Personal Independence Payment

An Independent Review of the Assessment Process

Northern Ireland

Walter Rader June 2018

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Foreword

By Walter Rader Independent Reviewer of the PIP Assessment Process NI



I want to begin by expressing my very sincere thanks to the over 330 claimants, family members, support workers and organisations that invested their time, knowledge and expertise in submitting thought provoking insights on the Personal Independence Payment (PIP) assessment process. I am grateful to the many respondents who set out their personal stories which provide graphic examples of their experiences. I greatly value the insights which the submissions provided.

I have benefited from the 'critical friend' function provided by the members of the Independent Scrutiny Group and I thank them for their support and input. I wish to convey my thanks to the hard working members of my excellent support team.

It was they who responded to my requests for urgent action, smoothing almost impossible diary schedules and responding to my on-going questions. Their professional approach and endless good humour have been appreciated.

I remain responsible for the views and recommendations which make up this Review Report.

The Review makes no claim that every view expressed can be substantiated. The views expressed by respondents were drawn from personal experiences of the PIP assessment process and are the reality for those individuals and organisations. Throughout this Report I use quotes from respondents to illustrate issues and develop recommendations. Therefore, it is those views that need to be acknowledged and addressed. Without such matters being understood, and addressed, there will be little progress in the development of an efficient, effective and credible PIP assessment process.

Having received such a significant number of submissions, upon which I could draw, was both helpful and frustrating. Helpful in that the submissions covered a very wide range of issues which I have used to form my views and recommendations. Frustrating in that, through the chapters of this Report, I will only be able to set out comments and quotes from a proportion of respondents. I want to assure all who responded that their submissions were read, analysed and contributed to the progress of this Review. I have listed the respondents at Annex 1.

Respondents' submissions and the dialogue resulting from meetings across Northern Ireland (NI) highlight matters of concern similar to those identified by Paul Gray in the first Great Britain (GB) Review, published in December 2014. In the Northern Ireland context this similarity of findings reinforces, for me as Reviewer, that there are matters which must be addressed in PIP processes. In accepting the Department for Communities' invitation to undertake this independent review, I was very much aware that the implementation of PIP across NI was still in its early days.

As I met with claimants and those who support them, I have been very aware that different people who have the same underlying, diagnosed conditions may very well experience significantly different functional impacts on their daily living and mobility. I have formed the view that a rigid one-size-fits-all process cannot respond to the circumstances of all claimants. The assessment process must, of necessity, be flexible. The reality for claimants is that their normality is living daily with their conditions and the resultant impact on functionality.

I have some experience of managing change and the implementation of PIP across NI is, by any standards, a significant and challenging management of change process. PIP is predicated on the assessment of functional impact on daily living, rather than on medically diagnosed conditions experienced by the claimant. Much remains to be done in order to communicate with claimants, their family and support organisations about PIP processes.

Respondents to the Call for Evidence have provided examples of positive practice and this was encouraging. I have referred to these matters in the latter part of the Report.

I valued the opportunity to meet with the President of the Appeals Tribunal and I welcomed his insights and views. There was agreement that it is not for this Review to comment on the workings of the Tribunal.

In presenting this Independent Review Report, which will be placed in the Assembly, I cannot set out a clear process by which the contents, including the recommendations, will be considered. I would urge the Department for Communities to set out a timescale within which such a response will be forthcoming.

Executive Summary

Overview of Findings

The Review welcomes the wide-ranging submissions received and the personal insights given. It was positive to hear of some constructive practices which are already in place. However, the current PIP assessment process is viewed with distrust and suspicion. It is a fragmented process that impacts negatively on both claimants and those who seek to support them. In particular the face-to-face assessment causes fear, anxiety, stress and frustration. This in turn has a knockon impact on the health and well-being of claimants, their family and wider support networks, placing even more demands on already stretched services.

Relevant and up-to-date evidence of claimants' medically diagnosed conditions must be taken into account from the start of the process. It is those conditions, and the associated medication, which impacts on the claimants' functionality in their daily living environment. Such relevant medical information could be obtained from GPs in a more focused way than at present.

Clarity is required regarding what constitutes relevant information, where it can be obtained and at what point in the process it should be submitted. Further attention should be given to, and value placed upon, gaining information on claimants' functionality from those who see and support them on a regular basis.

The evidence submitted to the Review from across Northern Ireland has similarities with the matters identified in Paul Gray's First Review in GB (2014) and in the recent Select Committee Report. Therefore, the issues raised are not solely experienced in Northern Ireland.

