The symptoms of fatigue are very difficult to articulate to assessors. Claimants report that they find it hard to describe its impact because they can complete a task but the effect of residual fatigue can be felt for hours or days after. People with fatigue and pain are encouraged to prioritise tasks and break tasks down over the course of a day. They often have to choose one task over another to manage fatigue levels and this may not be considered by the assessor if tasks are completed or delegated.

Assessment time limits; The assessor's experience of only being allowed 45 minutes to do a home visit assessment is difficult particularly for those with multiple complex conditions who live by themselves. Some claimants will have, for example, twenty different medications and seven different health conditions. The assessor has to go through each, look at the dosage and check it's the same amount on the records" PIR523

- 5.3.30 Political Party representatives reported seemingly obscure lines of questioning and the rigid approach taken to ensure all descriptors are addressed.
- 5.3.31 The Law Centre NI records concerns that the DA's are not probing all issues and are relying on informal observations to justify the selection of a particular descriptor choice.
- 5.3.32 One such example presented by WAVE concerns those with mental health conditions who find references to making eye contact or smiling being taken as evidence of a lack of needs. Claimants report often having to take anti-anxiety medication ahead of the Assessment to ensure they are able to cope, which is often not mentioned or explored.

- 5.3.33 The Review noted that many claimants attempted to underplay symptoms out of a sense of politeness when dealing with a figure in authority. This was raised specifically by the Step Up/Step Down team, which is part of Fostering Network NI in the South Eastern Trust, who felt families at the edge of care were particularly prone to do this. This group of families have significant contact with statutory bodies and they are often reluctant to divulge the real nature of their needs in the event that anything divulged would influence any court proceedings around their parenting capabilities.
- 5.3.34 The Reviewer believes that the correct use of probing questions at the initial scrutiny stage would avoid the need to proceed to a face-to-face Assessment. The Review urges Capita to consider more use of the telephone at this stage to establish as much supportive evidence as possible and avoid the need to secure new evidence at a later stage.

# Voice of the carer

- 5.3.35 The Review has also received reports of concern that vital evidence from carers is being missed or not given sufficient weight in the Assessment process.
- 5.3.36 Whilst the PIP Assessment is a functional Assessment, the Review notes the inconsistent approach taken in recognising and weighting the vital evidence provided by companions or care givers.
- 5.3.37 The Review has heard reports of good practice amongst DA's especially in the case of young people migrating from DLA to PIP at age 16 years where parents can provide relevant evidence of need. It should be noted however, that this is not consistent across all DA's.
- 5.3.38 The Review notes the Recommendation made by the DWP Committee in February 2018 of the importance of weighting evidence from advocates, care givers and family members who are acting as companions at the Assessment<sup>46</sup>.
- 5.3.39 The Review takes the view that where claimants tend to understate needs, evidence from care givers can provide a much needed clear picture. Whilst the removal of the 'statement from someone who knows you' from the PIP claim form was welcomed by GP's this was viewed negatively by claimant's as this provided an opportunity for the care giver to provide valuable evidence.

<sup>&</sup>lt;sup>46</sup> https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/82906.htm#\_idTextAnchor024- Para 50

## **Claimant Experience**

5.3.40 Evidence from claimants suggest most believe the DA will only weight evidence from another Healthcare Professional. They believe that evidence from a care giver, family member or anyone outside the Medical profession is viewed as not persuasive evidence.

"People feel obliged to send further evidence, but decision makers only seem to take note of professionals on headed paper, ask for writing from someone who knows you best, i.e. your carer, don't take this into account, can't even record their existence" PIP Claimant (PIR450)

5.3.41 Some feedback suggests a rigid approach taken by Capita when dealing with appointees. Some claimants and advocate groups indicated that at the face-to-face Assessment stage when an appointee wished to contribute to the Assessment they were ignored or told to remain silent.

"The assessor addressed the claimant (my son) although I was his legal appointee, she ignored what I said and directed all her questions to him and gave an inaccurate assessment of his needs which after a reconsideration was awarded. All the answers given were inaccurately portrayed or assumptions made instead of clarification on points or understanding his condition. It was an extremely stressful time through the assessment and reconsideration period" PIP Claimant (PIR1188)

"The form was very lengthy and complex. The disability assessor clearly did not understand his condition (ADHD), as she directed the vast majority of questions to him. She did not appreciate or consider that a 16 year old in formal setting may fear saying the wrong answer and that due to the very nature of his condition did not have insight into his functional ability. It would seem that the voice of the appointee/carer is largely ignored". PIP Claimant (PIR063)

"The assessor made the effort to understand the actual condition of the claimant prior to assessment and respected that an appointee had been granted and what they said should also be taken into consideration. Full clarification of all points and no assumptions made on what they may think". PIP Claimant (PIR1218)

#### **Evidence from organisations**

- 5.3.42 Feedback from advocacy organisations echoed the sentiments expressed by claimants with regard to the frustrations felt by those feeling side-lined and disregarded.
- 5.3.43 The Review notes the position of many of the Political Parties who report concerns at the vital evidence being overlooked by DA's which could avoid further unnecessary stress to claimants where the case presents at tribunal stage.

#### "Evidence of Carers

The Council believes that the evidence given by carers should be of equal weighting during the assessment process. Carers will be able to give a full account of how the individual's disability impacts upon their lives, they see everyone potentially multiple times per day and are well placed to give reliable evidence.

Apart from those outlined previously within this response document, the Council feels strongly that the evidence of carers should be given weighting in the assessment process. Carers see applicants on a daily basis, and some carers see the applicants on more than one occasion every day. They will be in a very good position to provide a factual statement of the impacts the applicant's condition has on them" Fermanagh and Omagh District Council PIR522

"We are mindful that an assessors report is only one piece of evidence. It is a brief glimpse into the impact a person's condition/s has on their daily lives. It should be balanced against all other evidence, particularly those with the most knowledge of the condition and the personal impact" Sinn Fein PIR517

#### 5.3.44 This is echoed by evidence submitted by the Women's Regional Consortium

"There should be an agreed process where carers/companions can input into the assessment and their evidence should be given sufficient weight in the decision making process. While medical evidence is often given more weight in assessments the value of evidence submitted by companions (including carers, family members and friends) seems to be less clear. This is despite the fact that they can often give very valuable insights into how the claimant's conditions impact on their everyday life. Many claimants, particularly those who are more vulnerable and those suffering from mental health conditions, greatly benefit from the input of companions. Not only can companions provide support with the stress/anxiety often experienced during the assessment but they can often describe better how a condition impacts on a claimant, prompt them to remember issues they have and talk about issues that the claimant may be too embarrassed to discuss. Companions can help them to articulate these and support claimants during a potentially stressful process. Their role in assessments is vital." PIR521

5.3.45 The Reviewer notes the role provided by advocacy organisations in helping tease out the need for a more consistent approach to the weighting given to further evidence.

"For example, there is no statistical record of how many claimants are accompanied to PIP assessment. Law Centre recommend that the Department develop official guidance on the use of evidence provided by carers/companions for contractors, case managers and claimants. Furthermore, the Department should provide clear communication on how companions/carers can provide evidence throughout the process: e.g. during the application stage through the provision of a written submission; during the assessment by supporting the claimant to answer questions/provide information; at Mandatory Reconsideration stage by supporting the claimant to access further evidence. Following the implementation of further measures to ensure carers / companions can input into the process, a sample of assessments, where carers/companions are presents should be audited to make sure that guidance is being followed (as also recommended by the Work and Pensions Committee)" Law Centre NI PIR2134

5.3.46 The Reviewer believes that this Recommendation will address the need to secure the valuable input provided by care givers/companions which claimants may not be able to convey themselves due to the impact of their condition. It will also provide transparency and create trust where mistrust exists. Formal recording of the weighting of this evidence will deliver greater understanding of the overall Assessment process particularly to claimants and those supporting them.

#### **Recommendation 5: Assessment Process**

To support claimants and Healthcare Professionals to navigate the Assessment process, and to improve the provision of information available and transparency of the process, the Review recommends that the Department take the following steps.

- a. To support Health Care Professionals and individuals in understanding the information used in the Assessment process, the Department should make available the Condition Insight Reports, detailing the information contained and explaining how this information is used in formulating advice to the Department. These should be published on the Capita website in line with current accessibility requirements.
- b. The Department, in conjunction with Capita, should consider the use of more targeted open questions throughout the Assessment process to ensure a full picture of needs is established as early in the claim as possible and avoid cases passing to appeal stage unnecessarily.
- c. The Department should ensure that evidence provided by the carer/parent/ appointee during the Assessment process is fully considered and used to inform the advice provided following the Assessment.
- d. The Department should ensure that evidence is sought from the person who knows the claimant best (medical/non-medical) and all evidence obtained should be weighted, considered and recorded on the Assessment report and Department records.

# Section 4: In-house Assessment Providers

## Introduction

- 5.4.1 The PIP Regulations state that whether a person has limited or severely limited ability to carry out daily living or mobility activities is to be determined on the basis of an Assessment taking account of relevant medical evidence<sup>47</sup>.
- 5.4.2 In NI, Capita is contracted to carry out the Assessment process on behalf of the Department. Assessments focus on how an individual's health conditions or impairments may impact on their ability to carry out key everyday activities rather than the health conditions themselves this is known as a functional Assessment rather than a medical Assessment.
- 5.4.3 Capita have been contracted by the Department to carry out these functional Assessments since PIP was introduced in June 2016. The Review understands that the contract is due for renewal in 2021.
- 5.4.4 In 2019 Justin Tomlinson, Minister of State for Disabled People, Health and Work, announced that DWP would be developing an integrated Assessment service with a single digital platform. In March 2020 he announced plans by DWP, under the HTP, to reform Assessment services for ESA, Universal Credit (UC) and PIP<sup>48</sup>. He stated that the new service would be developed on a small scale to start in a defined area of the country known as a Transformation Area.
- 5.4.5 Mr Tomlinson stated that Assessments for claimants in the Transformation Area would be carried out by DWP rather than outsourced to providers and the trial will be used to explore new ideas which include the following:
  - trialling better ways of carrying out face-to-face Assessments;
  - how to triage more effectively so that only those people who need a face-to-face Assessment will have to undergo one;
  - how to make it easier for claimants to understand the evidence they need to provide and why;
  - how to remove the need for claimants to give the same information twice;

<sup>&</sup>lt;sup>47</sup> https://www.legislation.gov.uk/nisr/2016/217/made - Reg 4

<sup>&</sup>lt;sup>48</sup> https://questions-statements.parliament.uk/written-statements/detail/2020-03-02/HCWS138

- how to ensure that claimants are aware of the whole range of support available to them both from DWP and more widely.
- 5.4.6 The Reviewer met with DWP's HTP who are taking this work forward and they have advised that the work is due to start in 2021 and will be scaled up in 2022 until around 10% of DWP claimants are using the new service. The new service will be tested for both PIP and the WCA.
- 5.4.7 The Review notes that on 6 October 2020 Minister Ní Chuilín, Minister for Communities, made the following statement to the NI Assembly:<sup>49</sup>

"Some Members mentioned the assessment, and I want to put it on record that Deirdre Hargey had already started a process of bringing that assessment in-house, but people are doing the assessments, too".

The Review also notes that a corresponding Project Team has been established in NI, the Health Transformation Project, to ensure NI requirements are factored in to any changes made.

## Findings from the Call for Evidence

- 5.4.8 As well as responses from claimants to the online survey the Review received a number of submissions from and held meetings with individuals, organisations, Healthcare Professionals and Political representatives and a number of concerns still remain on the use of external providers to carry out Assessments.
- 5.4.9 While the Review acknowledges that there have been some positive comments made about the Assessment process the evidence would suggest that the process is failing a lot of people.

"The whole process ran like clockwork, the form was straightforward and the health assessment was explained thoroughly and carried out in a caring but professional manner. I received my PIP confirmation letter very swiftly". PIP Claimant (PIR1202)

"I could not have asked for better, a professional approach throughout my assessment". PIP Claimant (PIR1232)

"It was a telephone assessment so happy enough" PIP Claimant (PIR1711)

<sup>&</sup>lt;sup>49</sup> http://data.niassembly.gov.uk/HansardXml/plenary-06-10-2020.pdf - Page 89

*"I think I got quite lucky because my assessment went OK."* Women's Regional Consortium Questionnaire Respondent

"Take a close look at how Capita have failed to follow PIP guidelines and not carry out proper assessments with relevant and available medical information. Having a private company do assessments where their involvement is to make money is not very ethical as has been proven by the number of claims that have been overturned at appeal. The system is not working and is causing people's health to be more affected by the degrading and humiliation of been told they have nothing wrong with them and they can do things which medical evidence says different. Private companies are there to make money and nothing else and will lie and bend policy to suit their agenda". PIP Claimant (PIR1175)

"We believe that a key element to restoring confidence and trust in the PIP assessment process is to end the provision of welfare assessments by a private company, and return this crucial function to Department. We understand that this may be challenging in the short term and therefore recommend that progress towards this is made and an anticipated timeframe outlined". Sinn Fein

"I would also ask that you recommend to the Minister that we no longer outsource disability assessors to a private company. Collectively we have heard one of many horror stories of an unsympathetic and ill-equipped Capita assessor; "a former nurse who assessed claimants for the controversial Personal Independence Payment scheme has claimed that the system is in chaos. The whistle-blower, who worked for Capita, says she quit her post because she felt that people seeking the benefit were not being given a fair deal. In her role as a disability assessor (DA), she was tasked with gathering evidence to help decide whether applicants were fit for work or entitled to benefits. The former staff member claimed there were major inconsistencies in the feedback to the DAs and those writing paper-based reports (PBRs), which made guidelines for assessment of claimants, in her opinion, blurred and confusing...The former assessor said that she eventually decided to resign because she felt that her professional reputation was at risk" Claire Hanna MP

- 5.4.10 The Review notes the similarities in the findings from this Review and from the findings of the 2018 Work and Pensions Committee inquiry<sup>50</sup> in relation to the Assessment process in that there is a lack of trust in the process and claimants find the process extremely stressful.
- 5.4.11 The Review also notes with interest the changes which will be introduced by the Scottish Government when PIP is replaced by the Adult Disability Payment in 2021<sup>51</sup>. One notable change being introduced is that face-to-face Assessments will not be carried out in every case and only in the following circumstances:
  - Where there are inconsistencies in the information provided. This could be where the impact an individual has described, about their condition or disability is not consistent with the diagnosis or condition;
  - To fill a significant gap in the individual's account of their condition and its impact, where this gap cannot be filled by other supporting information;
  - Other circumstances where it is identified that a face-to-face Assessment is required for the purposes of robust decision making and auditing.
- 5.4.12 The Review acknowledges that, while a move to the Scottish Model for NI would go some way to building trust and transparency in the PIP process, this move would require legislative changes. The Reviewer believes that this is something the Department should monitor and consider in the long term.
- 5.4.13 As already mentioned the Review met with DWP's HTP and discussed the trial in the Transformation Area for carrying out Assessments in-house. DWP has indicated that they would not be averse to the idea of NI being part of this trial therefore the Reviewer would urge the Department to explore this further.

## **Recommendation 6 – In-House Assessment Providers**

The Department should consider the outcome of the DWP pilot to bring Assessments for both Work Capability Assessment (WCA) and PIP Assessment in-house. The Review recommends that the Department conduct a similar pilot in NI.

<sup>&</sup>lt;sup>50</sup> https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/82904.htm

<sup>&</sup>lt;sup>51</sup> https://www.gov.scot/policies/social-security/benefits-disabled-people-ill-health/#ADP

# Part 6: Further Evidence, DA training, the Audit Process and Decision Making

# **Section 1: Further Evidence**

## Introduction

- 6.1.1 The provision of supporting medical evidence is a key part of the early evidence gathering phase as it informs the Department and the AP in decisions taken with regard to appropriate Assessment type. It also supports accurate awards and can determine award length.
- 6.1.2 Currently, claimants applying for PIP are advised to provide details of Healthcare Professionals involved in supporting them. In section 1 of the PIP2 question 1 suggests recording details of the Healthcare Professional(s) best placed to advise the Department on how the claimant's health condition or disability affects them.
- 6.1.3 Claimants are advised the Department may contact the relevant Healthcare Professional and they are encouraged to record details of Healthcare Professionals such as GP, Hospital Doctor, Specialist Nurse, Community Psychiatric Nurse, Occupational Therapist, Physiotherapist, Social Worker, Counsellor or Support Worker.
- 6.1.4 The information provided on the Information Booklet confirms

"Please only send in photocopies of things you already have available to you. Don't request other documents which might slow down your claim or for which you might be charged a fee – for example, from your GP. If we need this evidence, we'll ask for it ourselves." PIP2 Information Booklet P3.

#### **Current process**

- 6.1.5 The Review notes that the decision whether or not to source additional evidence rests with the AP and not the Department although it is acknowledged that there is noticeable confusion around the issue of responsibility.
- 6.1.6 The AP will not automatically request further evidence in every case but should consider it where they feel this will remove the need for a face-to-face Assessment or where this will add to the quality of the advice provided to the Department.
- 6.1.7 The PIPAG confirms the scenarios;
  - Where Health Professionals feel that further evidence will allow them to offer robust advice without the need for a face-to-face consultation for example, because the addition of key evidence will negate the need for a consultation
  - Where they feel that a consultation may be unhelpful because the claimant lacks insight into their condition
  - Where claimants have progressive or fluctuating conditions
  - Where they consider that a consultation is likely to still be needed but further evidence will improve the quality of the advice provided to DWP (DfC) – for example, because the existing evidence lacks detail or is contradictory or to corroborate other evidence
  - Where, in reassessment cases, further evidence may confirm whether or not there has been a change in the claimant's health condition or disability<sup>52</sup>.
- 6.1.8 The Review notes that whilst the AP is responsible for procuring any further medical evidence deemed necessary, the Department is responsible for making payment for any reports provided<sup>53</sup>.
- 6.1.9 Capita have confirmed that they have encountered problems in obtaining requests for further medical evidence. In 2019 Capita reported that further evidence was requested in 39% of all referrals made. However, they also reported they were only successful in 11% of these cases.