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

Outline of the Report

This Review Report comprises 13 Chapters and a number of Annexes. Chapter 1 provides an introduction to the Review detailing the Terms of Reference, the methodology used, and outlines the scope of the Review. The Review focuses on the PIP assessment process from the initial point of contact with the claimant through to the final outcome decision.

In Chapter 2 the report outlines the reform of DLA, the background to PIP including the policy intent, how PIP was designed and the consultations held on PIP and the assessment criteria.

Chapter 3 details the rollout of PIP in GB and subsequent rollout in NI, including information on the NI-specific mitigation measures, which support people in Northern Ireland to reduce the impact of welfare reform. The measures affect persons who were previously in receipt of DLA and who are financially worse off following their assessment for PIP. The mitigations were introduced as Welfare Supplementary Payments. The Chapter also sets out information regarding legislative changes relevant to PIP in NI.

Chapter 4 provides a breakdown of available statistical data in relation to PIP in Northern Ireland. This includes information on the volumes of PIP claims and how these claims are made up. Chapter 5 sets out the arrangements for the publication of the Call for Evidence, a breakdown of the methodology used to gather information to inform the Review, including, design of the questionnaire, meetings held, and analysis of submissions and responses received.

In Chapter 6 the Review makes observations on disability and the management of change. Consideration is then given to areas which result in confusion within the PIP assessment process. In order to frame the subsequent chapters Chapter 7 identifies seven stages of the PIP assessment process which will be further examined.

Chapter 8 considers how to apply for PIP, the application of special rules for those with terminal illness and the completion of the PIP2 form. The Review then comments on further evidence and the Initial Review by Capita. This, and subsequent chapters, feature quotes taken from responses received during the Call for Evidence.

The face-to-face assessment is discussed in Chapter 9 including how assessments are scheduled and the challenges claimants face in attending. The chapter then considers the role of the assessor and comments on the accuracy of reports and the use of informal observations by assessors. The chapter concludes with an analysis of questions regarding self harm and suicide, in addition to making comment on the effectiveness of the assessment.

Chapter 10 considers how PIP decisions are made by the Department and how they are communicated to claimants. Chapter 11 examines disputed decisions, Mandatory Reconsiderations and Appeals.

Chapter 12 considers the support and training provided to claimants and support organisations as part of the introduction of PIP. Comment is made on the current support available and reference is made to instances of good practice and positive engagement which the Review seeks to encourage. Chapter 13 looks ahead following publication of this report.

Summary of Review Recommendations

The 14 recommendations made by the Review are summarised below. They are also included at Annex 2.

Recommendation 1:

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.

Recommendation 2:

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.

Recommendation 3:

The use of DLA evidence to support reassessment cases should cease.

Recommendation 4:

(A) The Department should review written material, particularly

(i) the initial letters to claimants

(ii) the subsequent decision letters to claimants, ensuring clarity of message and the avoidance of jargon

(B) The Department should develop simple straightforward material describing the PIP assessment process.

Recommendation 5:

- (A) That the Department ensures there are suitable, accessible options for those with particular needs such as communication 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.
- (B) 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.

Recommendation 6:

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.

Recommendation 7:

So that the 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 to obtain a GP Short Summary Report to support the PIP2 submission. This should be requested for every claim.

Recommendation 8:

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.

Recommendation 9:

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.

Recommendation 10:

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

Recommendation 11:

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.

Recommendation 12:

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

Recommendation 13:

- (A) The Department, in conjunction with the assessment provider Capita, should remove or revise the use of informal observations to support assessor's reports. If revised, assessors should be required to justify the conclusions which they have drawn from their observations.
- (B) 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.

Recommendation 14:

The Department should put in place arrangements for a copy of the assessor's report to be made available to claimants along with the decision letter.

Chapter 1: Introduction

Background to the Review

- The Welfare Reform (Northern Ireland (NI)) Order 2015 and subsequent regulations¹ legislated for the introduction of Personal Independence Payment (PIP) to replace Disability Living Allowance (DLA) for eligible people who first claim when they are between the ages of 16 and 64.
- 2. The statute provides the basis for two Independent Reviews of the PIP assessment process. Article 94 of the 2015 Order states that:

The Department must lay before the Assembly an independent report on the operation of assessments under Article 85

- (a) within 2 years beginning with the date on which the first regulations under that Article come into operation
- (b) within 4 years beginning with that date.
- 3. This is the first Independent Review of the PIP assessment process. It aims to provide a robust examination of the operation of the PIP assessment process and makes recommendations for improvement and change.