<sup>&</sup>lt;sup>52</sup> https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/918328/pip-assessment-guide-part-1-assessment-process.pdf – Page 14

<sup>&</sup>lt;sup>53</sup> https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/918328/pip-assessmentguide-part-1-assessment-process.pdf – Chapter 1.4.1

6.1.10 The Review notes that whilst there are many factors influencing this low return rate it may be due to the fee assigned to completion of the request given the size and volume of data requested in its current form. There are also constraints faced due to the time assigned to the AP to provide the advice to the Department.

"Our members tell us that the form itself is not useful in its current form. It is too long and should be more practical. GPs can answer factual, specific questions and the forms should be redesigned accordingly. Ideally, any redesign of the form would include the ability for it to be filled in online" British Medical Association – PIR531

- 6.1.11 The Department acknowledges the need to produce information on supportive evidence and has produced information videos on NI Direct alongside the information in the associated claim form products.
- 6.1.12 The Review notes the information on the claim form and the information videos on NI Direct which attempt to clarify the matter. However, evidence gathered suggests there remains considerable confusion on where to access suitable evidence and who is responsible for requesting the evidence.
- 6.1.13 The Review notes that, due to the often conflicting nature of information available, the claimant has assumed it is their responsibility to source the evidence. This is causing undue stress for the individual and is also presenting challenges to the Healthcare Professional approached to provide this evidence.

"It is not clear to applicants what evidence they are being asked to provide. Most people think information from a doctor is the most important. While the PIP2 form says relevant information to send includes reports or information from health professionals such as a GP or hospital doctor, the NI Direct information video says only to send in information you already have and specifically advises against contacting your GP or health professional for evidence. Furthermore, the PIP2 form Q1 "About your health professionals" leads people to believe that the Department will ask for the evidence directly. However, this happens irregularly and is often limited to questionnaires, which GPs and other health professionals do not always know how to helpfully complete". Green Party PIR524 6.1.14 Notwithstanding the difficulties accessing suitable supportive evidence would normally present, the Reviewer notes the added impact on the health care system of the current world health crisis caused by Covid-19 which has caused huge pressures for all involved in health care provision.

### Use of further evidence

- 6.1.15 The Review has received evidence suggesting additional information/evidence has not been properly considered by both the Department and Capita. This is an obvious source of frustration and anxiety to all those involved in the claim process.
- 6.1.16 Supportive evidence provided at either the initial claim stage or at Mandatory Reconsideration stage has already been provided to Capita with a view to this supporting an award without recourse to a face-to-face Assessment and/or supporting a change of award.
- 6.1.17 The Review understands there is often no mention of the consideration given to the weighting of this evidence at either stage.
- 6.1.18 This is especially evident in key areas such as
  - the justification for selection of descriptor choice in the advice provided by the DA and in
  - the decision letter issued by the Department.

### **Claimant Experience**

- 6.1.19 Claimants report several difficulties with regard to supportive evidence. There is widespread confusion as to what is considered adequate supportive evidence and concerns expressed as to where to access this.
- 6.1.20 There are particular concerns for those with long-standing health issues as they may not have access to up-to-date information on their condition.

"A problem area exists regarding claimants whose conditions have not changed. Such individuals may not have recent medical documents relating to their health. We have experience in such circumstances of the assessor dismissing medical evidence in these cases and prioritising their own assessment report." Law Centre NI PIR527

- 6.1.21 Just under 57% of responders to the online 'Call for Evidence' questionnaire reported they were unclear about the type of evidence required. This is despite an overwhelming majority (83%) of responders going on to submit further evidence.
- 6.1.22 While the Review recognizes the efforts made by the Department to provide accessible information on what is a complex issue by way of information videos on NI Direct, there still appears to be confusion as to who should source the required supportive evidence. This may be an underlying factor in the high volume of overturned appeals, currently sitting at 59%<sup>54</sup> up to August 2020, where the main reason appears to be the provision of previously unseen supportive evidence.
- 6.1.23 The Review also notes that overturn rates in DWP decisions in GB are equally as high as those in NI. For the period April 2013 to March 2020, 67% of DWP decisions cleared at tribunal hearing were overturned in the claimant's favour indicating a fundamental flaw in the system.<sup>55</sup>
- 6.1.24 It was noted that many claimants opt to contact their GP in the first instance when the GP may not be best placed to comment on functional ability. The Reviewer notes the importance of independent advice from the advocacy sector on the type of and best source for, supportive evidence.
- 6.1.25 Responders to the online questionnaire also suggested crucial evidence from care givers and advocates was either discouraged or largely ignored. This was especially evident in the case of those migrating from DLA to PIP at age 16 where the evidence provided by their parent/care giver was often the best source of information.

"Without advice I was not aware what would or would not constitute relevant evidence". PIP Claimant (PIR478)

"They could make it clearer what can be used as evidence". PIP Claimant (PIR490)

"I sent everything I had because I was not sure what was required. The forms are very unclear when it comes to stating what evidence is relevant". PIP Claimant (PIR1125)

<sup>&</sup>lt;sup>54</sup> http://aims.niassembly.gov.uk/questions/printquestionsummary.aspx?docid=309144

<sup>&</sup>lt;sup>55</sup> https://www.gov.uk/government/publications/personal-independence-payment-april-2013-to-july-2020/personal-independencepayment-official-statistics-to-july-2020 – Para 9 – customer journey

*"Family member allowed to give input instead of the nurse asking them not to".* PIP Claimant (PIR1706)

6.1.26 Of particular concern to the Reviewer is the inability to conduct Musculoskeletal (MSK) examinations during the telephony Assessments being carried out as a result of Covid-19. This concern highlights the need for DA's to source additional evidence (if it has not already been provided) before sending an opinion to the Department for a decision to be made.

#### Evidence from organisations and stakeholders

- 6.1.27 Evidence gathered from meetings with organisations within the advocacy and Voluntary sector, Healthcare Professionals and Politicians confirm claimants are confused and anxious about attempting to source additional evidence which would be viewed as supportive by the Department and Capita.
- 6.1.28 Many of the advocacy organisations reported a lack of clarity around what will support functional disability as opposed to medical disability. The Review notes that whilst the PIP Assessment is predicated on the principle of a functional rather than medical Assessment, it takes the view that the majority of the terminology used throughout the whole Assessment process is medical in nature. It is therefore impossible to remove one from the other.
- 6.1.29 The Review notes that, building on progress made on the Recommendations from the first Review, work was progressing with Capita and Healthcare Professionals to develop a digital pathway for an electronic GP Short Summary Report to enhance the evidence gathering process. While the Review was informed that this work had to be temporarily paused because of other priorities in relation to Covid-19 it is now understood that Capita have recommenced work to develop a proof of concept to test an electronic version of the GP Short Summary Report.
- 6.1.30 The Review believes that the comments provided by the various Healthcare Professionals who gave evidence should be incorporated into the design of the online GP Report.

"That it is recommended to the minister that a short GP summary report of a client's functionality and conditions is provided with every claim as this will allow a decision maker the opportunity to frame a more comprehensive picture of a client's needs. This would also benefit the many claimants who have found, after presenting their medical notes at an appeal, their disallowed decision overturned

due to revealing functionality issues relevant to a claimant's condition. If the GP is not aware of a client's functionality, but a consultant or physiotherapist is, then I would urge you challenge the Department to find a creative way of sourcing such a short summary report from the relevant medical professional to ensure the most comprehensive decision is made by the PIP process." Claire Hanna, SDLP – PIR505

6.1.31 Evidence suggests there is significant concern that DA's appear to prefer the content of Assessment report regardless of where additional evidence is sourced.

"However even when GP reports are detailed and supportive of an award, we have had cases where Capita favour their own assessor's report, even if contradictory of the GP statement. It appears unclear why this occurs as a GP has long standing knowledge and history of his patient, has access to all medical records and is better qualified." WAVE trauma – PIR529

6.1.32 Feedback from Victims Support Service indicates a potential issue where the DA does not have the required skills to consider the evidence from other clinicians who are more qualified to provide accurate advice.

"However, there is a perception that these types or reports are not given adequate consideration or valued. In some cases it is felt that the assessors do not have the clinical knowledge to make a judgment on clinical reports or from a list of medication that an individual is on and how it can impact on their functionality. Welfare Advisors also report that letters of support from clinical psychologists regarding PTSD are not appropriately recognised within the assessment process. This could be overcome by ensuring that applications are assessed by those who have the appropriate clinical background to do so." Victims and Survivors Service – PIR530

6.1.33 Another issue raised by advocacy groups highlights a potential concern with regard to cases where Capita have requested a GP report but have moved to a face-to-face Assessment before the GP report has been returned.

"(Case 1144143) Capita issued a GP factual report to the claimant's GP but within 10 days of the GPFR being sent to the GP, they had sent the claimant for a face-toface assessment. Post the assessment, Capita received the GPFR. However, he was disallowed on the basis of the Disability Assessor's report despite the GP stating that he needed encouragement with all areas of Daily Living. The decision was appealed and the appeal allowed." WAVE trauma – PIR529

- 6.1.34 The provision of information, in accessible and/or video format, will support both claimants and their representatives in accessing appropriate and useful additional supportive evidence. This will address the reported levels of uncertainty and stress around gathering this evidence.
- 6.1.35 It will also inform Healthcare Professionals ensuring they are clear about the exact nature of evidence needed to help the AP assess the claimant's functional ability accurately. This will remove the likelihood of the evidence being disregarded.
- 6.1.36 Evidence from the Royal College of GP's suggests that where a report from a GP would best support the claimant's PIP application, they ask that the information requested needs to be shorter, more to the point and preferably sent electronically.
- 6.1.37 This will deliver benefits for both parties as it is estimated that current contact regarding PIP applications generates several further unnecessary GP contact with the claimant as the GP is unable to comment on functional ability without an appointment to assess their patient.
- 6.1.38 The Review notes the success rate enjoyed by Maximus, who are a DWP AP. They have managed to secure a 46% success rate when they request written evidence from medical and non-medical professionals with 82% of this being returned within 20 days<sup>56</sup>. The Review urges Capita to explore ways of securing a better success rate in the return of essential supportive evidence in the Assessment process.
- 6.1.39 The consideration and weighting of this evidence should be detailed and recorded for audit purposes. This issue was raised at the DWP Committee when they met on 18 March 2020 to discuss PIP and ESA Assessments. Representatives from the Voluntary and Community sector such as Zacchaeus 2000 Trust, RNIB, MIND, Z2K, Citizens Advice Bureau and Scope made this recommendation.<sup>57</sup>
- 6.1.40 The Review believes that a record of any deliberation taken by either Capita or the Case Managers when reviewing any evidence may influence the subsequent decisions taken with regard to pursuing dispute rights and helping the individual focus on specific areas of disagreement.

<sup>&</sup>lt;sup>56</sup> https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/82906.htm#\_idTextAnchor017 - Para 36 Chapter 3 – DWP Committee – PIP and ESA Assessments

<sup>57</sup> https://parliamentlive.tv/Event/Index/05ba5411-0964-40ec-847b-f84686d16f94

6.1.41 The Reviewer also believes that the formal recording of consideration of additional supportive evidence will also increase trust and transparency in the process especially where claimants and their representatives are concerned their evidence has not been given proper scrutiny.

#### **Recommendation 7 - Further Evidence**

- a. The Department should produce guidance/examples for claimants, advocacy services and Healthcare Professionals of appropriate evidence to support the PIP process and where this evidence should be obtained.
- b. The Department, in conjunction with Capita and relevant Healthcare Professionals, should examine and implement new ways to improve the current poor return rate of GP factual reports.
- c. Proper consideration and recording of evidence when making decisions is essential. All evidence needs to be carefully considered, in relation to the particular circumstances of the individual case, to ensure the correct decision is reached. The Department should ensure the evidence is fully documented and that further evidence, medical or otherwise, has been correctly weighted and documented.

# Section 2: Disability Assessor Training

## Introduction

- 6.2.1 The functional Assessments for PIP are carried out by Health Professionals, also known as Disability Assessors (DA), recruited by Capita and approved by the Department. A DA must meet the following requirements<sup>58</sup>:
  - » Be an occupational therapist, nurse, physiotherapist, paramedic or doctor
  - Be fully registered with the relevant licensing body (doctors must have a licence to practise)
  - » Have no sanctions attached to registration unless they relate to disability. In individual cases, this requirement may be wavered subject to prior written agreement with DWP
  - Have at least 2 years post full registration experience (this refers to either UK registration or equivalent overseas registration for non-UK HPs) or less than
     2 years post full registration experience by individual, prior, written agreement with the Department
  - » Have passed a Disclosure and Barring Service check.
- 6.2.2 Each DA must undergo a 12 week training programme approved by the Department. This training programme includes classroom based training, practical and theoretical Assessments and supervised Assessments in the live environment.
- 6.2.3 The DA's role is to assess the overall functional effects of the claimant's health condition or impairment on their everyday life over a 12 month period, using the Assessment criteria<sup>59</sup>. The key elements of the DA's role are to:
  - consider information in the claimant questionnaire and any supporting evidence provided along with it
  - determine whether a claim can be assessed on the basis of a paper review and provide appropriate advice

<sup>&</sup>lt;sup>58</sup> https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pipassessment-guide-part-3-health-professional-performance#training-of-health-professionals – Para 3.1.1

<sup>&</sup>lt;sup>59</sup> https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pipassessment-guide-part-1-the-assessment-process#the-health-professional-role – Part 1.2

- determine whether any additional evidence needs to be gathered from health or other professionals supporting the claimant
- carry out face-to-face consultations as required
- having considered all the information and evidence, produce a report for the Department containing information on the claimant's circumstances and **recommendations** on the Assessment criteria.
- 6.2.4 In the first Review Walter Rader made the following Recommendation:

"The Department and Capita should develop enhanced training for assessors specific to certain groups of conditions, which could be informed by the prevalence of those conditions as recorded in the Departmental statistical analysis. If a claimant indicates, and can prove, they are affected by one of these conditions they should have the opportunity to see an assessor with enhanced training relevant to their condition, or to have a paper-based review".

6.2.5 The Department did not accept this Recommendation and in their interim response<sup>60</sup> stated:

"The Department accepts that it is vitally important that Disability Assessors have the most appropriate training to allow them to deliver the assessment effectively. The PIP assessment is not a clinical assessment involving diagnosis of conditions or the recommendation of options for treatment. Instead, the Disability Assessor must engage objectively with the claimant and record any information that clearly explains the functional effects of the reported conditions. Understandably this involves a very different set of skills from those required to diagnose and treat individuals, with less requirement for specialist knowledge. The Department considers that, whether a health professional is a specialist in a given area or not, this should not impact on their ability to carry out a functional assessment. The Gray reviews in Great Britain supported this position albeit with the prerequisite that adequate training had been provided to the assessor. All PIP assessors in Northern Ireland are health professionals with specialist training in conducting functional assessments. They must go through the formal Department for Communities' approval process to ensure they meet the Department's experience, skills and competence requirements. There are two fundamental elements to the qualifications and experience of assessors. The first is their qualifications and

<sup>&</sup>lt;sup>60</sup> https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-interim-response-to-pip-independent-review. pdf – Pages 24 and 25

experience relevant to the health care field they work in. The second fundamental element is the disability analysis training all assessors receive from Capita. The Capita Disability Assessor Foundation programme has been developed to ensure assessors carefully explore each claimant's particular circumstances to assess their individual needs".

- 6.2.6 The Review acknowledges the Department's response however, the evidence received during the second Review does not support the Department's view that "whether a health professional is a specialist in a given area or not, this should not impact on their ability to carry out a functional assessment".
- 6.2.7 The Review has received substantial evidence indicating that knowledge of the condition is crucial to making an accurate determination on a person's functional ability. The Review would question why a Medical Professional or medical evidence would be necessary if the medical condition and the functional impacts are not inextricably linked.

## Findings from the Call for Evidence

- 6.2.8 As well as responses from claimants to the online survey the Review received a number of submissions from and held meetings with individuals, organisations, Healthcare Professionals, PIP staff and Political Representatives.
- 6.2.9 A number of comments have been raised about the DA's lack of knowledge about certain conditions which is resulting in reports being inaccurate and potentially leading to claimants being disallowed benefit or receiving a lower award than expected.

"everything was fine till I seen my report. it was straight up full of lies, got the time and date wrong I attended the face to face, got my details and medical conditions mixed with another claimants. Talked about my physical ability the whole report nothing on mental health. I'm autistic with numerous mental health problems that's what I was claiming on. The assessor was a physiotherapist what they know about mental health I don't know but this girl didn't have a clue what she was doing or talking about". PIP Claimant (PIR1563)

"I am the appointee for my child who turned 16 years old last year and had to move to PIP. The form was very lengthy and complex. The disability assessor clearly did not understand his condition (ADHD), as she directed the vast majority of questions to him. She did not appreciate or consider that a 16 year old in formal setting may fear saying the wrong answer and that due to the very nature of his condition did not have insight into his functional ability". PIP Claimant (PIR063) The form is clearly not designed to accommodate those with mental health conditions, there is no parity between mental and physical health conditions in the application process. The assessor lied in her report. I was having an anxiety attack, she said I was calm and relaxed and made good eye contact. The wording of report, where she made reference to my intelligence (not relevant to mental health), also suggested the assessor did not have the professional expertise to make a mental health assessment. PIP Claimant (PIR1534)

"It was evident that the lady undertaking my assessment & the appeal panel had a lack of knowledge of Epilepsy. I'm also concerned that my Type1 Diabetes was not taken into account along with my Epilepsy condition. This meant they had little or no understanding of how Type1 Diabetes can affect my Epilepsy or vice versa".PIP Claimant (PIR1562)

"Often the mental health impact on some people due to their physical illness is ignored. Assessors do not always seem to have a full knowledge of the condition they are assessing. Claimants have a more knowledgeable outlook on their health condition but can be made to feel undervalued and inconsistent in their replies. Via Wings

"Assessments are inconsistent and there is a lack of awareness of deafness" National Deaf Children's Society (NDCS)

"Crucially we suggest that assessors should have a clear understanding of the impact of the condition/s of the person they are assessing. All questions asked should be appropriate and measured. Given the high number of people who have a mental health condition as their main disabling condition it should reasonable to expect that mental practitioners would form a significant part of the assessment team". Sinn Fein

"We note that the Department has not accepted Radar's recommendation 11, that assessors should have enhanced training for a specific set of prevalent conditions. Assessors are medically trained but are not specialists in certain illnesses or conditions (Cystic Fibrosis for example).This is unfortunate, as an assessor needs to have a good understanding of a condition in order to sensitively question a claimant and draw out possible functional impacts, particularly for complex conditions". The Green Party "Informal observations are problematic from a legal standpoint too. The assessor is observing the claimant once when PIP legislation specifies that the claimant should be assessed on whether they can carry out a task repeatedly. If they cannot repeat it, they cannot do it at all. Assessors and DfC officials should be trained to ensure they understand the requirements of the Regulations and case law and how to properly apply the legislation". Advice NI

"The assessor needs to have some experience of working with individuals with mental health conditions in order to understand their needs and difficulties". Royal College of Psychiatrists PIR520

6.2.10 The APGLD provided evidence to the Review which indicated that 66% of the people who completed their survey disagreed or strongly disagreed that the DA understood their condition. Comments made in their findings include the following:

'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).

- 6.2.11 The Review acknowledges and welcomes the fact that Capita have engaged with some organisations to enhance the knowledge of DA's in certain conditions e.g. The Multiple Sclerosis (MS) Society, the Cystic Fibrosis Trust and The Commission for Victims and Survivors. There has been some positive feedback received about this engagement therefore the Review would urge Capita to continue to engage with expert organisations on a regular basis to address the concerns raised during this Review about the DA's lack of knowledge around certain conditions.
- 6.2.12 The Review has received evidence about information being relayed to the DA and getting lost in translation. This was particularly evident in meetings with the Deaf community who have advised the Review that, as English is not their first language and because information is being relayed by an interpreter, DA's are assuming claimants can do things that they cannot.

"Need to acknowledge that English is not their 1st language and deaf people cannot express themselves on a form" BDA Meeting

PIP2 heavily laden with language which young deaf people find difficult to understand. A lot of input required when completing the PIP2 – while the examples given may be communicated by the deaf person the form is actually completed by a literate adult. The DA needs to understand that the PIP2 will not be completed by the young deaf person. Young deaf people have many challenges with communication, they strive to be independent but aren't. Companions (usually parents) at the assessment are discouraged from jumping in to aid/assist the young person by the DA – DA wants to hear from the young person however this demonstrates the difficulties the young person has in communicating information. National Deaf Children's Society (NDCS)

The Review is of the view that this also supports the need for DA's to have knowledge about the conditions they are assessing.

6.2.13 The Review has also received evidence about the DA's behaviour during the Assessment. While the Review acknowledges that this is not reflective of all DA's, as there have been some positive comments about DAs behaviour, it is evidence that some DA's would benefit from empathy skills training. Examples of comments received are provided below.

"The assessor was very nice but had little understanding or interest in what was being said, answers". PIP Claimant (PIR1653)

"The assessor was warm, friendly but also very clear in her professional role and the purpose of her visit. Her interaction with my son was appropriate and non intrusive". PIP Claimant (PIR611)

"The assessor was very kind and nice though she did tell some lies on the form e.g. she said some parts of the exam would be too painful for me yet wrote on the form that I declined to do the requested exercises". PIP Claimant (PIR1655)

"Honest assessor who actually listen to your issue instead of automated box ticks no one persons case is the same". PIP Claimant (PIR1656)

"The assessor (on both occasions) were rude, abrupt and condescending". PIP Claimant (PIR1654) "The assessor was rude and mocking. A complaint was made but pretty much rejected as they said there was no evidence of what I said". PIP Claimant (PIR1704)

"Assessor seemed opinionated and had no idea about the condition". PIP Claimant (PIR081)

"The assessor should be competent in health issues and have some empathy for the claimants issues with everyday living". PIP Claimant (PIR881)

**Recommendation 8 - Disability Assessor Training** 

Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 11 from the first Review and implements the Recommendation, taking into consideration the following factors:

- a. The Department and Capita should ensure enhanced training and support is provided to DA's on conditions, acknowledged by DA's, as outside their normal experience and expertise.
- b. The Department and Capita should consider training for DA's similar to that provided to Departmental Case Managers and ensure that DA's are aware of regulations and their interpretation.
- c. The Department and Capita should provide more empathy skills training given the nature of the DA's role.
- d. The Department should ensure the annual Training Needs Analysis, completed in conjunction with Capita, reflects feedback from the Independent Panels recommended in Recommendation 9 (The Audit Process) and Recommendation 11 (The Complaints Process).

## **Section 3: The Audit Process**

## Introduction

- 6.3.1 Capita are contracted by the Department to carry out the functional Assessments, complete a report and provide this to the Department so that Case Managers can make a decision on entitlement to benefit.
- 6.3.2 DA's can only be approved, by the Department, to carry out assessments if Capita can demonstrate that each DA meets the following competence standards:
  - » Have appropriate knowledge of the clinical aspects and likely functional effects of a wide range of health conditions and disabilities.
  - Have appropriate skills in assessing people with physical health conditions,
     including history taking, observation and ability to perform a relevant examination.
  - » Have appropriate skills in assessing people with conditions affecting mental, intellectual and cognitive function, including history taking, observation and ability to perform a relevant examination.
  - » Are able to critically evaluate evidence and use logical reasoning to provide accurate evidence based advice
  - » Have excellent interpersonal and written communication skills that include the ability to:
    - Interact sensitively and appropriately, with particular regard for an individual's cultural background and issues specific to disabled people
    - Take a comprehensive, appropriately focused and clear history
    - Accurately record observations and formal clinical findings
    - Produce succinct, accurate reports in plain English, fully justifying conclusions from evidence gathered, and dealing appropriately with apparent conflicts of evidence and fluctuating conditions.

6.3.3 The approval process for new entrants consists of 4 stages:

**Stage 1 – Training** - Each DA must undergo a training programme approved by the Department which includes both practical and theoretical Assessments.

**Stage 2 – Assessment of Competence** - Once Stage 1 is complete, Capita will carry out an Assessment to ensure the DA meets the required competence and knowledge standards which includes, but not limited to, the writing of reports, providing advice and when further evidence should be requested.

**Stage 3 – Supervision** - Once Stage 2 is complete the DA will have provisional approval to carry out supervised Assessments until Capita is satisfied that the DA is continuing to meet the required standards in an operational setting. The number of supervised Assessments is at the discretion of Capita.

**Stage 4 - Approval-related Audit** - Once Stage 3 is complete, the DA will be able to carry out unsupervised Assessments which will be subject to 100% audit.

- 6.3.4 Capita can seek full approval from the Department once the DA has shown an ability to consistently apply the competence standards by achieving consecutive Acceptable (A Grade) audit results in the following:
  - 5 reports produced following a face-to-face consultation; and
  - 5 reports produced following a paper-based review including Terminal Illness (where descriptor advice is provided).
- 6.3.5 The Audit process, carried out by Capita, is explained in Chapter 3 of the PIPAG<sup>61</sup> and states:

"Audit has a central role in ensuring that decisions on benefit entitlement, taken by DWP, are correct. It supports this by confirming that independent HP advice complies with the required standards and that it is clear and medically reasonable. It also provides assurance that any approach to assessment and opinion given is consistent so that, irrespective of where or by whom the assessment is carried out, claimants with conditions that have the same functional effect will ultimately receive the same benefit outcome".

<sup>&</sup>lt;sup>61</sup> https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/831261/PIP-assessment-guide-part-3-health-professional-performance.pdf

- 6.3.6 Auditing of cases is carried out before the report is submitted to the Department's Case Manager. As well as conducting an audit of all reports completed by new entrants, Capita also audit a random selection of reports completed by each DA every month, known as a rolling audit. Targeted auditing is also carried out on cases where an issue has been identified through, for example a complaint, to establish if there is evidence of an ongoing problem. Targeted auditing is carried out at the discretion of Capita or if requested by the Department.
- 6.3.7 The Departmental HAA also carries out an independent audit on a selection of the cases audited by Capita and a random selection of other cases.
- 6.3.8 The outcomes of the audit process feed into the Training Needs Analysis used to capture all aspects of DA performance and can be used to validate whether new initiatives have worked and identify if further support is required.
- 6.3.9 The Review understands that the Department's HAA has put forward a proposal to bring all the auditing functions in-house.

## Findings from the Call for Evidence

- 6.3.10 As well as responses from claimants to the online survey the Review received a number of submissions from and held meetings with individuals, organisations, Healthcare Professionals, PIP staff and Political Representatives.
- 6.3.11 A number of comments have been raised about the audit process and in particular whether it is appropriate for Capita to audit itself.
- 6.3.12 The case summary below, provided by Law Centre NI, is indicative of the comments made to the Review about cases which have gone through the audit process:

Client was in receipt of DLA and HRM and was unsuccessful when reassessed for PIP and appealed. As part of the appeal process it was confirmed that the client's case was subject to audit and the audit documents were contained within the appeal bundle. A review of these documents showed when the PA4 was first written up, client was awarded the enhanced mobility and standard daily living of PIP. When audited, the Auditor suggested a much lower award and advised the original Disability Assessor to make amendments to the MSK, MSE and IOs. This is contrary to PIP Assessment Guidance. There were repeated exchanges between the Auditor and the original Disability Assessor, with the auditor continually encouraging the Disability Assessor to make amendments to the MSK, MSE and IOs and commenting that Disability Assessor should "please consider awarding much lower descriptors." The Disability Assessor did end up making a NIL award, which is now subject to appeal.

#### 6.3.13 Some other comments made about the audit process include the following:

"I feel the process should be to include all evidence not rely on assessment only. Assessors should be audited in another way as auditor was not at assessment to see if report was correct or not in my case a report that had many incorrect statements and assumptions was graded A. The process should be sensitive to difficulties and not set out to disprove everything you say as its very difficult process" PIP Claimant (PIR1025)

"Many documents from oncologists, surgeons, specialists, clinical nurse specialist, document sent by Macmillan, dieticians, still 0 points- the only thing that is relied on is capita assessment by a hcp that is not fully qualified and is still under 'approval related audit" PIP claimant (PIR1126)

"The Council understands that the audit process consists of an independent person going through applications and removing points when they feel they have been inappropriately awarded. This is despite the fact that the auditor has never met the applicant, nor would they have a full understanding of their condition and its impacts on the person. This is entirely unacceptable – no individual should be making judgements on applicants without meeting them and obtaining a full understanding on how their daily activities are affected. Removing points, and potentially removing payments will have a significant detrimental impact on the applicant and their mental well-being, as well as that of their family and friends. Therefore, it is vital that everyone involved in the process understands the needs of the individual and their condition". Fermanagh and Omagh District Council

"The auditing of such Reports, on the vast majority of occasions, results in the customer achieving a lesser score than they otherwise would have done so. It is extremely rare for a customer to attain an additional score as a result of the audit process. The perception of the customer is a lack of trust, confidence and suspicion in a 'system' that operates in such a manner. It is very apparent that, on the advice of the Auditor, the Disability Assessor is effectively re-writing parts of the Report, based on the same evidence/information, but to say something different. Essentially almost a case of playing about with words to give an entirely different meaning/slant. When some Reports are audited the original Disability Assessor

is no longer available to make amendments. Capita are inclined to give the Report to another Disability Assessor to make those changes rather than arrange another 'Assessment'. The second Disability Assessor is then making judgements, expressing an opinion, without having been present and often re-wording what the original Disability Assessor said". Advice North West

"However, it remains difficult to access auditing information. Capita will not directly provide the information. Instead, a claimant must submit a request for the information from the Department who then ask Capita for it. This process is drawnout and cumbersome and may result in some claimants giving up on their efforts to obtain the auditing information. We remain steadfast in our position that the auditing process is made more transparent". Law Centre NI

"Audits should be focussed on assessing the performance of the Capita assessor rather than influencing the factual contents of the Assessment Report. Example: Case 4501676 (extract from appeal submission). "The reliability of the 2019 Consultation Report is further undermined by the fact that significant changes were made to it pursuant to an audit (which included directions such as "please negate tremor reported by customer.") Significant changes (not marked) were made to History of Conditions, Functional History, Mental State Examination and under three Activities, some of which were intended to bolster the justification for not awarding points for anxiety. We enclose a further letter of complaint to PIP in this regard. " Moreover, when an Assessor fails an 'audit' of their report, it is unsatisfactory that a claimant is called multiple times to go through an assessment. We are currently working on two cases where an DA's report was sent audited 3 times and in another case 4 times, corrections were sent back and forth between the Auditor and the Assessor including requests to remove vital evidence. This is unacceptable" (sic). WAVE Trauma

6.3.14 The Review is concerned about the volume of comments received during the Call for Evidence around the audit process. In particular comments relating to auditing changes made to a DA's report which could impact on the decision as to whether a claimant is entitled to benefit or not. The lack of transparency and independence around this process will inevitably lead to a feeling of mistrust by both claimants and advocacy groups. 6.3.15 While training of the DA's was covered in Part 6, Section 2 the Review is of the opinion that the audit process should also identify areas in which the DA needs further or enhanced training. The Review notes the following comments which were made in relation to this:

"Medical and gp reports should be given a more important role in deciding the award. Whoever is undertaking the assessment should have knowledge about your medical or mental disability this includes how to spell it; Disability Action experts should also be involved in decisions experience and advice to both applicants and the assessors" PIP Claimant (PIR1109)

"I feel there needs to be specialist understanding of conditions and not just a blanket health care professional (i.e. nurse) undertake any assessment. I feel that clarity should be sought and no assumptions made without clarity. Mental health and Learning difficulties present themselves differently to a physical disability which is easy to see, I think we judge each individual on an individual basis and not a blanket basis as each person has their challenges which is why they are applying for PIP to begin with". PIP claimant (PIR1319)

"I would urge you ask the Department to reconsider their response to Recommendation 11 (First Review). For the Department to state that it "considers that whether a health professional is a specialist in a given area or not, this should not impact on their ability to carry out a functional assessment" is absurd. We have heard both publicly through media outlets and privately through our offices of claimants experiencing some of the most torturous face-to-face assessments at the mercy of a misunderstanding Capita assessor. I would point you to the experience of that by John in the evidence he provided to the Northern Ireland Affairs Committee; "The assessor was working for Capita and she made me relive everything that happened to me in the past 37 years. Thirty-seven years ago, my son lived for five days and unfortunately, he passed away. It was his anniversary last week. When I was down there, she asked me the questions and I told her that I was in and out of hospital all my life, psychiatric hospitals sometimes. I was working in the Ambulance Service at that time and after my son passed away, roughly two years after, there were things happening in the Ambulance Service that I could not cope with and I had to leave. I resigned. From that, I was in and out of hospitals, psychiatric hospitals, Downshire, and every type of hospital. But the assessor kept on asking the questions and I turned around and said I would like to not answer all the questions but she started saying, 'You are going to have to answer all the questions' because then it would make it easier for me, in order

for her to put it all on the PIP, from DLA on the PIP. But I had to relive everything from the day our son was born to when he died, and I had to go through all the arrangements that I had done. Then I had to walk out of the door after three hours with no support whatsoever. My wife was with me and she had to relive that, after going through the same thing four weeks prior to that" (Northern Ireland Affairs and Work & Pensions, 2019). In John's case, an assessor with a background in mental health would have been logically best placed to determine the effect his mental health conditions have on his daily day-to-day living". Claire Hanna MP

6.3.16 The Review is by no means questioning the qualifications of the DA's and acknowledges the importance of their role. However, there is clear evidence to support the need for the DA's to have training in the conditions they are assessing. The Review is of the opinion that this training could be identified as part of the audit process.

### **Recommendation 9 – The Audit Process**

- a. The Review recommends that the Department bring all auditing functions inhouse as this would go some way to improving trust in the auditing process.
- b. The Review recommends that the Department's Health Assessment Advisor (HAA) uses the audit process and observations to identify the conditions/ disabilities where DA's require enhanced training. This should be regular, updated and kept under review. The Department's HAA should engage with expert organisations and medical professionals to deliver the condition specific awareness/training required.
- c. The Review recommends that the Department appoint an Independent Panel to scrutinise and provide support mechanisms for reviewing the standard of Assessment, quality of reports, outcomes from the audit process and incorporate any learning identified.