Terms of Reference for the Review

4. In December 2017 the Department for Communities (hereafter referred to as "the Department") commissioned Walter Rader to undertake the first Independent Review of the PIP assessment process. The Terms of Reference for the Review are:

To provide the Department for Communities with an independent report evaluating:

- The operation of the PIP assessments since its introduction including issues that the Department has been made aware of since implementation
- PIP claimants' experiences of taking part in the assessment
- Perceptions of healthcare professionals and other staff involved in carrying out the assessment
- How effectively further evidence is being used to assist the correct claim decision, exploring the balance between how much, and the type of, evidence sourced and what the claimant is asked to provide

¹ Welfare Reform (NI) Order 2015, Part 5, Personal Independence Payment http://www.legislation.gov.uk/nisi/2015/2006/contents

Independent Scrutiny Group

5. The Department also appointed an Independent Scrutiny Group to provide constructive challenge and support to the Reviewer. Details of the scrutiny group, including Terms of Reference are set out at Annex 3.

Methodology

- 6. The Review used a variety of sources and methodologies to gain insight into the PIP assessment process including:
 - Conducting a public Call for Evidence which ran from 15 January to 16 March 2018 and received over 330 responses from claimants, their families and individuals involved in supporting people through the process
 - Meetings with, and submissions from, representative organisations, charities and support groups
 - Observing a number of face-to-face assessments at Capita assessment centres across Northern Ireland
 - 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 Reconsideration and Appeals
 - Analysis of official statistics
 - Meetings with elected representatives
 - Meetings with professional bodies representing doctors and health care professionals

Scope of the Review

- 7. The Review focuses on the PIP assessment process from the initial point of contact with the claimant, through to the final outcome decision. This includes any Departmental Mandatory Reconsideration or the implementation, by the Department, of a decision made by the Tribunal.
- 8. A number of areas have been excluded from the scope of the Review including:
 - The policy underpinning the introduction of PIP
 - The descriptors used to assess entitlement to PIP
 - The operation of the PIP Tribunal
 - Commercial arrangements
- 9. Having set out in this chapter the background to the Review, Chapter 2 will make reference to the context in which PIP was introduced.

Chapter 2: Background to Personal Independence Payment

Context in which PIP was introduced

- 10. The June 2010 Budget stated that the most urgent task facing the country was to implement an accelerated plan to reduce the budget deficit². Part of the announced spending reductions was £11 billion of welfare reform savings³. 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.
- In December 2010 the then United Kingdom (UK) Government set out, in a consultation on Disability Living Allowance Reform⁴, its intention to replace DLA with a new benefit called PIP. The response to the consultation states:

"DLA was introduced in 1992 and is no longer in step with the needs of the 21st Century welfare system. It lacks consistency in the way it supports disabled people with similar needs, and there is no straightforward way of reviewing people's entitlement to DLA on a regular basis, to ensure that they receive the right level of benefit. We know that people's conditions can change over time, but 70 per cent of DLA awards are indefinite, with no clear guidance to the individual on how they can report any changes in their circumstances to us."⁵

- 12. In NI, as of November 2015, around 152,000 (73%) of the total 208,000 DLA caseload had indefinite awards with no mandatory checks in place or other arrangements which ensured regular contact with the Department. This is comparable with GB figures⁶ published in March 2011.
- 13. In November 2009 DLA spend in NI was £13.8 million per week rising to £19.0 million per week by November 2015, a 37.7% rise in six years. This expenditure was seen as unsustainable in the longer term. Of the 208,000 DLA recipients in NI, at November 2015, approximately 125,000 were aged 16-64 and spend on this working-age group was over £11.1 million per week.

² BUDGET 2010, (HC 61), HM Treasury, June 2010, p.1. http://webarchive.nationalarchives.gov.uk/20130129110402/http://cdn. hm-treasury.gov.uk/junebudget_complete.pdf

³ BUDGET 2010, (HC 61), HM Treasury, June 2010, p.2.

⁴ Disability Living Allowance Reform Consultation, December 2010

<sup>www.gov.uk/government/uploads/system/uploads/attachment_data/file/181633/dla-reform-consultation.pdf
Disability Living Allowance Reform Response, p.3</sup>

www.gov.uk/government/uploads/system/uploads/attachment_data/file/181637/dla-reform-response.pdf

⁶ assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/223063/analysis_of_disability_living_ allowance_DLA_awards.pdf

Policy Intent

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

"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"⁷

15. The response further indicated:

"Our aim, through the introduction of Personal Independence Payment, is to make the benefit fairer, more straightforward to administer, and for it to be easier and clearer to understand."⁸

16. The Government considered that reform of DLA was needed to ensure that financial support was targeted on those with the greatest need and to make the benefit affordable in the longer term. To achieve this, a more objective assessment, with regular reviews, would be introduced for all PIP claimants to ensure that those on the benefit continued to receive the right level of support, and only for as long as they need it.