# **Section 4: Decision Making**

# Introduction

- 6.4.1 The role of a Departmental Case Manager in PIP is to consider and decide the claimant's entitlement to PIP, the level of award, length of award and the review date. The Case Manager must decide the facts from all of the evidence and apply the law to the facts to make this decision.
- 6.4.2 If a favourable decision is made, the Case Manager must decide the length of the award and a review date. The length of the award can range from 9 months to 10 years or it can be an on-going award with no end date. If a review date is set it is generally set for 12 months before the award end date or where the award is on-going, the review date will be set for 10 years after the date of the Assessment.
- 6.4.3 Where a review date is set the Department will issue a "How your disability affects you" AR1 to the claimant 26 weeks before the PIP award is due to end. The AR1 is a shorter version of the PIP2 and is used by the claimant to advise PIP how they carry out the 12 daily living and mobility activities and if anything has changed since they were awarded PIP.
- 6.4.4 Where no review date is set a letter is issued to the claimant 14 weeks before the award is due to end. This letter is issued as a reminder that the award is due to end and that the claimant can make an advance claim. If the claimant wishes to claim PIP again they must go through the new claims process i.e. complete the PIP1 by telephone and then complete the "How your disability affects you" PIP2 form.

It is worth noting that the Review has been advised that the Department has instigated a change request so that this letter will be issued 26 weeks before the award ends instead of 14 weeks.

6.4.5 Advice on the review date is provided by the DA on the final report. The PIPAG<sup>62</sup> states that the DA's advice should be based on their Assessment of when there is likely to be a significant change in the overall functional effect of a claimant's main disabling condition. The PIPAG provides guidance on when a review date should/should not be set and provides illustrative examples. One example quoted states:

<sup>&</sup>lt;sup>62</sup> https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers/pipassessment-guide-part-1-the-assessment-process#award-review-dates - Section 1.10

"no review required – 'His learning disability has been present since birth and his functional limitations are unlikely to change now. He lives in supported accommodation and there has been no change to his functional ability in the last few years. A review is not likely to be considered necessary".

The Review notes with interest the illustrative example given above and notes that evidence has been provided to the Review where claimants with a learning disability have had review dates set.

6.4.6 The Review acknowledges that evidence from Case Managers indicates that the review date is the only part of the advice given by the DA that they can amend.

## Findings from the Call for Evidence

- 6.4.7 As well as responses from claimants to the online survey the Review received a number of submissions from and held meetings with individuals, organisations, Healthcare Professionals, PIP staff and Political representatives. A number of comments have been raised about decision making, the review process and the provision of the Assessment report.
- 6.4.8 As already mentioned decisions on claims are made by the Department, specifically Case Managers, however, the findings from the Call for Evidence suggest that there is the perception that decisions are made by Capita and too much weight is given to the Assessment report rather than looking at all of the available evidence. Some of the comments made about decision making are as follows:

"I think the copy + paste buttons were used... I really didn't feel that much "reconsidering" happened. Too much emphasis is put on the capita assessment" PIP Claimant (PIR154)

"poor, no verbal explanation, cut and paste decision. decision based on unsound evidence" PIP Claimant (PIR166)

"We invite the Review to recommend that the decision maker makes its own decision on whether Further Evidence changes the decision to award PIP without the need to seek advice from Capita and to consider the apparent conflict of interest". Law Centre NI "There seems to be an abdication of responsibility on the part of the DfC when it comes to making decisions about PIP awards. We highlight in our paper on PIP Process and Appeals that bad decisions routinely go unnoticed at Mandatory Reconsideration (MR) and that rather than scrutinise the original award, DfC more often than not rubberstamp the Capita decision, even in the face of clear evidence for an award or higher award. Some advisers have been told that decisions, new evidence or reconsideration of decisions always have to go back to Capita. And in response to submissions to previous reviews, Advice NI has been told that decisions are based on the assessment reports. If that is the case, then it is Capita who is the decision-maker and not DfC. The general feeling within the advice sector is that Capita makes the decisions and that their decision is final. It is clear therefore that the Department must take steps to provide confidence in the decision making process" Advice NI.

"Whilst NIPSA acknowledges certain advantages of amendments to the current process in respect of claims maintenance and submission via telephone correspondence, we contend that the process of PIP is fundamentally flawed. This relates to the dramatic reduction in the role of the case worker whereby their position is reduced to that of rubber stamping the decision of a Capita assessor as opposed to that of a decision maker, making a decision based on their applicable knowledge. Case workers and Mandatory Reconsideration Officers have further stated that when anomalies exist between customer evidence and the scoring provided by a private sector company, that this often goes unchallenged due to the excessive administration required in challenging the same". NIPSA

- 6.4.9 The Reviewer notes evidence from the Department's Case Managers whereby they feel that their role has diminished when their job title was changed from Decision Maker to Case Manager.
- 6.4.10 Case Managers should be enabled to make decisions based on all of the evidence available and should be empowered to amend descriptor choices if the evidence is there to support this, without having to return cases to Capita for advice.
- 6.4.11 As mentioned at paragraphs 6.4.3 and 6.4.4 there are two different claim processes in place when a review date has/has not been set. Where a review date has been set the claimant is invited to reclaim using the shorter AR1 form. However, where a review date is not set the claimant is required to complete the new claims process.

6.4.12 This was highlighted in relation to cases which were awarded on appeal and no review date was set. There may also be cases awarded by the Department where no review date has been set which also fall into this category.

"Claimants awarded PIP on appeal had to start the review process from scratch; whereas claimants who were awarded PIP by the Department followed a different review process which was more straightforward", East Belfast SOS

- 6.4.13 The Reviewer is of the opinion that claimants should not be penalised or treated differently because a review date has not been set and the process for renewing a claim should be the same for everyone.
- 6.4.14 The Review has heard many concerns about the length of award in cases where the condition is long term, life limiting or degenerative. Short awards are given to these claimants which means they have to go through the whole process again.

"It was stressful and emotional, but successful. However, the award was for a 3 year period, now up, for a permanent condition. Now facing another assessment. I cannot see the point in going through all the stress every three years for a disability condition which will never improve". PIP Claimant (PIR1198)

"Some deaf people will receive an ongoing award (10 years) and others only get a 2 year award. Find it difficult to understand this when deafness is not going to get any better" National Deaf Children's Society

"Chronic diseases – don't seem to take into consideration the fluctuation of conditions and that they will not change – need to complete another claim to renew award" Royal College of Nursing

"We have concerns about the ability of the PIP assessment process to correctly determine if someone living with MND should be on the standard or enhanced rates when someone claims PIP, especially if someone with MND is experiencing the early onset of symptoms. We find the need to better account for progressive conditions comes into focus here, and a lot depends on the individual assessor's knowledge and understanding of MND. Due to the rapidity of disease progression we would hope and expect the majority of claimants with MND are given the enhanced rates. If disease progression is not sufficiently taken into account, this could lead to the need for a reassessment relatively soon after a PIP award and would represent a waste of time and resource for Capita and the DfC". MND Association The following comments were made by people who completed a survey issued by the APGLD:

'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)

6.4.15 The Review acknowledges the Department's response to Recommendation 9 of the first Review which stated:

"In cases were a claimant has a progressive condition, with no prospect of improvement, and are awarded the highest level of PIP support, Case Managers are to consider if it would be appropriate to make an ongoing award. This type of award does not have an end date and will be subject to a light-touch review at the 10 year point. The Department views this as a significant development to ensure those claimants whose conditions have no prospect of improvement are engaged with in as sensitive a manner as possible and unnecessary assessments are avoided".

The Review believes that claimants should not be put through Assessments unnecessarily and therefore ongoing awards should be considered on all cases, regardless of the level of award, where the condition is lifelong, life limiting or degenerative. If the award in place is not at the highest level and the claimant's needs increase or decrease then the claimant can report this change and ask for the decision to be reviewed.

6.4.16 Walter Rader, in the first Review, recommended that the Department should put in place arrangements for a copy of the Assessor's report to be made available to claimants along with their decision letter. This Recommendation was not accepted by the Department, however, the issue has been raised again as part of the Call for Evidence for this Review.

- 6.4.17 This Review acknowledges the Department's response to the Recommendation fro the first Review which states:
  - » Claimants are provided, in their decision letter, with the number of points they scored against each activity and a summary of the reasons that informed our decision on their entitlement to support. We believe that sending this information is the best way to explain to claimants how a decision has been reached.
  - » Claimants can request a more detailed explanation of our decision, and a full copy of their assessment report. Copies of the assessment report, including any previous iterations and audit findings, are provided as standard if a claimant lodges an appeal.
  - » As part of its response to the Work and Pensions Select Committee Report on ESA and PIP Assessments, DWP has already undertaken to improve PIP communications to clearly highlight to everyone that they can request a copy of their assessment report should they wish to. Changes to DWP notifications are normally carried through into Departmental notifications unless there is reason not to follow suit. Therefore it is expected that DfC will also have updated notifications clarifying the availability of the report to claimants. Once we have improved the PIP communications to clearly highlight to all that they can request their report we believe those claimants who want to see their report will do so.
  - » We believe this is the best way to achieve transparency without providing claimants with material that they do not want. To date 75% of PIP claims have not resulted in a disputed decision with 36% of claimants receiving the highest rate of support. The Department does not see the need to issue more paperwork with the decision letter in large numbers of cases where claimants are content with the decision they have received.
  - » The Review itself acknowledged how claimants can be intimidated by the amount of literature they must read when applying for PIP. This would appear contrary to that assertion and the concept of more simplified communications with claimants in general.
- 6.4.18 The Review acknowledges the Department's response to the first Review in relation to the provision of the Assessment report, however, evidence received during the Call for Evidence indicates that the provision of the Assessment report and the lack of transparency around this is still a concern.

"Many claimants are unaware that they may request assessment reports. We have described under Q3 above criticism from many claimants who have seen their reports and who have gone on to request reconsiderations or lodged appeals with success. It is unfortunate that the Department did not accept the recommendation in the Walter Rader Report that assessment reports should be sent out with the decisions; a lot of claimants who do not know they can request these may be unaware of contentious statements or omissions that they would have challenged and which might have prompted them to lodge an appeal". WAVE Trauma

"Perception of a lack of accountability within the assessment process and on decisions made (examples of victims/survivors that were given no points in initial assessment and receiving enhanced rate level points following tribunal). This ties in with the lack of openness and transparency that could have been addressed under Recommendation 14 of the previous review" VSS

6.4.19 The Review has received substantial evidence around inaccurate reports therefore in the interests of fairness and transparency the Review is of the opinion that if the claimant had a copy of the Assessment report at the initial outcome stage it would allow them to make an informed decision about whether or not to dispute the outcome.

#### **Recommendation 10 - Decision Making**

- a. The Department should ensure that Case Managers are empowered to carry out their role as Decision Makers and amend descriptor choices, recommended by Capita, if they have evidence to support this.
- b. The Department should ensure that the process for renewing a claim for PIP is the same for all claimants. The current process means that those without a review end date have to complete the new claims process rather than the shortened AR1 form.
- c. The Department should ensure on-going awards are made on all cases where the claimant's condition is lifelong, life-limiting or degenerative. This should include adopting a subsequent 10 year light touch review on awards made.
- d. Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 14 from the first Review and provides a copy of the DA's report, including audited versions, to claimants along with their decision letter.

# Part 7: Complaints, Statistical Information and Other Considerations

# Section 1: The Complaints process

## Introduction

7.1.1 In September 2018 the Department revised their complaints process and updated their guidance to reflect these changes, however, the Review notes these changes are not reflected on the Departmental Website<sup>63</sup>. The Complaints Process guide states:

"The aim is to provide a seamless complaints service for all our customers. The DfC are committed to providing the highest standard of service to all our customers. Current government policy aims to make public services more responsible to their users. This means setting standards of service and acting quickly and effectively when these standards are not met or when things go wrong".

7.1.2 All complaints received by the Department are registered and used to identify trends and training needs. The complaints process is comprised of four stages which are as follows:

**"Dissatisfaction Stage"** – This provides the business area an opportunity to resolve complaints before proceeding to a formal complaint. The Department aim to respond to complaints at this stage from the outset either by telephone or face-to-face.

**"Stage 1"** - If the complaint cannot be resolved at the dissatisfaction stage then it will move automatically to Stage 1. Stage 1 complaints are signed off by the PIP Business Manager and claimants are signposted to Stage 2 if they remain dissatisfied. The Department aim to respond to Stage 1 complaints within 10 working days.

Complaints from MP's and MLA's are registered as a Stage 1 complaint from the outset.

**"Stage 2"** - If the complaint is not resolved at Stage 1 the claimant can proceed to Stage 2. Stage 2 complaints are signed off by the Assistant Director and claimants are signposted to Stage 3 if they remain dissatisfied. The Department aim to respond to Stage 2 complaints within 10 working days.

<sup>&</sup>lt;sup>63</sup> https://www.communities-ni.gov.uk/dfc-complaints-procedure#skip-link

**"Stage 3"** – If the complaint is not resolved at Stage 2 then the claimant can proceed to Stage 3 – Northern Ireland Public Service Ombudsman (NIPSO) and the Independent Case Examiner (ICE).

**NIPSO**<sup>64</sup> - People can complain to the Ombudsman if they feel that a public service provider has treated them unfairly, or if they have received a poor service and their complaint, to that organisation, has not been resolved to their satisfaction.

NIPSO provides a professional, independent, impartial and free service to the people of Northern Ireland and they provide the following:

(1) provide for the public an independent review of their complaints where they believe that they have sustained an injustice or hardship as a result of the action or inaction of a public service provider (this is known as "maladministration").

(2) aim to ensure that public services improve as a result of the complaints that people bring to them and to their office.

**ICE**<sup>65</sup> - The Independent Case Examiner's Office provides a complaint resolution and investigation service for people who are unhappy with the way their complaint has been dealt with. Examples of complaints they look at include failure to follow proper procedures, excessive delays and poor customer service - this is known as maladministration or service failures.

- 7.1.3 Capita are contracted to carry out the Assessment process on behalf of the Department. Capita do not make decisions on entitlement to PIP.
- 7.1.4 If a claimant is dissatisfied with Capita's service, they can contact Capita directly by phone or in writing<sup>66</sup>. Capita's aim is to respond to complaints within 10 working days.

The Capita complaints process is comprised of three stages and complaints are classed as either "Standard" or "Serious". Regardless of the type of complaint lodged with Capita they both follow a two stage process, however, serious complaints can only be processed by a Senior Case Handler. A complaint is registered as Stage 1 irrespective of whether the complaint is serious or standard.

<sup>64</sup> https://nipso.org.uk/nipso/

<sup>&</sup>lt;sup>65</sup> https://www.gov.uk/government/publications/how-to-take-a-complaint-to-the-independent-case-examiner/how-to-bring-acomplaint-to-the-independent-case-examiner#cases-we-cant-deal-with

<sup>&</sup>lt;sup>66</sup> http://capita-pip.co.uk/ni/complaints.html

#### **Stage 1 – Standard complaint:**

Once a complaint is received it is investigated and responded to by a Case Handler in the Customer Relations Team (CRT). Should the claimant remain dissatisfied with the response, details of the escalation process are included in the letter.

#### **Stage 2** – Standard complaint:

If the claimant remains dissatisfied following the Stage 1 response they can escalate their concerns to a Stage 2 complaint. A Senior Member of CRT will review the Stage 1 investigation to determine whether the original response appropriately addressed all the issues raised by the claimant and take further action where necessary.

#### **Stage 1** - Serious Complaint

A complaint in which there is an allegation of professional malpractice against a DA is classed as a serious complaint. This includes, but is not limited to, allegations of:

- Assault / injury during the course of an Assessment
- Inappropriately intimate examinations
- Abuse relating to any protected characteristic under the Equality Act 2010
- Theft or fraud
- Criminal activity

Serious complaints are managed by a senior member of the CRT who will initiate an investigation meeting to include Clinical Governance, Business Assurance, Human Resources and the Line Manager and Regional Manager of the DA. This meeting will decide the course of action to be taken and will usually include the DA being formally interviewed. Once the investigation is complete, Capita will respond to the claimant within 10 days as per the Service Level Agreement.

#### Stage 2 - Serious Complaint

If the claimant remains dissatisfied following the Stage 1 response they can escalate their concerns to a stage 2 complaint. This will involve the original investigation being reviewed by a different senior member of the CRT.

#### Stage 3 – All complaints

If the claimant remains dissatisfied following the Stage 2 response (standard or serious complaint) they can escalate their concerns to a Stage 3 complaint. Claimants are signposted in the Stage 2 responses to the Director of PIP who will carry out a further investigation of the issues raised.

7.1.5 The Review notes that complaints to Capita are reviewed monthly at the Performance Management Review Board and a sample of Capita complaints are also subject to audit by the Department.

### Findings from the Call for Evidence

- 7.1.6 As well as responses from claimants to the online survey the Review received a number of submissions from and held meetings with individuals, organisations, Healthcare Professionals and Political representatives and a number of concerns still remain around the complaints process.
- 7.1.7 The Review notes that while the majority of concerns raised during the Call for Evidence relate to the Capita complaints process there were some comments about the Department's complaints process and also the role the Department play in monitoring Capita complaints.
- 7.1.8 The Review understands that, while complaints are being investigated, the decision making process ceases. While the Review appreciates the rationale for this, an elongated process means a delay in the claimant receiving benefit and/or compensation which they may be entitled to.
- 7.1.9 Some of the comments received from claimants include the following:

"I was more or less told there was nothing wrong with me. The nurse made several unprofessional comments. I put in a complaint to Capita which wasn't looked at in a (sic) unbiased manner. I had two doctors support my claim for PIP. I had originally been in receipt of lower level for both parts and submitted a request for a review because my mobility had decreased. Now I get nothing despite being able to do very little for myself". PIP Claimant (PIR043)

"The assessment report was fabricated. Lies told, contradictions within the report. Incorrectly reported. I have exhausted all complaints routes, still not satisfied. Now awaiting an Independent case examination. Got to appeal stage and still not satisfied. Due to the fact that I work and work for the Department for Communities with a variety of adjustments to enable me to do that, it has been assumed that I do not qualify. I thought that PIP was to help keep me independent with my disability". PIP Claimant (PIR045)

The assessor was rude and mocking. A complaint was made but pretty much rejected as they said there was no evidence of what I said. The other staff at the assessment centre were also curt and rude. Comments were made about me that they thought I didn't hear. Assessor didn't offer me the choice to refuse the physical part of the assessment, as is my right, had I not known this I would have greatly exasperated my conditions and suffered negative affects (sic) for many days. Assessor had little to no knowledge of my condition and it's affects, or understanding of basic medical terms. Assessor acted as though I was of inferior intelligence and scoffed when I mentioned things like attending university as though my condition means I am stupid and could not have done so. Clear disdain for disabled and discrimination. PIP Claimant (PIR1704)

7.1.10 A number of organisations and Political Parties have also expressed concerns about the complaints process.

"Constituent suffers from manic depression and had attempted suicide prior to applying for PIP. During an at home visit assessment, constituent mentioned the suicide attempts and was asked why they thought they did not go through with it. Further to this assessment and the line of questioning, constituent's mental health deteriorated and they had to seek support. Constituent did not want to make a complaint for fear of being turned down for the PIP payments". Green Party

"Capita need to develop an effective complaints process. We have made many complaints on behalf of claimants (as can be seen from extracts set out in this response). None of our complaints have been accepted. The Capita responses tend to be formulaic and no further action is taken due to lack of evidence and/or the disability assessor having moved on; or the Assessor cannot recall as they deal with so many cases. As a result, complaints to Capita are widely regarded to be a waste of time and resources. Universal audio-visual recording of assessments is required to achieve the necessary public confidence. The complaints process needs an overhaul so that a complaint is registered as such the first time it reaches Capita. Capita should have to inform the Department at this stage. The current set up gives the impression that complaints are being suppressed and leads to a lack of trust. Investigations should be independent. Assessments should be recorded so that there can be no argument as to what was said and make the process more transparent. It would also help in the complaints process. A copy should be available to all claimants. WAVE Trauma

"Responses to complaints are always from Capita—who themselves even acknowledge problems with the complaints process. Responses are almost identical in wording, essentially 'copy-and-paste'. Advisers believe that this onesize-fits-all approach is off-putting and they have no faith in the complaints process. Many do not even bother to help claimants make complaints. Claimants

themselves are reluctant to make complaints because they believe it will have negative repercussions, will be used against them or will impact their assessment outcome. The complaints process can be so lengthy that claimants who do go to the bother of lodging a complaint give up. A complaint halts the assessment procedure until whenever the complaint is resolved. This poses another barrier for the claimant who simply wants to get their award as soon as possible and does not want a complaint holding things up. At Tier 1 of the process, an issue raised is not even flagged as a complaint but it should be. So clearly the concern is that DfC data in relation to complaints is inaccurate and flawed. In some cases, claimants who made complaints received monetary sums in compensation. For example, a deaf claimant who asked to have a speech-to-text machine at his assessment, had four assessments cancelled because the machine was not available; his adviser lodged a complaint and provided comprehensive medical information; finally, a paperbased assessment was carried out and the claimant got £200 in compensation for days taken off work. But in general, this does not happen often and more often than not, both advisers and claimants give up on the complaints process. The fact that so many claimants are deterred from making complaints is a genuine concern because DfC uses complaints statistics as a gauge of the Department's effectiveness. In years gone by, a Minister has been quoted as saying that "this process [assessment process] works as we've only had 9 complaints". Few DfC staff seem to be focused on complaints or on monitoring complaints. It is an important role that needs more robust monitoring by DfC, especially on the performance of Capita. We would be interested in knowing what the monitoring process is in the first place. We would like more clarity on the actual complaints process and more clarity on the pathway i.e. whether the complaint be lodged with DfC or Capita. We would like to see a more robust and effective complaints process. Advice NI

**Recommendation 11 - Improvements to the Complaints Process** 

- a. The Department and Capita should publish more comprehensive guidance on how the complaints process works. More comprehensive guidance will help allay fears and assure claimants that making a complaint does not impact or influence the final decision.
- b. The Department should establish an Independent Panel to monitor and scrutinise complaints and responses from the Department and Capita. This will remove any mistrust around effective complaint handling.

#### Section 2: Improvements to published Statistical Information

#### Introduction

- 7.2.1 Statistical data in relation to PIP is compiled by PSU and published on the Departmental website<sup>67</sup>. The statistics cover the PIP customer journey from registration through to payment.
- 7.2.2 The data provided by PSU includes information on the following:
  - Registered Claims
  - Cleared Claims
  - Clearance Time
  - Awards
  - Claims in Payment
  - Reassessed DLA claims
  - Mandatory Reconsiderations
  - DLA to PIP reassessment outcomes
- 7.2.3 The statistics are produced quarterly and are classified as experimental statistics meaning that they are new official statistics undergoing evaluation. At the time of writing this report the last statistical information published was for the period up to and including 31 May 2020.

#### Findings from the Call for Evidence

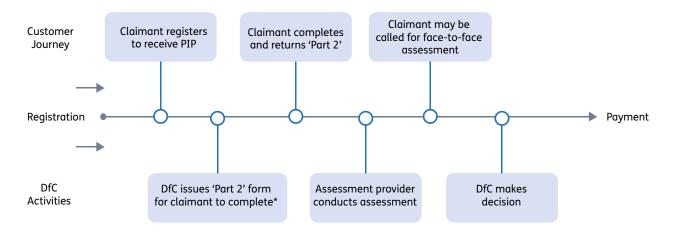
7.2.4 As well as responses from claimants to the online survey the Review received a number of submissions from and held meetings with individuals, organisations, Healthcare Professionals, PIP staff and Political representatives. A number of comments were raised about the statistical data available on the Department's website and these include the following:

"When we asked for statistics the Department stated it does not capture data on when Decision Makers disagree with the Capita advice and escalates matters internally (FOI DFC2018-0268). It is concerning, given the commercial relationship

<sup>&</sup>lt;sup>67</sup> https://www.communities-ni.gov.uk/articles/personal-independence-payment-statistics

between the assessment provider and the Department that no data is recorded to note when Decision Makers disagree with the recommendations of the assessment provider. This would provide reassurance that the Decision Maker was not just rubber stamping the Capita Advice". Law Centre NI

How many customers have been disallowed following a telephony based assessment? Integrated Care Partnership



\* The 'Part 2' form, is referred to in the application process as the 'How your disability affects you' form.

"Marie (Curie) would strongly support the regular publication of much more detailed data on Special Rules PIP claims/awards in Northern Ireland. At present, the main data published by the Department for Communities on SRTI covers the number of new and reassessed Special Rules claims, award outcomes and clearance times.

In England, DWP's Stat-Xplore website provides public access to a significantly larger bank of data, including detailed breakdowns of PIP Special Rules awards by factors including main disabling condition, age and gender. This data, which we believe is crucial to assessing how well the Special Rules process is working for different claimant groups, can only be accessed in Northern Ireland via a direct request to the Department for Communities. We would support the publication of more detailed data of this nature in Northern Ireland". Marie Curie 7.2.5 The Review notes the concerns raised by the Advocacy Groups around the lack of statistical information available in Northern Ireland compared to the information available in Great Britain via Stat-Xplore<sup>68</sup> and would echo these concerns. Availability of more comprehensive statistical information and open data would increase public confidence and generate trust in the system and could potentially lead to less Freedom of Information requests.

Recommendation 12 - Improvements to published statistical information

The Review recommends that the Department provide in-depth statistical data in line with DWP published information to promote confidence and transparency.

<sup>&</sup>lt;sup>68</sup> https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml

#### Section 3: Other considerations

#### Introduction

- 7.3.1 During the Call for Evidence, the Review received evidence from a wide range of individuals, organisations and Healthcare Professionals. Not all of the evidence presented has resulted in a Recommendation.
- 7.3.2 However, the Review notes these concerns and acknowledges the issues mentioned and their impact on the claimant's experience of the PIP process.
- 7.3.3 The Review takes the view that the Department should consider the issues in context and take opportunities, where available, to improve on the claimant experience by way of good practice.

#### **Rural Impact**

- 7.3.4 The Rural Needs Act (Northern Ireland) 2016<sup>69</sup> places a duty on public authorities to have due regard to rural needs when carrying out their activities.
- 7.3.5 Rural proofing is the process by which all major policies and strategies are assessed to determine whether they have a differential impact on rural areas and, where appropriate, adjustments are made to take account of particular rural circumstances. Effective rural proofing ensures that rural communities can receive maximum benefit from government policies.
- 7.3.6 The Review has heard evidence from rural communities about the following areas:
  - Accessibility of Assessment Centres;
  - Access to advocacy; and
  - Lack of reliable broadband.
- 7.3.7 The Review has received evidence from the Rural Resident's Forum (RFF) that some PIP claimants living in remote rural locations do not having access to private transport and their access to public transport is very limited. The RFF acknowledges that the facility for home visits (pre-Covid-19) was beneficial.

<sup>&</sup>lt;sup>69</sup> https://www.legislation.gov.uk/nia/2016/19/contents

- 7.3.8 The Department's Rural Needs Impact Assessment states "no claimant is expected to travel more than 90 minutes (by public transport) in a single journey to attend their consultation. Any claimant who lives outside the 90 minute travel limit by public transport will be offered a home consultation".
- 7.3.9 The Review is of the opinion that a 90 minute journey for people who have physical and mental health problems can be a very stressful and difficult journey to undertake therefore the Review would urge the Department to reassess this policy.

#### Access to Advocacy

- 7.3.10 The Review would encourage the Department to ensure that the services of the MtC Outreach Team are promoted and publicised to claimants living in rural areas. During the Covid-19 lockdown access to the various advocacy support organisations was restricted and as detailed in Paragraph 7.3.37 the Review understands access to free and impartial advice and support is vital in the PIP process.
- 7.3.11 The Review understands that, during this period, a list of Independent Advice Sector organisations was sent out to those receiving DfC and Council food packages. The Review would urge the Department to send out this information leaflet to everyone who makes a claim to PIP to improve awareness of and ensure access to, recommended advocacy services.

#### Lack of reliable broadband

- 7.3.12 Many of the services provided by Government Departments are moving to a digital platform. PIP has recently introduced an email service for claimants to receive and return the PIP2 "How your disability affects you" form.
- 7.3.13 While the Reviewer welcomes these advances in digital technology, they are not accessible to everyone. The Review has received evidence from the RFF indicating that "most areas had little or no broadband coverage and 4G coverage on personal devices (where applicants had access to a smartphone/tablet) was patchy".
- 7.3.14 The Review would urge the Department to ensure that alternative formats of PIP products are available for those claimants in rural areas who may have difficulty accessing information online.

#### **General Data Protection Regulations (GDPR)**

- 7.3.15 The Data Protection Act was revised in 2018 and sets out safeguards for processing personal data. These safeguards relate to how data is collected, what organisations do with it, what information can be shared and the access rights of individuals.
- 7.3.16 The Review understands that when the regulations came into force, the Department took all necessary action to ensure their processes were compliant. The Review understands there have been no issues of non-compliance.
- 7.3.17 The Review has received evidence from a variety of sources on the continuing impact of GDPR particularly around the area of GP notes.
- 7.3.18 Whilst many PIP claimants request GP notes to support their PIP application and/or their Mandatory Reconsideration or appeal, it should be noted that the Department does not actively source GP notes and firmly discourages the request of additional information where there may be a potential cost involved to the claimant.
- 7.3.19 GP notes may be requested by tribunal members at appeal stage however the appeals process is not within the remit of this Review. The Reviewer is of the opinion that the Department should source relevant evidence at the earliest opportunity in the process. She believes that if the Department sourced the correct evidence, from the most appropriate person and ensured that all evidence is fully considered, this would go a considerable way to ensuring that cases do not have to progress to appeal stage.

#### Safeguarding of claimants

7.3.20 The NI Policy on Safeguarding of adults states:<sup>70</sup>

- Adult safeguarding is based on fundamental human rights and on respecting the rights of adults as individuals, treating all adults with dignity and respecting their right to choose. It involves empowering and enabling all adults, including those at risk of harm, to manage their own health and well-being and to keep themselves safe.
- recognising that adults sometimes have complex interpersonal relationships and may be ambivalent, unclear or unrealistic about their personal circumstances and therefore potential risks to their safety or well-being.

<sup>&</sup>lt;sup>70</sup> https://www.health-ni.gov.uk/publications/adult-safeguarding-prevention-and-protection-partnership-key-documents

- 7.3.21 Any organisation who works with or around children and vulnerable adults, should have strict safeguarding policies and procedures in place. It is widely acknowledged that persons with a disability would fall into this category. Therefore it is imperative that the Department is aware of where safeguarding impacts on the PIP Assessment process.
- 7.3.22 The Review acknowledges that the Department has published guidance on safeguarding for their sponsored Arms-Length Bodies<sup>71</sup> on the Departmental website. There is also evidence of measures put in place by the Department to support vulnerable claimants involved in the PIP Assessment process.
- 7.3.23 The Department's MtC team are involved where potential vulnerabilities are identified in helping complete the PIP 2 form. There is also procedural guidance or a 'six point plan' for staff on dealing with callers (face to face or by telephone) who express either self-harm or suicidal intent.
- 7.3.24 Within the Department there is also further procedural guidance in the form of a 'toolkit' which is broader in scope than the six point plan and was specifically developed with UC claimants in mind.
- 7.3.25 The Review has heard evidence that the PIP process has generated some safeguarding concerns and would recommend the Department ensure that guidance is strengthened on this issue with opportunities taken to improve on existing measures.

Answering such invasive questions by a complete stranger about my mental health and suicide attempts made me feel utterly drained and left me in need of extra support. PIP Claimant PIR1707

7.3.26 The Review also encourages the Department to share this information with all staff and ensure that the Assessment Provider has comprehensive safeguarding measures and guidance in place.

<sup>&</sup>lt;sup>71</sup> https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-alb-safe-guarding-policy.pdf

#### **Impact of Covid-19**

- 7.3.27 It would be remiss of the Review not to mention the impact of Covid-19 on the Review and on the PIP processes. The Reviewer thanks the Department for agreeing to the request for an extension, without this the Review would not have been able to gather sufficient evidence to conduct the Review in a meaningful way.
- 7.3.28 When the Assembly announced the Covid-19 restrictions in March 2020 the Review had just begun its Call for Evidence. The Reviewer was planning to meet a number of organisations face-to-face however these organisations were also impacted with many involved in providing ongoing services to the most vulnerable members of our society.
- 7.3.29 As face-to-face meetings were out of the question the Review Team worked on establishing audio and video resources to secure meetings. The Reviewer thanks all of the participants for agreeing to meet via these methods as it allowed the Review to collect very valuable evidence.
- 7.3.30 As the face-to-face Assessments, carried out by Capita, were suspended by the Department and replaced by telephone Assessments the Reviewer was unable to observe Assessments in the centre environment. It was however possible to listen in to a number of telephony Assessments and view the final reports produced following the Assessments.
- 7.3.31 As restrictions are likely to continue for some time it is likely that the use of telephony Assessments will also continue. Having observed a number of Assessments conducted by telephone, the Review reports initial concerns around the following:
  - Telephone Assessments are not recorded. The Reviewer understands that the Department is currently looking at this and would urge the Department to ensure recording of telephony Assessments are introduced as soon as possible
  - MSK examinations cannot be carried out therefore assumptions are being made about a claimant's physical ability. The Reviewer would encourage the Department to ensure that further relevant evidence is pursued to ensure correct decisions are made. She also believes that the introduction of video Assessments could be beneficial for establishing physical abilities. These video Assessments should also be recorded.

The Reviewer has received mixed feedback about the use of telephony Assessments from both claimants and DA's. The Department should examine all feedback received about the use of telephony Assessments with a view to informing the future use of this method of Assessment.

#### Impact of Covid-19 on PIP:

- 7.3.32 In response to the restrictions imposed by the Assembly as a result of Covid-19 the Department acted quickly to ensure that their services continued with minimal impact on claimants.
- 7.3.33 The Review understands that the Department put the following measures in place for PIP claimants:
  - Face-to-face Assessments were suspended and replaced with telephony Assessments;
  - All review action on claims was suspended and benefit payments were automatically extended;
  - 16 year olds who would have been transitioning from DLA to PIP continued to receive DLA payments and review action was suspended;
  - The time for returning the PIP2 was extended to 90 days; and
  - An email facility for receiving and returning the PIP2 was introduced.
- 7.3.34 The Reviewer welcomes these easements however she understands that as restrictions have been relaxed some of the easements introduced have now been removed. They are as follows:
  - Review action has commenced for all working age claimants and for 16 year olds transitioning from DLA to PIP; and
  - The time for returning the PIP2 form has reverted back to the 1 month period although claimants can ask for an extension if they are having difficulties in returning it.
- 7.3.35 The Department has to be commended for their quick response to the pandemic and ensuring that their services continued throughout this period. While it is too early to gauge what learning can be taken from this, the Department should ensure that any learning is used to improve the PIP process for the claimant.

7.3.36 Issues to be considered should include, but not be limited to the following:

- Monitor outcomes from the use of telephony Assessments to ensure consistency of awards;
- Increase audit to ensure consistency of points allocated where no MSK exam completed;
- Ensure no person is disadvantaged where a request for access to advocacy during telephony Assessment is requested;
- Increase the use of Paper Based Reviews and consider more use of further medical/ non-medical evidence (where possible) to avoid recourse to use of telephony Assessments;
- Ensure no person is disallowed where a successful phone call could not be made and/or good cause not established; and
- Extend the use of electronic means of communicating with claimants and their advocacy organisations.