Design of the Benefit

- 17. PIP is designed to maintain the key principles of DLA in that it helps toward some of the extra costs that result from a long-term condition. It is neither means tested nor subject to tax, and it is payable to those in and out of work. PIP however, focuses on how a person's condition impacts on their daily-living functionality, not on the condition itself. PIP is made up of two components; a daily living component and a mobility component. Each component has a standard or an enhanced rate of payment.
- 18. Eligibility for PIP is determined by satisfying some initial basic criteria. This is followed by a functional assessment of need against a set of key components deemed fundamental to everyday life. These fall into two groups, the first of which features 10 daily living activities, and the second focuses on two mobility activities. Each of the components has a number of descriptors indicating a level of functional impact, with respect to an individual claimant, and an associated score in points format.

⁷ Disability Living Allowance Reform Response, p.1

⁸ Disability Living Allowance Reform Response, p.4

19. The points given for each component are totalled, with 8-11 points resulting in a standard rate award and 12 points or above resulting in an enhanced rate award. Enhanced rate of the mobility component is one of the eligibility criteria for the Motability Scheme⁹.

Consultations on PIP and the Assessment Criteria

- 20. In 2011/12 the Department for Work and Pensions (DWP) consulted on the implications of the wider reforms (including PIP) as part of the Welfare Reform Bill consultation process, including a public consultation on the equality impact assessment. There have been five formal consultations and one informal consultation on the introduction of PIP in Great Britain and Northern Ireland. Initial proposals for the reform of DLA, including the high-level principles of the PIP assessment criteria, were first consulted on between December 2010 and February 2011.
- 21. The assessment criteria focus on an individual's ability to carry out some key daily activities such as making a meal or planning a journey. The criteria were developed in collaboration with a group of independent specialists. The criteria were subject to lengthy testing and consultation by DWP between December 2010 and October 2013.
- 22. A first draft of the detailed proposals, for the assessment criteria and regulations, was published in May 2011 and was subject to informal consultation until August 2011. A second draft of the assessment criteria was published in November 2011 and a formal consultation on the criteria followed from January to April 2012. A formal consultation on the detailed rules underpinning PIP ran from April to June 2012. Consultation on the *moving around* activity took place between June and August 2013. Between December 2015 and January 2016 views were sought on the use of aids and appliances in the PIP assessment.
- 23. In total over 80 responses to the formal consultations were received in NI, including almost 20 from individuals. These responses were shared with DWP and considered alongside those they received in GB. The official Westminster government response to the first consultation was published on 4 April 2011. The responses to the assessment criteria and detailed design consultations were published on 13 December 2012. The formal government response to the consultation on the *moving around* activity was published on 21 October 2013, with the response to the consultation on the use of aids and appliances being published on 11 March 2016. A full list of, and links to, each consultation can be found on the Government Welfare Policy 2010-2015 webpage¹⁰.

⁹ Motability - www.motability.co.uk

¹⁰ www.gov.uk/government/publications/2010-to-2015-government-policy-welfare-reform/2010-to-2015-government-policy-welfare-reform

- 24. During the consultation period the then Department for Social Development NI held a number of events with the NI Customer Representative Group Forum (comprising over 60 groups) regarding PIP. This forum first met in November 2011 as part of the Department's commitment to engage with relevant stakeholder groups around welfare reform issues. As a result of the UK-wide consultations and engagement, with disabled people and the organisations that represent them, a number of changes were made to the assessment criteria and provisions, resulting in the final version as included in the PIP regulations.
- 25. The final version of the criteria, as part of the PIP regulations¹¹, was approved by Parliament ahead of the go live of PIP in GB in 2013. The criteria were approved for PIP in NI as part of the NI PIP regulations¹² laid in 2016.

Context of PIP in Northern Ireland

- 26. The introduction of PIP in NI came at a time when the number of people claiming DLA across the UK was over 3.3m¹³. The DLA caseload in NI as at November 2015 was 208,000, with approximately 125,000 in the working age category and consequently subject to reassessment for PIP. In NI the number of people claiming DLA represents one in nine of the population, relative to one in 20 in GB¹⁴. Rollout began in GB during April 2013 however, due to legislative delays PIP was introduced in NI on 20 June 2016.
- 27. An application for PIP regularly involves family members, carers and health care professionals, amongst others. Given that a higher proportion of the NI population is affected by the move to PIP than in GB, the effect of its introduction could be expected to impact on a significant portion of the NI population.
- 28. The rollout of PIP represented a significant change for all involved. For many of those in receipt of DLA, which was introduced in 1992, they had become both accustomed to DLA and reliant upon the payments received.
- 29. The changes brought about through the welfare reform process were for many a shock and were seen as the rules they had lived within for some time being significantly altered.

¹¹ The Social Security (PIP) Regulations 2013 www.legislation.gov.uk/ukdsi/2013/9780111532072/contents

¹² The PIP Regulations (NI) 2016 www.legislation.gov.uk/nisr/2016/217/contents/made

¹³ Disability Living Allowance Reform Response, p.14

¹⁴ PIP Regulations (NI) 2016 Explanatory Memorandum www.legislation.gov.uk/nisr/2016/217/memorandum/contents

- 30. It is commonly acknowledged that NI has a higher instance of mental health conditions, per head of the population, than GB¹⁵. Consequently it could be expected that the introduction of PIP would also have a greater impact on the NI population.
- 31. It is within this context that the Review examines the PIP assessment process in more detail and makes its recommendations.
- 32. In the following chapter the Review considers the implementation of PIP across GB and in NI. Reference is also made to legislative changes since the go live date and the implications of the recent High Court Ruling are considered. The NI arrangements for Supplementary Payments are explained.

¹⁵ Department of Health, Social Services and Public Safety (2014). Making Life Better: A whole system strategic framework for public health 2013-2023

Chapter 3: Implementation of Personal Independence Payment

Rollout of PIP in Great Britain

- 33. In GB the first PIP new claims were taken in April 2013, in limited geographical areas, in what was called a controlled start.
- 34. Government decided that full PIP rollout in GB would start during July 2015, with a small number of trial cases to allow DWP to test and learn before wider rollout.
- 35. The most recently publicised DWP statistics, which relate to GB, on the reassessments, indicate that 947,000 DLA claimants had undergone the reassessment process¹⁶. The breakdown of the outcomes of these reassessments is set out in Table 1 below.

Table 1: GB Reassessment Outcomes

Reassessment Outcome	Number	Percentage
Award Increased	373,400	39%
Award Unchanged	124,300	13%
Award Decreased or Disallowed	443,000	47%
of which		
Award Decreased	211,000	22%
Award Disallowed	231,900	24%
of which		
Disallowed post referral to the assessment provider	196,000	21%
Disallowed pre referral to the assessment provider	36,000	4%
Withdrawn	6,300	1%
Total	947,000	100%

¹⁶ DLA to PIP Reassessment Statistics www.gov.uk/government/statistics/personal-independence-payment-april-2013-tooctober-2017

Rollout of PIP in Northern Ireland

- 36. The rollout of PIP in NI was subject to legislative delays and followed a distinctive legislative path. *The Northern Ireland (Welfare Reform) Act 2015* provided a power for Her Majesty to legislate on certain matters including social security in NI by Order in Council. Any such Order in Council then confers power on the Secretary of State, or an NI department to make further provision regarding these matters by regulations or order.
- 37. The Welfare Reform (Northern Ireland) Order 2015 was made on 9 December 2015 and subsequently The Personal Independence Payment Regulations (Northern Ireland) 2016 were made in May 2016 coming into effect from 20 June 2016. Details of legislation can be found at the UK Legislation website¹⁷.
- 38. In NI the first new claims to PIP were taken from 20 June 2016. PIP was rolled out across NI in one stage. The managed reassessment of DLA claimants (moving from DLA to PIP) began in December 2016 and is expected to be completed in April 2019. It is anticipated that some 125,000 DLA claimants will be reassessed for PIP.
- 39. As the Review finalised this Report (early June 2018) there were no official statistics available which provide a breakdown of reassessment outcomes in NI. The explanation for this, which was given to the Review, is contained in Chapter 4 where the available statistics regarding PIP in NI are also set out.

Reviews of the PIP Assessment Process in GB

- 40. The PIP regulations in GB provided for two reviews similar to this one. Due to the differing implementation timelines these reviews have already been completed. Both GB reviews were carried out by Paul Gray, the first was presented in December 2014 and the second in March 2017.
- 41. Government responded twice to the first GB review, in February and November of 2015. It responded to the second review in December 2017. A number of the recommendations included in the GB reviews have been progressed; however, the NI Review understands that much remains to be actioned by DWP.