#### Importance of advocacy

- 7.3.37 The Review has received substantial evidence from individuals, community and voluntary sector and Political Parties as to the vital role played by advocacy in ensuring the best outcome for PIP claimants.
- 7.3.38 Many claimants have reported feelings of being overwhelmed and stressed at the prospect of completing the PIP2 and sourcing the right piece of supportive evidence. This has been echoed by the organisations themselves who acknowledge the complexities of navigating the process from claim form to tribunal stage.
- 7.3.39 The Review notes that some form of advocacy has become a must. The new Scottish approach acknowledges the importance of advocacy in the new Assessment process.<sup>72</sup>

<sup>&</sup>lt;sup>22</sup> https://www.gov.scot/publications/consultation-disability-assistance-scotland-scottish-government-response/pages/9/

ADVOCACY SERVICES	
Concern that Advocacy support is not sufficient to assist people with disabilities to engage sufficiently when applying or being assessed for disability benefit eligibility.	People will have a right to independent advocacy, if owing to a disability they require the help of an advocate to engage effectively with the Scottish social security system. We are developing 'advocacy service standards'. We are working closely with advocacy organisations to ensure that those organisations delivering advocacy services are delivering their services in line with these standards.

7.3.40 The Review urges the Department to ensure a partnership approach is taken with regard to the important role undertaken by the advocacy sector. Funding streams should be made available to ensure standards are maintained with regard to access and support for those who would ordinarily struggle with the complexities of the PIP process.

# Part 8: Forward Look and Conclusion

#### Section 1: Forward look and Conclusion

#### Scottish model

- 8.1.1 Much has been made of the Scottish model with regard to Social Security and in particular the announcement made to replace PIP with a new benefit called Adult Disability Payment.
- 8.1.2 Roll-out of the new benefit was expected to begin in April 2021 but this has been delayed due to Covid-19. DWP will continue to deliver disability benefits in Scotland until a new launch date is agreed.
- 8.1.3 The main features of the new benefit<sup>73</sup> are as follows
  - Return of in-house Assessments no outsourcing to private firms
  - Reducing number of face-to-face Assessments carried out
  - Audio recording of Assessment as standard
  - Six month rule removed on terminal illness cases
  - 10 year awards for those with conditions unlikely to change
  - DLA will continue until age 18 for young people
- 8.1.4 Among the main changes listed above there were improvements in relation to facilitating access to advocacy, improved accessibility layers, flexibilities in the Assessment appointment system and an acknowledgement of the vital role of the carer at the Assessment.<sup>74</sup>
- 8.1.5 The new system was built using a co-design approach which followed a public consultation and built on work previously completed with Experience Panels and stakeholder groups of which disabled people themselves were members.

<sup>&</sup>lt;sup>73</sup> https://www.gov.scot/publications/consultation-disability-assistance-scotland-scottish-government-response/pages/4/

<sup>&</sup>lt;sup>74</sup> https://www.gov.scot/publications/consultation-disability-assistance-scotland-scottish-government-response/pages/5/

- 8.1.6 The Scottish approach to Social Security has been held up by many of the advocacy organisations and Political Parties as an example of what can be done on a regional basis with devolved matters.
- 8.1.7 There have been unilateral commendations for the position taken specifically with regard to SRTI with the removal of the contentious six month rule.
- 8.1.8 The Review encourages the Department to consider a similar model to the Scottish model which is a rights based approach in line with the United Nations Committee on the Rights of Persons with Disabilities (UNCRPD) recommendations and observations following their investigation into the UK Welfare Reforms in 2015 and their periodic review and examination of the UK's progress on the implementation of the Convention in 2017.<sup>75</sup>

"Changing the methodology and processes by which disabled people meet the threshold for disability benefits does not automatically translate into the need for additional expenditure, or better outcomes for disabled people. For example savings made from the removal of private sector companies involved in both the PIP and Work Capability Assessments may offset the short term cost associated with introducing new secondary legislation. Primarily considering an alternative to medical based intrusive stressful assessments would likely have the effect of protecting the dignity of disabled people". North West Disability Forum

8.1.9 The Review encourages the Department to monitor the roll-out of the new Adult Disability Benefit and consider incorporating any learning identified from this into consideration of any changes of strategic direction for NI.

#### **Digital reforms**

- 8.1.10 The Review is aware of the proposed reforms to the PIP process currently being examined by DWP and acknowledges that under the parity Health Transformation Project, NI will benefit from the DWP/NI concordat.
- 8.1.11 A significant improvement being developed by this Project is the delivery of a single DWP owned Information Technology (IT) system which will handle PIP, ESA and UC. Work had commenced on procurement but was paused due to Covid-19. It is envisaged this work will recommence soon. It is worth noting that the new IT system will be designed to

<sup>&</sup>lt;sup>75</sup> https://www.gov.uk/government/publications/disabled-peoples-rights-the-uks-2019-report-on-select-recommendations-of-theun-periodic-review

ensure flexibility should the strategic direction move towards returning the Assessment Providers in-house.

- 8.1.12 The single IT system will remove the reliance on the IT provided by the AP and will ensure sharing of mutual information across the three benefits using a common platform in a timely manner. This could address issues identified around access to supportive evidence early in the PIP Assessment process.
- 8.1.13 Other areas of interest for the Review are the move to trial audio-visual Assessments and the Transformation Area in which 10% of DWP caseload is expected to be handled using a new in-house Assessment Provider.
- 8.1.14 Current plans to trial audio-visual recording of Assessments have been impacted by Covid-19, although initial uptake was low. The Review urges the Department to monitor progress in this area. It should be noted that there is some evidence to suggest the use of and familiarity with audio-visual methods of communication have improved as an unintended consequence of the impact of Covid-19.
- 8.1.15 Work will begin later this year on the DWP Transformation Area in two dedicated test sites in England, scaling up to 10% of the caseload by 2022.
- 8.1.16 The Reviewer encourages the Department to discuss using NI as a test site during the scaling up period.
- 8.1.17 The Health Transformation programme in NI is currently working on developing systems to enable recording of the current telephony Assessments and developing a customer satisfaction survey for those who have experienced the telephony Assessments.
- 8.1.18 The Reviewer urges the Department to ensure feedback from this survey is in place at the earliest opportunity. This will enable the AP to incorporate recommendations for improvement into telephony assessment as she is concerned that this was introduced as a contingency measure in response to Covid-19.
- 8.1.19 The Reviewer commends the current use of electronic secure email to send in the PIP2. This was a planned change which has been brought forward as a result of Covid-19. Plans are in progress to develop a Hypertext Markup Language (HTML) version of the form that has the capacity to handle additional evidence, which can also be used via secure email. This, and the planned online claim form capability by 2021 announced by DWP minister Justin Tomlinson, will go some way to improving the current system which is heavily reliant on postal and hand-written forms.

#### Conclusion

- 8.1.20 There is universal acknowledgement that PIP is a challenging and complex system to deliver. There are a number of contact points with a variety of individuals from claimants, staff within the Department, the Assessment Provider, GP's and other Healthcare Professionals, family members, care givers to representatives from advocacy organisations. Combined with further contacts with Tribunal members within the Department for Justice if the case moves to appeal stage, the volume of interaction is huge.
- 8.1.21 These interactions take a variety of forms, telephone, email, correspondence and in person and have a lasting effect on the individual navigating this process.
- 8.1.22 As there are no further statutory obligations on the Department to independently review the PIP process, it is important that all involved in the process create a culture of learning, improvement and review to ensure that PIP fulfils its original policy objectives. Central to this is the need to ensure transparency at all levels, the encouragement of trust in the process by ensuring fair and consistent outcomes. This can be achieved by acknowledging social security as a human right and understanding the rights of the disabled person to 'live full active and independent lives'. <sup>76</sup>

<sup>&</sup>lt;sup>76</sup> https://www.gov.uk/government/consultations/disability-living-allowance-reform

## Annexes

### Annex 1: Progress on Recommendations from First Review

#### First Independent Review of Personal Independence Payment (PIP).

The first Independent Review was published on 28 June 2018. The Department published its response on 20 November 2018. The Department accepted or partially accepted 10 of the 14 Recommendations.

Since then the Department has been working to implement the accepted Recommendations.

Whilst a number of changes have been made the Department remains fully committed to making further improvements to the service for people claiming PIP.

The following table outlines progress below each accepted or partially accepted Recommendation.

#### **Recommendation 1 Awareness of the PIP Process**

That the Department, in conjunction with advice and thematic support organisations, coordinates a series of information and outreach events, across Northern Ireland. The aim of such events would be to assist and support claimants, their family members and support workers to have a clear understanding of the PIP Assessment process and purpose. Such events should aim to clarify the type of relevant information which is required in support of a claim and when it should be submitted.

In response to this Recommendation the Department partnered with Disability Action, to coordinate a series of regional events across NI, with the objective of providing a clear understanding of the PIP Assessment process.

The presentations were co-delivered by the Department and Capita with the Law Centre and Advice NI delivering a short presentation about the help and services they provide. A number of people also took the opportunity at the end of the sessions to discuss their personal case in detail with either the Department's Officials or Capita. The main themes were captured at each event to ensure lessons learned were incorporated into training and awareness for Disability Assessors and PIP Centre staff.

In addition, the Department working with Department for Work and Pensions (DWP) published a series of five videos which provided information on different aspects of the PIP process. To further support and increase awareness on the PIP Assessment process, the Department published two short videos that (i) provide information on the Assessment activities and scoring mechanism and (ii) what to expect at a PIP Assessment. These videos are all available on NI Direct.

#### Recommendation 2 and 4 Terminology used in the PIP process.

That the Department updates the terminology used to describe roles and functions throughout the PIP Assessment process and simplifies and consolidates the terms used in advice and guidance documents. Particular care should be taken to ensure that the terms, words and titles used do not misrepresent the roles undertaken, or the nature of the PIP Assessment process.

The Department should review written material, particularly the initial letter to claimants. The subsequent decision letters to claimants, ensuring clarity of message and the avoidance of jargon. The Department should develop simple straightforward material describing the PIP Assessment process.

To address recommendation 2 and 4, a review of PIP communication products to implement the terminology recommended by the Reviewer, was completed and the products republished. The revised products have been awarded the Crystal Mark by the Plain English Campaign. The PIP information videos also reflected the terminology recommended in the first Review.

In relation to recommendation 4, the Department uses DWP Information Technology systems to administer PIP including issuing forms and notifications. These systems are owned and maintained by DWP with the Department for Communities acting as a stakeholder, providing input from a NI perspective. The Department continues to regularly engage with DWP colleagues in relation to initiatives to review and improve written communication, as outlined by the first Reviewer in Recommendation 4.

#### Recommendation 5 Applying for PIP – accessibility

That the Department ensures there are suitable, accessible options for those with particular needs such as communicating requirements, including those with visual and hearing impairment, as well as those who cannot hand write, to allow them to apply for PIP where telephone and hand written completion of PIP forms is not suitable.

That the Department reviews the training provided to staff ensuring that awareness is raised regarding the options available for claimants who find it challenging or impossible to communicate by telephone.

In the published response the Department confirmed the primary method for making an application to PIP is by telephone. However, the availability of a text phone and the option of a nominated person acting on their behalf is also available. In line with Recommendation 5, a desk aid was issued to staff, as a reminder of the available options. To enhance accessibility to PIP, a new Video Relay Service for British and Irish Sign Language users was introduced on 23 October 2019. The implementation of the service was welcomed by the British Deaf Association (BDA) in NI

The Department continued to work with DWP colleagues to extend the Video Relay Service for inbound telephony services. The service is now available in all benefit areas.

The Department has, from September 2020, introduced a solution to enable claimants to receive a PIP2 application form via secure email. The solution allows people to download, complete and return their PIP2 and supporting evidence via a secure link.

#### **Recommendation 6 Special Rules Terminal Illness (SRTI)**

That the clinical judgment of a medical practitioner, indicating that the claimant has a terminal illness, should be sufficient to allow special rules to apply. The 6 months life expectancy criterion should be removed.

The Department has been fully involved with the Department for Work and Pensions (DWP) review of provision for those with severe conditions and those nearing the end of life. The review commenced in July 2019. The review consists of three main strands of research:

- Hearing directly from claimants and charities about their first-hand experiences.
- Considering international evidence to find out what works in other nations and the support they provide.
- Reviewing current performance to better understand how Special Rules for Terminal Illness and Severe Conditions processes operate and perform.

The Department has ensured that local input was gathered from clinicians, charities and claimants and fed into the evaluation work. This included holding an expert stakeholder event in December 2019, in January 2020 issuing an online survey to clinicians and gathering the views of people who have first-hand experience of the special rules process in June 2020. All stages of the review have now been completed and DWP is expected to report on the outcome shortly.

On 6 October 2020 the NI Assembly agreed to a Motion that called for the removal of the six-month criterion from the special rules provision in social security benefits. A member from every Executive party spoke at that debate in favour of changing the status quo and Minister signalled her commitment to reforming terminal illness provision in social security benefits in NI.

#### **Recommendation 7 Further evidence**

So that relevant up-to-date medical information is available early in the PIP Assessment process, the Department should reach agreement with the relevant professional bodies as to how they may best obtain a GP Short Summary Report to support the PIP2 submission. This should be requested for every claim.

In relation to the recommendation of introducing a GP summary report, work was progressing with Capita and Healthcare Professionals to develop a digital pathway for an electronic GP Short Summary Report to enhance the evidence gathering process. This work had to be temporarily paused because of other priorities in relation to Covid-19. Capita have now recommenced work to develop a proof of concept to test an electronic GP Short Summary Report.

#### Recommendation 8 Receipt of Further Evidence.

The Department 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.

In response to Recommendation 8, the Department subsequently agreed the importance of Capita having evidence, as early as possible, in the process. This improves decision making at key points of the process. The Reviewer had also identified that documents submitted with the PIP2 were being separated on arrival at the Department's Mail Opening Unit and scanned as separate documents.

In September 2018, a revised process was implemented in the Department's Mail Opening Unit to ensure additional evidence is associated with the PIP2. This process was successfully tested with a sample of documents.

#### **Recommendation 9 The Initial Review**

The Department should establish a short term 'Task and Finish' group, involving stakeholder organisations and medical experts, to develop a set of criteria detailing which conditions would be more appropriately addressed through the Paper-Based Review Approach.

This should cover conditions with no prospect of improvement and/or with life-limiting implications. It could also cover those who face challenges representing their condition and functionality in the face-to-face Assessment. It will be vital to set out clearly the relevant information and evidence which would be required to permit an Assessor to complete a Paper-Based Review in these cases.

The Department partially accepted this Recommendation as the Review noted that, some people had been required to attend an Assessment where due to the nature of their own conditions they faced challenges. The Department does not want anyone to undergo a faceto-face Assessment unnecessarily.

To ensure the Assessment process is appropriate to meet individual needs, all applications for PIP undergo an initial review conducted by a Capita Disability Assessor with training to identify people who may be considered vulnerable due to their condition or severe anxiety. A Paper-Based Assessment may be most appropriate or other specific arrangements to support the person during the Assessment process.

To further support the decision as to whether a Paper-Based Review or face to face Assessment is appropriate a decision-making matrix was developed by Capita senior clinicians. This matrix supports Capita Healthcare Professionals, when determining what type of Assessment is most appropriate for each individual.

A comprehensive review was carried out, changes and enhancements were made to the matrix following discussion at the Disability Consultative Forum. The Department continues to monitor the initial review process to ensure its effectiveness and correct application.

#### **Recommendation 10 Appointments and the Assessment Centre**

The Department should urgently address the issues raised by claimants. This includes but is not limited to:

How appointments are scheduled. This should include reasonable adjustments, taking account of claimants' conditions and the practicalities of attending appointments.

Cancelling or rescheduling appointments. Ensure changes or cancellations are minimal and, if they occur, that claimants are informed as soon as possible and by an appropriate communication method

The Assessment room – layout of the room should consider both the space required for claimants with mobility aids and the presence of their accompanying person.

A number of changes have been implemented to enhance the person's experience in relation to scheduling/cancelling and rescheduling appointments. Capita have improved their internal procedures, along with producing scripts and desk aids for their staff. The service is designed to provide transparency in relation to appointment scheduling and assist with any reasonable adjustments an individual may require.

Following collaboration with stakeholders and the Department, Capita's appointment letters were revised to provide a clearer message in relation to the opportunity to reschedule appointments. The letters were made clearer, with a more straightforward layout and including the provision of key information about the Assessment process such as:

- What happens when an individual's case is passed from the Department to Capita
- What to do before an appointment
- What to expect during an appointment
- How to change an appointment date and time
- How to contact Capita

Work has also concluded on the layout of the Assessment rooms to ensure there is adequate space for people with mobility aids.

#### **Recommendation 12 Audio-visual Recording**

The Department should introduce audio-visual recording of Assessments in both home and Assessment centre locations.

To address recommendation 12, the facility to record all clinic-based PIP Assessments was introduced 18 November 2019, the availability of the service is included on appointment letters. Training of Disability Assessors and other implementation activities had been completed to expand the service for home-based Assessments from Spring 2020. However, deployment of the service has been 'put on hold' due to Covid-19 restrictions, which means all Assessments are now carried out by Paper Based Review or by telephone Assessment. Given that face to face Assessments remain suspended, the Department is currently working on introducing a solution that allows for recording of telephone Assessments.

#### **Recommendation 13 Assessor's Report**

The Department, in conjunction with the Assessment provider Capita, should remove or revise the use of the informal observations to support Assessor's reports. If revised, Assessors should be required to justify the conclusions which they have drawn from their observations.