¹⁷ www.legislation.gov.uk/

Legislative Changes Since Go Live

- 42. Since PIP went live in NI there have been two revisions to the legislation supporting it. The Social Security (Disability Living Allowance and Personal Independence Payment) (Amendment) Regulations (Northern Ireland) 2016¹⁸ removed rules in DLA and PIP around hospitalisation of persons aged under 18 based on the Supreme Court judgment in the case of Cameron Mathieson vs. Secretary of State for Work and Pensions.
- 43. The Personal Independence Payment (Amendment) Regulations (Northern Ireland) 2017¹⁹ amended Schedule 1 of the PIP Regulations (NI) 2016 in order to clarify drafting and reverse the effect of two recent judgments of the Upper Tribunal in Great Britain. The judgments interpreted the Schedule in the corresponding Great Britain regulations (*The Social Security* (*Personal Independence Payment*) Regulations 2013) in ways which the Government did not intend. This in effect amended how claimants should be assessed against a number of the daily living and mobility activities during their application for PIP.

2017 High Court Ruling

44. In December 2017 the High Court in GB ruled that *The Social Security (Personal Independence Payment) (Amendment) Regulations 2017* were unlawful and should be quashed²⁰. This ruling found that the amendment to the mobility activity descriptor was discriminatory to those with mental health conditions. This will now result in the reassessment of around 1.6 million PIP cases by DWP. While this ruling did not quash the corresponding NI legislation the Department for Communities stated via its Twitter account that:

"Following the judicial review decision on the Personal Independence Payment (PIP) mobility component in Great Britain the relevant legislation in NI will be amended and the Department for Communities will mirror the approach being taken by DWP to revisit all PIP cases that may have been impacted by the judgment."²¹

45. The Review understands that the process is currently underway to amend the legislation in line with GB and to revisit the affected NI cases. The Department is currently working to identify the number of claimants impacted and has indicated that those affected will be contacted in due course. The Review notes that, as of the time of publication of this report, no change has yet been implemented in how PIP claims are processed either in GB or NI as a result of this ruling.

¹⁸ www.legislation.gov.uk/nisr/2016/235/contents/made

¹⁹ www.legislation.gov.uk/nisr/2017/69/contents/made

²⁰ www.bailii.org/ew/cases/EWHC/Admin/2017/3375.html

²¹ twitter.com/CommunitiesNI/status/960914431445274624

Work and Pensions Committee Inquiry into the Personal Independence Payments and Employment and Support Allowances Assessments

- 46. In September 2017 the Work and Pensions Committee launched an inquiry on how the assessment processes for both Employment Support Allowance (ESA) and PIP were handled. The inquiry examined Department for Work and Pensions contractors ATOS, Capita and Maximus, and how the application, assessment and appeals processes for these two benefits were working.
- 47. The Committee published two reports in January and February 2018 titled *PIP and ESA Assessments: Claimant Experiences*²² and *PIP and ESA Assessments*²³. The inquiry made a series of recommendations aimed at correcting the worst problems in the application and assessment process and rebuilding claimant trust.
- 48. Government published its response to the inquiry on 18 April 2018 titled PIP and ESA assessments: Government Response to the Committee's Seventh Report of 2017–19²⁴. NI is reliant on the processes and systems used to administer PIP in GB and there is a long-standing principle of parity in these matters. It is therefore expected that, similarly to the outcome of the High Court ruling, any actions taken in GB will also affect or be reflected throughout PIP in NI. The Review would hope that this is implemented promptly and duplicated in NI.

Welfare Supplementary Payments

- 49. In 2016, the Northern Ireland Executive introduced a series of mitigation measures, termed as Welfare Supplementary Payments, to reduce the impact of welfare reform. The measures include support for persons who were previously in receipt of DLA and who are financially worse off following their assessment for PIP.
- 50. If after their assessment, a claimant doesn't qualify for PIP and lodges an appeal, a Welfare Supplementary Payment, equal to their DLA payment, may be provided until their appeal is heard and a decision is made.

²² publications.parliament.uk/pa/cm201719/cmselect/cmworpen/355/355.pdf

²³ publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/829.pdf

²⁴ publications.parliament.uk/pa/cm201719/cmselect/cmworpen/986/986.pdf

- 51. A Welfare Supplementary Payment can be provided for one year if a claimant qualifies for PIP, but at a reduced rate, and their weekly loss is more than £10. This payment will be equal to 75% of the difference in benefit. For example, if the difference is £20 they will receive a £15 Welfare Supplementary Payment.
- 52. To qualify for PIP a claimant must score at least eight points in the assessment process. If they score between four and seven points in one component and therefore do not qualify for PIP, but can show that their disability or illness is a result of a Northern Ireland conflict-related injury, they may be awarded four extra points.
- 53. Additionally, a person will no longer be entitled to Carer's Allowance or Carer's Premium if the person they care for doesn't qualify for PIP. However, in these circumstances a Welfare Supplementary Payment will be provided for one year.
- 54. The Review now moves to set out further details of PIP in Chapter 4. Statistics are analysed and reference is made to the Main Disabling Conditions.

Chapter 4: Understanding Personal Independence Payment Awards

Introduction

- 55. In order to contextualise the PIP caseload in NI, the Review has used the available Departmental statistics. At the time of finalising this Report, four sets of PIP Departmental statistics had been released; the most recent²⁵, published on 30 May 2018, covered the period up to 28 February 2018, when 59,650 PIP awards were in payment.
- 56. As of 28 February 2018 there were 112,670 registrations to claim PIP comprising 40,680 new claims and 71,990 reassessment claims. Therefore 58% of the total anticipated 125,000 reassessments from DLA to PIP have commenced.
- 57. All figures contained within this chapter are published by the Department's Analytical Services Unit and are classed as experimental statistics, meaning that they are new Departmental statistics undergoing evaluation. Additionally, the figures, which are NI specific, are rounded to the nearest 10 and as a result may not sum to totals.

Availability of NI Statistics

- 58. In order to aid openness and transparency the Review sought to include NI statistical data which was comparable to that in Gray's first GB report. Such data would have specifically referred to the breakdown of DLA to PIP reassessment outcomes. In attempting to source this data the Review has been told, by Analytical Services Unit, that they do not currently have comparable figures to those found in the Gray Report.
- 59. The Review understands that the statistical releases in relation to PIP, which the Analytical Services Unit has quality assured and provided, are based on the data which the Department has received from DWP thus far.

Notes: All figures quoted in this chapter in respect of PIP awards and claims in payments are a composite of those made under 'special rules for terminal illness' and non 'special rules for terminal illness'

²⁵ www.communities-ni.gov.uk/sites/default/files/publications/communities/personal-independence-payment-statistical-bulletinfebruary-2018.pdf

- 60. As with other social security benefits, a single DWP system is used to collect and store PIP claimant data throughout the UK. In order to facilitate the production of comprehensive statistics, the Department has worked closely with DWP to secure full access to the data held in relation to NI claimants. This includes the DLA to PIP reassessment analysis featured in the Gray Report. The Review understands that the full suite of data has now been made available to the Analytical Services Unit at the beginning of May 2018. However, a substantial period of testing and quality assurance is required before any figures can be published. As a result, it has not been possible to re-create the DLA to PIP reassessment analysis (similar to that in the Gray Report) in time for the publication of this Review Report.
- 61. The Review notes that the Analytical Services Unit has committed to publishing figures in relation to the newly acquired data in a standalone document, anticipated to be released in summer of 2018.
- 62. As a result of the issues outlined above and in the absence of more in-depth data, the Review has found it difficult to make definitive statistical conclusions about the PIP assessment process in NI thus far. It has therefore, not been possible to draw informed comparisons in relation to the data included in Chapter 3 of Gray's first Report.
- 63. Given that PIP roll out in NI was some three years after the commencement in GB; the Review expresses profound concern that there is a limited range of data available for NI. This is particularly frustrating given that comprehensive data is in the public domain for GB, through DWP Stat-Xplore which provides a guided way to explore DWP benefit statistics. Using the available data, released on 31 May 2018, Tables 2 6 provide PIP data up to end February 2018. The Review urges the Department to publish the full suite of statistics as soon as is possible. This will allow for a fuller understanding of the impact of PIP.

Breakdown of PIP Claims in Payment

64. Based on the NI statistics, there were a total of 59,650 PIP claims in payment²⁶. Table 2 below shows the split between new claims and reassessments.

Table 2: PIP Claims in Payment as at 28 February 2018

	Total	New Claims	Reassessment
Total Claims in Payment as at 28 February 2018	59,650	16,390 (27%)	43,260 (73%)

²⁶ Includes claims which may have been changed as a result of a Mandatory Reconsideration or Appeal.

65. Table 3 below shows the breakdown of awards in payment by level of award, by new claims and reassessments. The most frequent award made is enhanced daily living and enhanced mobility, which accounts for 35% of all claims in payment. This combination of 'enhanced and enhanced' is the maximum award that can be given to a claimant.