The Department and Capita should remove all questions about suicide and self-harm from the Assessment. If they deem this information essential, they should source it in an alternative manner.

In the published response the Department confirmed the continued use of informal observations as part of the PIP Assessment process as set out in the PIP Assessment guide but did acknowledge that it is critical these informal observations are factual and not opinion based. The Department's staff have been advised to challenge any observations contained in reports if they deem them unjustified to ensure correct application.

The Department accepted that questions regarding suicide and self-harm should not be asked unless raised by the person at the Assessment or included on the PIP2 questionnaire. Capita completed a review of their processes which resulted in updated guidance to Disability Assessors to ensure that suicide and self-harm are only addressed where it is relevant and that this is done in a sensitive and professional manner. Capita updated and reissued training and guidance to all staff. Capita also produced a desk aid and updated guidance for Assessors to prevent any inappropriate discussions on suicide and self-harm.

### Annex 2: Independent Scrutiny Group Membership

#### **Independent Scrutiny Group**

- **Margaret Kelly (Chair)** Director of Mencap in Northern Ireland since September 2015. She has over 25 years' experience in the voluntary and community sector, working primarily with families and children's charities. Margaret has previously held leading roles in Barnardo's NI and The Fostering Network. She has worked with the NI Assembly and a range of government departments on the development and improvement of policy and practice for families. Margaret has extensive experience in commissioning, managing and publishing research, as well as ensuring that an evidence base underpins both policy and practice. Margaret resigned from her role in the Scrutiny Group on 8 July 2020 to take up her new position as the Northern Ireland Public Services Ombudsman. She was replaced as chair of the Scrutiny Group by Mary Anne Webb.
- Mary Anne Webb (Chair) Mary Anne Webb has 25 years' policy and practice experience in the voluntary and community sector, and is currently Co-Director and Head of Policy and Influencing with Mencap NI. Since June 2017 she has managed the organisation's policy, research and campaigns activities, and takes a leading role in demonstrating service impact. Previous roles include Senior Policy and Research Officer with Barnardo's NI, and Policy Officer with the NI Commissioner for Children and Young People (NICCY). All these positions have involved working with the NI Assembly, government departments and in coalition with a range of organisations to improve policy and services for children, young people and families. They also entailed leading the development of evidence-informed influencing and practice, including commissioning, managing and undertaking research projects and service evaluations. In addition to learning disability, Mary Anne's key areas of experience include early intervention, adverse childhood experiences, youth unemployment, child poverty / welfare reform, safeguarding and child sexual exploitation.
  - Walter Rader OBE DL MA Dip YCS Walter has over 45 years' experience of working in a range of Public Sector and Voluntary & Community organisations. In several career appointments, he has been the first appointee and therefore has gained considerable experience in establishing organisational culture, structure, systems and processes. He has wide ranging experience of working with communities across Northern Ireland, in the development of grant programmes, application assessment, monitoring expenditure, risk assessment, compliance and evaluation. He has had experience of several significant 'management of change' initiatives in both Northern Ireland and across GB. In this context partnerships and collaborations have been the hallmark of Walter's approach. Walter

'retired early' in the autumn of 2010 and now undertakes a number of other roles. He was made OBE in 2010 for Service to the Community in Northern Ireland and appointed Deputy Lieutenant of the County Borough of Belfast in 2019. He was the first Independent Reviewer of the PIP Assessment Process in 2018.

Siobhan Rooney MSc. RN RM Dip HV Dip HSM - Siobhan has trained as a General Nurse, Midwife and Specialist Public Health Community Nurse and has held several senior positions at Health and Social Care Trusts and Department of Health in Northern Ireland (NI). Siobhan has also held several Board Chair and Non-Executive Director positions in the Statutory and Voluntary Sector. Siobhan recently completed 9 years as a Non-Executive Director on the Southern HSC Trust Board in Northern Ireland where she chaired the Board Performance, Endowments and Gifts and Trust Organ Donation Committees. Siobhan also worked with the former Commission for Healthcare Improvement (CHI) and participated in health care reviews in England and Wales. She is currently an elected Trustee on the Motor Neurone Disease Association National Board, Honorary Officer and Chair of the MNDA Care Committee, MNDA NI Branch member, MNDA Association Visitor and member of the Northern Ireland Neurological Charities Alliance. Siobhan has an extensive knowledge of corporate and clinical and social care governance, risk management, patient safety, performance management and accountability systems within both the health and social care and voluntary sector organisations.

Majella McAteer - Majella started with the BDA NI in 1997 as a Community Advocacy Officer and since that time has been promoted into a variety of roles, resulting in her most recent position in June 2015 of Community Development Manager for Northern Ireland. Throughout her time in BDA NI, Majella has led, managed and delivered a wide range of projects and programmes involving a diverse range of funding sources and stakeholders. Majella has worked with politicians, Assembly Members and various other government departments while simultaneously advocating and encouraging the Deaf community to speak out for what they feel is necessary to achieve equality. Majella is heavily involved in government and other consultations and was the lead manager on the Sign Language Framework consultation, the Regional Review of Communication Support Services (Department of Health & Social Services) and Children and Young People's Strategy 2017-2027 (Northern Ireland Executive and Department of Education).

## Annex 3: Assessment Criteria and Points

### Assessment Criteria for PIP

ΑCTIVITY	DESCRIPTOR	POINTS
DAILY LIVING		
1. Preparing food.	a. Can prepare and cook a simple meal unaided.	0
	b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal.	2
	<ul> <li>c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave.</li> </ul>	2
	d. Needs prompting to be able to either prepare or cook a simple meal.	2
	e. Needs supervision or assistance to either prepare or cook a simple meal.	4
	f. Cannot prepare and cook food	8
2. Taking nutrition.	a. Can take nutrition unaided.	0
	<ul> <li>b. Needs -</li> <li>(i) to use an aid or appliance to be able to take nutrition, or</li> <li>(ii) supervision to be able to take nutrition, or</li> <li>(iii) assistance to be able to cut up food.</li> </ul>	2
	c. Needs a therapeutic source to be able to take nutrition.	2
	d. Needs prompting to be able to take nutrition.	4
	e. Needs assistance to be able to manage a therapeutic source to take nutrition.	6

ΑCTIVITY	DESCRIPTOR	POINTS
	f. Cannot convey food and drink to their mouth and needs another person to do so.	10
3. Managing therapy or monitoring a health condition.	<ul> <li>a. Either -</li> <li>(i) does not receive medication or therapy or need to monitor a health condition, or</li> <li>(ii) can manage medication or therapy or monitor a health condition unaided.</li> </ul>	0
	<ul> <li>b. Needs any one or more of the following-</li> <li>(i) to use an aid or appliance to be able to manage medication,</li> <li>(ii) supervision, prompting or assistance to be able to manage medication.</li> <li>(iii) supervision, prompting or assistance to be able to monitor a health condition.</li> </ul>	1
	c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week.	2
	d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week.	4
	e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week.	6
	f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week.	8
4. Washing and bathing.	a. Can wash and bathe unaided.	0
	b. Needs to use an aid or appliance to be able to wash or bathe.	2

ΑCTIVITY	DESCRIPTOR	POINTS
	c. Needs supervision or prompting to be able to wash or bathe.	2
	d. Needs assistance to be able to wash either their hair or body below the waist.	2
	e. Needs assistance to be able to get in or out of a bath or shower.	3
	f. Needs assistance to be able to wash their body between the shoulders and waist.	4
	g. Cannot wash and bathe at all and needs another person to wash their entire body.	8
5. Managing toilet needs or incontinence.	a. Can manage toilet needs or incontinence unaided.	0
	b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence.	2
	c. Needs supervision or prompting to be able to manage toilet needs.	2
	d. Needs assistance to be able to manage toilet needs.	4
	e. Needs assistance to be able to manage incontinence of either bladder or bowel.	6
	f. Needs assistance to be able to manage incontinence of both bladder and bowel.	8
6. Dressing and undressing.	a. Can dress and undress unaided.	0
	b. Needs to use an aid or appliance to be able to dress or undress.	2

ΑCTIVITY	DESCRIPTOR	POINTS
	<ul> <li>c. Needs either -</li> <li>(i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed, or</li> <li>(ii) prompting or assistance to be able to select appropriate clothing.</li> </ul>	2
	d. Needs assistance to be able to dress or undress their lower body.	2
	e. Needs assistance to be able to dress or undress their upper body.	4
	f. Cannot dress or undress at all.	8
7. Communicating verbally.	a. Can express and understand verbal information unaided.	0
	b. Needs to use an aid or appliance to be able to speak or hear.	2
	c. Needs communication support to be able to express or understand complex verbal information.	4
	d. Needs communication support to be able to express or understand basic verbal information.	8
	e. Cannot express or understand verbal information at all even with communication support.	12
8. Reading and understanding signs, symbols and words.	a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses.	0
	b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information.	2

ΑCTIVITY	DESCRIPTOR	POINTS
	c. Needs prompting to be able to read or understand complex written information.	2
	d. Needs prompting to be able to read or understand basic written information.	4
	e. Cannot read or understand signs, symbols or words at all.	8
9. Engaging with other people face to face.	a. Can engage with other people unaided.	0
	b. Needs prompting to be able to engage with other people.	2
	c. Needs social support to be able to engage with other people.	4
	<ul> <li>d. Cannot engage with other people due to such engagement causing either –</li> <li>(i) overwhelming psychological distress to the claimant, or</li> <li>(ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person.</li> </ul>	8
10. Making budgeting decisions.	a. Can manage complex budgeting decisions unaided.	0
	b. Needs prompting or assistance to be able to make complex budgeting decisions.	2
	c. Needs prompting or assistance to be able to make simple budgeting decisions.	4
	d. Cannot make any budgeting decisions at all.	6

ΑCTIVITY	DESCRIPTOR	POINTS
MOBILITY		
1. Planning and following journeys.	a. Can plan and follow the route of a journey unaided.	0
	<ul> <li>Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant.</li> </ul>	4
	c. Cannot plan the route of a journey.	8
	d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid.	10
	e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant.	10
	f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid.	12
2. Moving around.	a. Can stand and then move more than 200 metres, either aided or unaided.	0
	b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided.	4
	c. Can stand and then move unaided more than 20 metres but no more than 50 metres.	8
	d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres.	10
	e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided.	12
	<ul> <li>f. Cannot, either aided or unaided, -</li> <li>(i) stand, or</li> <li>(ii) move more than 1 metre.</li> </ul>	12

### Annex 4: Recommendations from Second Review

#### **Recommendation 1: Communications and Accessibility**

To improve accessibility for those claiming PIP, the Department, in consultation with stakeholders should explore and develop alternative methods of communication and improve existing communication products and information. The Review recommends the following:

- An easy read version of guidance material and claim form (PIP1 and PIP2);
- Signed guidance material;
- Promoting/publicising the clerical claim form where online access is not available
- The Department should promote the services of and publish the contact details for the Make the Call (MtC) Outreach Team on all PIP literature. This will broaden the service provided by the MtC Outreach Team to assist with the completion of the PIP1 and the PIP2. The Department should utilise this service to make contact with all claimants who make the initial PIP1 claim but do not return the PIP2;
- Staff should be reminded that when a representative, relative or Social Worker contact PIP on behalf of a claimant they should take this as implicit consent; and
- Information on changes to PIP, in particular legislative changes, should be published in an easily accessible central location.

#### **Recommendation 2: Claiming PIP**

- a. The Department should establish a "Task and Finish" group, involving stakeholders and Medical Professionals, to look at the PIP2 and AR1 forms. This group should consider, but not be limited to the following points:
  - Compliance with the legislation in particular PIP Regulation 7 (the majority test), Regulation 4 (the reliability tests), Regulation 2 and Schedule 1 (the need for aids and appliances);
  - Style and format of questions asked; and
  - Guidance to assist completion of the PIP form, ensuring the functional test descriptors and activities are fully explained.
- b. The Department should raise awareness about the availability of the two week extension which can be requested for returning the PIP2/AR1 form.

#### **Recommendation 3: Special Rules Terminally Ill (SRTI)**

Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 6 from the first Review that the 6 months life expectancy criterion for terminally ill claimants should be removed and replaced with a system based on clinical judgement similar to that enacted by the Social Security (Scotland) Act 2018. This should include adopting a subsequent 10 year light touch review on awards made where special rules apply.

#### **Recommendation 4: Assessment Type**

- a. The Department should consider the use of new methods of Assessment, embracing the full range of technology available and this should include use of telephony or audiovisual method where available. This should include a range of options from which the claimant can choose in order to best suit their needs.
- b. In the interests of transparency, the Review recommends that the Department's position should be that all Assessments are audio-recorded with the claimant given the option to opt-out.

#### **Recommendation 5: Assessment Process**

To support claimants and Healthcare Professionals to navigate the Assessment process, and to improve the provision of information available and transparency of the process, the Review recommends that the Department take the following steps.

- a. To support Health Care Professionals and individuals in understanding the information used in the Assessment process, the Department should make available the Condition Insight Reports, detailing the information contained and explaining how this information is used in formulating advice to the Department. These should be published on the Capita website in line with current accessibility requirements.
- b. The Department, in conjunction with Capita, should consider the use of more targeted open questions throughout the Assessment process to ensure a full picture of needs is established as early in the claim as possible and avoid cases passing to appeal stage unnecessarily.
- c. The Department should ensure that evidence provided by the carer/parent/appointee during the Assessment process is fully considered and used to inform the advice provided following the Assessment.
- d. The Department should ensure that evidence is sought from the person who knows the claimant best (medical/non-medical) and all evidence obtained should be weighted, considered and recorded on the assessment report and Department records.

#### **Recommendation 6 – In-House Assessment Providers**

The Department should consider the outcome of the DWP pilot to bring Assessments for both Work Capability Assessment (WCA) and PIP Assessment in-house. The Review recommends that the Department conduct a similar pilot in NI.

#### **Recommendation 7 - Further Evidence**

- a. The Department should produce guidance/examples for claimants, advocacy services and Healthcare Professionals of appropriate evidence to support the PIP process and where this evidence should be obtained.
- b. The Department, in conjunction with Capita and relevant Healthcare Professionals, should examine and implement new ways to improve the current poor return rate of GP factual reports.
- c. Proper consideration and recording of evidence when making decisions is essential. All evidence needs to be carefully considered, in relation to the particular circumstances of the individual case, to ensure the correct decision is reached. The Department should ensure the evidence is fully documented and that further evidence, medical or otherwise, has been correctly weighted and documented.

#### **Recommendation 8 - Disability Assessor (DA) Training**

Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 11 from the first Review and implements the Recommendation, taking into consideration the following factors:

- a. The Department and Capita should ensure enhanced training and support is provided to DA's on conditions, acknowledged by DA's, as outside their normal experience and expertise.
- b. The Department and Capita should consider training for DA's similar to that provided to Departmental Case Managers and ensure that DA's are aware of regulations and their interpretation.
- c. The Department and Capita should provide more empathy skills training given the nature of the DA's role.
- d. The Department should ensure the annual Training Needs Analysis, completed in conjunction with Capita, reflects feedback from the Independent Panels recommended in Recommendation 9 (The Audit Process) and Recommendation 11 (The Complaints Process).

#### **Recommendation 9 – The Audit Process**

- a. The Review recommends that the Department bring all auditing functions in-house as this would go some way to improving trust in the auditing process.
- b. The Review recommends that the Department's Health Assessment Advisor (HAA) uses the audit process and observations to identify the conditions/disabilities where DA's require enhanced training. This should be regular, updated and kept under review. The Department's HAA should engage with expert organisations and medical professionals to deliver the condition specific awareness/training required.
- c. The Review recommends that the Department appoint an Independent Panel to scrutinise and provide support mechanisms for reviewing the standard of Assessment, quality of reports, outcomes from the audit process and incorporate any learning identified.

#### **Recommendation 10 - Decision Making**

- a. The Department should ensure that Case Managers are empowered to carry out their role as Decision Makers and amend descriptor choices, recommended by Capita, if they have evidence to support this.
- b. The Department should ensure that the process for renewing a claim for PIP is the same for all claimants. The current process means that those without a review end date have to complete the new claims process rather than the shortened AR1 form.
- c. The Department should ensure on-going awards are made on all cases where the claimant's condition is lifelong, life-limiting or degenerative. This should include adopting a subsequent 10 year light touch review on awards made.
- d. Given the substantial supporting evidence gathered during the second Review, the Review recommends the Department revisits Recommendation 14 from the first Review and provides a copy of the DA's report, including audited versions, to claimants along with their decision letter.

#### **Recommendation 11 - Improvements to the Complaints Proces**

- a. The Department and Capita should publish more comprehensive guidance on how the complaints process works. More comprehensive guidance will help allay fears and assure claimants that making a complaint does not impact or influence the final decision.
- b. The Department should establish an Independent Panel to monitor and scrutinise complaints and responses from the Department and Capita. This will remove any mistrust around effective complaint handling.

#### Recommendation 12 - Improvements to published statistical information

The Review recommends that the Department provide in-depth statistical data in line with DWP published information to promote confidence and transparency.

### Annex 5: Notes associated with Statistical Information

#### Part 1, Section 2 - Background to PIP - Statistical Data Table 1: PIP Claims in Payment as of 31 May 2020 Notes:

- 1. The status of claims as 'Normal Rules' or 'SRTI' (Special Rules for the Terminally III) is shown as at the point of registration.
- 2. Some claims may not be marked SRTI at the point of registration but become a SRTI claim at the point of clearance, and vice versa. This could lead to figures showing more SRTI clearances than registrations.
- 3. The status of claims as 'New Claim' or 'Reassessment' is shown at the point of registration. Some claims may not be marked as reassessment at the point of registration but are identified as such at the point of clearance, and vice versa. This could lead to differences between registration and clearance figures for reassessed claims.
- 4. Reassessment of DLA to PIP for Working Age Claimants was completed in November 2019. Subsequent reassessments are for DLA Claimants who have turned 16.
- 5. Reassessment claims registered during the temporary suspension period implemented by DfC in response to Covid-19 were not progressed during that period and these claimants continued to receive DLA.

# Table 2: PIP claims in payment by level of award as of 31 May 2020 Notes:

- 1. Percentages are rounded to the nearest 1% and some may not sum to totals.
- 2. When a claim is first registered, it is assumed to be a new claim unless there is evidence to suggest that it is a reassessment. If evidence is presented between registration and clearance, the claim will then show as a reassessment clearance and will move from being a new claim registration to being a reassessment registration. Therefore this data is subject to retrospective revision.
- 3. Reassessment of DLA to PIP for Working Age Claimants was completed in November 2019. Subsequent reassessments are for DLA Claimants who have turned 16.

#### Table 3: PIP claims registered vs PIP claims cleared as of 31 May 2020 Notes:

- 1. The status of claims as 'Normal Rules' or 'SRTI' (Special Rules for the Terminally Ill) is shown as at the point of registration.
- 2. Some claims may not be marked SRTI at the point of registration but become a SRTI claim at the point of clearance, and vice versa. This could lead to figures showing more SRTI clearances than registrations.
- 3. When a claim is first registered, it is assumed to be a new claim unless there is evidence to suggest that it is a reassessment.
- 4. The status of claims as 'New Claim' or 'Reassessment' is shown at the point of registration. Some claims may not be marked as reassessment at the point of registration but are identified as such at the point of clearance, and vice versa. This could lead to differences between registration and clearance figures for reassessed claims.
- 5. If evidence is presented between registration and clearance, the claim will then show as a reassessment clearance and will move from being a new claim registration to being a reassessment registration. Therefore this data is subject to retrospective revision.

- 6. Reassessment of DLA to PIP for Working Age Claimants was completed in November 2019. Subsequent reassessments are for DLA Claimants who have turned 16.
- 7. Reassessment claims registered during the temporary suspension period implemented by DfC in response to Covid-19 were not progressed during that period and these claimants continued to receive DLA.

#### Table 4: PIP Clearance Periods as of 31 May 2020 Notes:

- 1. The status of claims as 'Normal Rules' or 'SRTI' (Special Rules for the Terminally Ill) is shown as at the point of registration.
- 2. Some claims may not be marked SRTI at the point of registration but become a SRTI claim at the point of clearance, and vice versa. This could lead to figures showing more SRTI clearances than registrations.
- 3. When a claim is first registered, it is assumed to be a new claim unless there is evidence to suggest that it is a reassessment.
- 4. If evidence is presented between registration and clearance, the claim will then show as a reassessment clearance and will move from being a new claim registration to being a reassessment registration. Therefore this data is subject to retrospective revision.
- 5. Reassessment of DLA to PIP for Working Age Claimants was completed in November 2019. Subsequent reassessments are for DLA Claimants who have turned 16.

#### Table 5: Average (median) Clearance Periods as of 31 May 2020 Notes:

- 1. Not all claims will be sent to the assessment provider therefore totals in Table 4a will differ from those in Table 4b.
- 2. The status of claims as 'Normal Rules' or 'SRTI' (Special Rules for the Terminally Ill) is shown as at the point of registration.
- 3. Some claims may not be marked SRTI at the point of registration but become a SRTI claim at the point of clearance, and vice versa. This could lead to figures showing more SRTIs at clearance than at registration.
- 4. Reassessment of DLA to PIP for Working Age Claimants was completed in November 2019. Subsequent reassessments are for DLA Claimants who have turned 16.

#### Part 2, Section 2 - PIP Reassessment Outcomes - Statistical Data Table 1: Claims cleared and outcomes as at November 2019 for SRTI and non-SRTI Notes:

- 1. Awards statistics are based on the initial decision and do not include awards given as a result of mandatory reconsiderations or appeals.
- 2. The status of claims as 'Normal Rules' or 'SRTI' (Special Rules for the Terminally Ill) is shown as at the point of registration.
- 3. Some claims may not be marked SRTI at the point of registration but become a SRTI claim at the point of clearance, and vice versa. This could lead to figures showing more SRTI clearances than registrations.
- 4. Award rate is calculated as the number of claims awarded as a percentage of total claims excluding withdrawn claims based on unrounded figures.

# Table 2: Claims cleared and outcomes as at November 2019 for new claims and reassessment claims

#### Notes:

- 1. Awards statistics above are based on the initial decision and do not include awards given as a result of mandatory reconsiderations or appeals.
- 2. When a claim is first registered, it is assumed to be a new claim unless there is evidence to suggest that it is a reassessment.
- 3. If evidence is presented between registration and clearance, the claim will then show as a reassessment clearance and will move from being a new claim registration to being a reassessment registration. Therefore this data is subject to retrospective revision.
- 4. Award rate is calculated as the number of claims awarded as a percentage of total claims excluding withdrawn claims based on unrounded figures.

#### **Table 3: Reassessment Outcomes**

#### Notes:

## + Figures include a small number of disallowed cases that are listed as 'reason unknown'.

- 1. PIP reassessment outcome shows the outcome based on the initial decision and does not include awards given as a result of mandatory reconsiderations or appeals.
- 2. For each individual who has a PIP reassessment outcome their PIP entitlement has been compared to their DLA entitlement at the time of their PIP reassessment registration.
- 3. 'Award Increased' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is higher than the total monetary value of the DLA award (Care component plus Mobility component).
- 4. 'Award Unchanged' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is the same as the total monetary value of the DLA award (Care component plus Mobility component).

- 5. 'Award Decreased' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is less than the total monetary value of the DLA award (Care component plus Mobility component).
- 6. 'Disallowed post-referral to the assessment providers (AP)' includes claims that have been disallowed following the assessment due to the claimant not scoring enough points at the assessment to be awarded the benefit, or the claimant failing to attend the assessment without good reason.
- 7. 'Disallowed pre-referral to the assessment providers (AP)' includes claims that have been disallowed due to failure of basic eligibility criteria or non-return of the Part 2 form within the time limit and have not been marked as requiring additional support.
- 8. 'Withdrawn' includes all claims that have been withdrawn by the claimant prior to a decision being made. This can take place at any point in the claimant journey following registration of a claim.
- 9. Figures include reassessment outcomes for individuals who were aged between 16 and 64 on 20th June 2016, and include both PIP Normal Rules and Special Rules for the Terminally III claims.
- 10. Figures have been rounded to the nearest 10 and percentages have been rounded to the nearest 1%.
- 11. Totals and percentages may not sum due to rounding.

# Table 4: Comparison of DLA and PIP entitlement by award type Notes:

### + Figure includes a small number of disallowed cases that are listed as 'reason unknown'.

- 1. PIP reassessment outcome shows the outcome based on the initial decision and does not include awards given as a result of mandatory reconsiderations or appeals.
- 2. DLA entitlement shows the DLA award for each individual at the time of their PIP reassessment registration.
- 3. Figures include reassessment outcomes for individuals who were aged between 16 and 64 on 20th June 2016, and include both PIP Normal Rules and Special Rules for the Terminally Ill claims.
- 4. Figures have been rounded to the nearest 10 and percentages have been rounded to the nearest 1%.
- 5. '-' indicates fewer than 5 claims in this category.
- 6. Components may not sum to totals due to rounding.
- 7. There are a small number of claims who are reassessed cases who have been transferred from GB which PSU do not have their original DLA award.

### Table 6: Percentage breakdown of DLA working Age recipients by component and rate of claim (June 2016) Notes

- 1. Working Age Recipients (16-64).
- 2. Figures have been rounded to the nearest 10 and percentages have been rounded to the nearest 1%.
- 3. Totals and percentages may not sum due to rounding.

#### Table 7: Percentage breakdown of PIP recipients by level of award (November 2019) Notes

- 1. Figures have been rounded to the nearest 10 and percentages have been rounded to the nearest 1%.
- 2. Totals and percentages may not sum due to rounding.
- 3. This includes both New claims and Reassessed DLA claims.
- 4. Claims in payment do include those who have been awarded PIP after a mandatory reconsideration or appeal.

## Table 8: PIP reassessment outcomes by Main disability Notes:

- 1. PIP reassessment outcome shows the outcome based on the initial decision and does not include awards given as a result of mandatory reconsiderations or appeals.
- 2. For each individual who has a PIP reassessment outcome their PIP entitlement has been compared to their DLA entitlement at the time of their PIP reassessment registration.
- 3. 'Award Increased' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is higher than the total monetary value of the DLA award (Care component plus Mobility component).
- 4. 'Award Unchanged' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is the same as the total monetary value of the DLA award (Care component plus Mobility component).
- 5. 'Award Decreased' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is less than the total monetary value of the DLA award (Care component plus Mobility component).

- 6. Figures include reassessment outcomes for individuals who were aged between 16 and 64 on 20th June 2016, and include both PIP Normal Rules and Special Rules for the Terminally Ill claims.
- 7. Figures have been rounded to the nearest 10 and percentages have been rounded to the nearest 1%.
- 8. Main disabling condition in this table is the disability recorded on the DLA administrative system for each individual. This is used because disability information is recorded on the PIP computer systems only for the group of cases who have a PIP assessment report.
- 9. Claimants may often have multiple disabling conditions upon which their entitlement decision is based but only the primary condition is shown in these statistics. It is possible that a reassessment claim could have a different main disabling condition recorded on the DLA and PIP systems.

#### **Table 9: Outcome by Gender**

Notes:

## + Note figure includes a small number of disallowed cases that are listed as 'reason unknown'.

- 1. PIP reassessment outcome shows the outcome based on the initial decision and does not include awards given as a result of mandatory reconsiderations or appeals.
- 2. For each individual who has a PIP reassessment outcome their PIP entitlement has been compared to their DLA entitlement at the time of their PIP reassessment registration.
- 3. 'Award Increased' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is higher than the total monetary value of the DLA award (Care component plus Mobility component).
- 4. 'Award Unchanged' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is the same as the total monetary value of the DLA award (Care component plus Mobility component).

- 5. 'Award Decreased' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is less than the total monetary value of the DLA award (Care component plus Mobility component).
- 6. 'Disallowed post-referral to the assessment providers (AP)' includes claims that have been disallowed following the assessment due to the claimant not scoring enough points at the assessment to be awarded the benefit, or the claimant failing to attend the assessment without good reason.
- 7. 'Disallowed pre-referral to the assessment providers (AP)' includes claims that have been disallowed due to failure of basic eligibility criteria or non-return of the Part 2 form within the time limit and have not been marked as requiring additional support.
- 8. 'Withdrawn' includes all claims that have been withdrawn by the claimant prior to a decision being made. This can take place at any point in the claimant journey following registration of a claim.
- 9. Figures include reassessment outcomes for individuals who were aged between 16 and 64 on 20th June 2016, and include both PIP Normal Rules and Special Rules for the Terminally Ill claims.
- 10. Figures have been rounded to the nearest 10 and percentages have been rounded to the nearest 1%. Totals and percentages may not sum due to rounding.

### Table 10: Outcome by age band Notes:

## + Note that this includes a small number of disallowed cases that are listed as 'reason unknown'.

- 1. PIP reassessment outcome shows the outcome based on the initial decision and does not include awards given as a result of mandatory reconsiderations or appeals.
- 2. For each individual who has a PIP reassessment outcome their PIP entitlement has been compared to their DLA entitlement at the time of their PIP reassessment registration.
- 3. 'Award Increased' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is higher than the total monetary value of the DLA award (Care component plus Mobility component).
- 4. 'Award Unchanged' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is the same as the total monetary value of the DLA award (Care component plus Mobility component).
- 5. 'Award Decreased' means the Department have made a decision to award PIP and the total monetary value of the PIP award (Daily Living plus Mobility component) is less than the total monetary value of the DLA award (Care component plus Mobility component).
- 6. 'Disallowed post-referral to the assessment providers (AP)' includes claims that have been disallowed following the assessment due to the claimant not scoring enough points at the assessment to be awarded the benefit, or the claimant failing to attend the assessment without good reason.
- 7. 'Disallowed pre-referral to the assessment providers (AP)' includes claims that have been disallowed due to failure of basic eligibility criteria or non-return of the Part 2 form within the time limit and have not been marked as requiring additional support.
- 8. 'Withdrawn' includes all claims that have been withdrawn by the claimant prior to a decision being made. This can take place at any point in the claimant journey following registration of a claim.

- 9. Figures include reassessment outcomes for individuals who were aged between 16 and 64 on 20th June 2016, and include both PIP Normal Rules and Special Rules for the Terminally Ill claims.
- 10. Figures have been rounded to the nearest 10 and percentages have been rounded to the nearest 1%. Totals and percentages may not sum due to rounding.
- 11. Age band shows the age of each individual at their PIP registration date.

### Table 11: Mandatory Reconsideration Outcomes

#### Notes:

- 1. Each PIP claim can have more than one reconsideration registered against it. The counts shown represent all registered reconsiderations.
- 2. Figures may change when compared to previous published statistical releases. This is due to some mandatory reconsiderations being entered late into the PIP Computer System and developments in the structure and format of the measures.
- 3. The Department commenced an administrative exercise on 28th June 2018 to review all current PIP claims to check if customers are eligible for more support as a result of two Upper Tier Tribunal judgements in Great Britain. As a result these figures include such reviews and are likely to elevate the mandatory reconsideration figures.
- 4. When a claim is first registered, it is assumed to be a new claim unless there is evidence to suggest that it is a reassessment.
- 5. If evidence is presented between registration and clearance, the claim will then show as a reassessment clearance and will move from being a new claim registration to being a reassessment registration. Therefore this data is subject to retrospective revision.
- 6. Figures exclude mandatory reconsideration of claims made under 'Special Rules for the Terminally Ill'.

### Annex 6: Record of meetings

MEETING	DATE
Disability Consultative Forum	11 March 2020
Law Centre NI, WAVE trauma, Compass Advocacy Network, Newry Mourne and Down Advice, Marie Curie, Ulster University, Women's Resource and Development Association, National Deaf Children's Society	27 March 2020
Capita	31 March 2020
Royal College of Occupational Therapists (RCOT)	08 April 2020
Health Assessment Advisor (DfC)	24 April 2020
Kellie Armstrong (Alliance Party)	04 June 2020
Mencap/All Party Group on Learning Disability	05 June 2020
East Belfast SOS	09 June 2020
British Deaf Association BSL (BDA)	18 June 2020
British Deaf Association ISL (BDA)	19 June 2020
Advice NI	23 June 2020
Royal College of Nursing (RCN)	02 July 2020
Rural Community Network	03 July 2020
Integrated Care Partnerships	23 July 2020
Relatives for Justice	23 July 2020
Ligoneil Advice Village/Citywide	30 July 2020
PIP Claimant	03 August 2020
Mark H Durkan (SDLP)	11 August 2020
Fostering Network	12 August 2020
Mervyn Storey (DUP)	14 August 2020
Andy Allen (UUP)	19 August 2020

MEETING	DATE
Rachel Woods (Green Party)	26 August 2020
Dr Mary Donnelly	07 September 2020
British Medical Association	16 September 2020
DfC Communities Committee	16 September 2020
Southern Health Social Care Trust	17 September 2020
Victims and Survivors Service	17 September 2020
NIPSO	18 September 2020
Handsthattalk	21 September 2020
Marie Curie	21 September 2020
Fostering Network - Step Up/Step Down team	22 September 2020
Sinn Fein	25 September 2020
Royal College of GP's NI	29 September 2020
DfC - PIP Telephony staff	30 September 2020
PIP Claimant	02 October 2020
DfC Health Transformation Project/Commercial Services	02 October 2020
Sensory Social Work team Western Health Social Care Trust	05 October 2020
Rural Community Network	05 October 2020
PIP Case Managers	06 October 2020
PIP Disputes Staff	06 October 2020
President of Tribunals Service	07 October 2020
Cystic Fibrosis Team Belfast Trust	08 October 2020
Law Centre NI	09 October 2020
MS Society	09 October 2020
DfC Quality Assurance Manager Team - PIP Centre	12 October 2020

MEETING	DATE
Epilepsy Action	15 October 2020
DfC Health Assessment Advisor	16 October 2020
Compass Advocacy Network	19 October 2020
DWP Health Transformation Project	20 October 2020
DfC Make the Call Outreach Team	26 October 2020
Disability Strategy Advisory Panel	30 October 2020
Families involved NI	30 October 2020
North West Disability Forum	3 November 2020
Northern Ireland Audit Office	12 November 2020
NIPSO	27 November 2020

### Annex 7: Record of Submissions

AREA	SOURCE
Advice Sector and Support Groups	Law Centre NI Marie Curie Commission for Victims and Survivors Via Wings Autism NI Neighbourhood Development Association Camphill Community Glencraig Victims and Survivors Service Advice NI South East Fermanagh Foundation - Victims and Survivors North West Advice Justin Greenwood Community Advice Ards and North Down Motor Neurone Disease Association Women's Support Network Policy Choice Housing Rural Community Network STEP
Healthcare Professional Organisations	WAVE trauma Royal College of Psychiatrists Royal College of Occupational Therapists British Medical Association
Political Representatives	Paul Frew MLA Sinn Fein Claire Hanna MP Green Party

AREA	SOURCE
Local Council/Trade Union	Fermanagh and Omagh District Council NIPSA
Individuals	12 PIP Claimants

Available in alternative formats.

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