Table 3: PIP Claims in Payment by Level of Award as at 28 February 2018 ²⁷

	New Claims		Reassessment		Total Claims in Payment	
Award	Claims	% of New Claims	Claims	% of Re- assessment Claims	Claims	% of Total Claims
Enhanced Daily Living & Enhanced Mobility	3,680	22	17,280	40	20,970	35
Enhanced Daily Living & Standard Mobility	840	5	2,210	5	3,050	5
Standard Daily Living & Enhanced Mobility	3,170	19	8,960	21	12,130	20
Standard Daily Living & Standard Mobility	2,700	16	4,490	10	7,200	12
Enhanced Daily Living Only	1,870	11	3,490	8	5,360	9
Standard Daily Living Only	3,470	21	5,640	13	9,110	15
Enhanced Mobility Only	240	1	550	1	790	1
Standard Mobility Only	410	2	630	1	1,040	2
Unknown ²⁸	10	0	0	0	10	0
Total	16390		43260		59650	

²⁷ Table subject to rounding and therefore may not sum to totals

²⁸ Unknown figures relates to where there is a confirmed claim in payment, but there has been a delay in categorizing the claim into its respective award category in time for this statistical release.

Breakdown of PIP Awards²⁹

- 66. Of the 112,670 registered claims at end February 2018, 90,520 had been cleared. This means that an initial decision has been made by a Departmental Case Manager on whether the claimant should or should not be awarded PIP. It does not mean that an award is yet in payment.
- 67. Table 4 below shows the total number of registered claims which have progressed to initial decision (referred to as cleared).

Table 4: Total Clearances as at 28 February 2018

	Total	New Claims	Reassessment
Total Registrations	112,670	40,680 (36%)	71,990 (64%)
Total Clearances as at 28 February 2018	90,520	35,430 (39%)	55,090 (61%)

68. Clearances are then further broken down into three³⁰ categories, awarded, disallowed and withdrawn; this is illustrated in Table 5 below.

Table 5: Breakdown of Clearances as at 28 February 2018

	Award Summary Outcomes			
	Awarded	Disallowed	Withdrawn	Total
New Claims	15,780 (45%)	18,870 (53%)	780 (2%)	35,430
Reassessment	40,120 (73%)	14,640 (27%)	330 (1%)	55,090
Total	55,900 (62%)	33,510 (37%)	1,110 (1%)	90,520

PIP award data is based on clearances which is the initial decision where the Departmental Case Manager has determined whether the claimant should or should not be awarded PIP. They do not include awards given as a result of Mandatory Reconsiderations or Appeals.

³⁰ Awarded refers to where a decision has been made by a Departmental Case Manager to award the claimant PIP. A disallowed case is when a decision has been taken by the Case Manager not to award (turned down) a claimant PIP. A withdrawn case is when the claimant makes the decision to remove their application for PIP.

- 69. The 90,520 decisions deemed to becleared can be further broken down as follows:
 - a) 960 (1%) were made under 'special rules for terminal illness'. This is a fast-track PIP claim procedure for anyone who is terminally ill and not expected to live more than six months.
 - b) The current award rate³¹ as at 28 February 2018 is 46% for new claims and 73% for reassessment cases. The outcome of a previous testing exercise³², which sought to develop the PIP assessment criteria, showed that of 180 volunteers from NI who went through the reassessment process, there was an anticipated 75% success rate for reassessment cases. Therefore, the actual and anticipated award rates for reassessment cases in NI are broadly aligned.
 - c) A prevalent disallowance reason for new claims was failure to return the PIP2 Form which accounted for 15% (5,150) of cases as opposed to only 3% (1,410) of reassessment cases.
- 70. The median time from when a claimant registers their PIP application to an initial decision being made by the PIP Case Manager is 13 weeks. In GB the time from the point of registration to a decision being made on the claim is 11 weeks³³.

Mandatory Reconsiderations

- 71. Where the Case Manager makes a decision on a claim the claimant has the right to ask the Department to explain the decision further or have their decision looked at again. This is known as Mandatory Reconsideration and is outlined in greater detail in Chapter 11.
- 72. By the end of February 2018, there were 22,560 Mandatory Reconsiderations registered, with 14,850 for DLA reassessed claims and 7,710 for new claims. A total of 20,650 Mandatory Reconsiderations have been cleared³⁴. Of these, 7,100 (34%) were new claims and 13,550 (66%) DLA reassessed claims. 79% of new claims and 76% of reassessed DLA Mandatory Reconsiderations resulted in no change to the award. In GB³⁵ this is 84% and 78% respectively.

³¹ These percentages exclude withdrawn claims.

³² www.communities-ni.gov.uk/publications/welfare-changes-personal-independence-payment-information

³³ For non special rules claims only

³⁴ Excludes withdrawn/cancelled MRs

³⁵ For non special rules claims only

Main Disabling Conditions

- 73. The Department collects information on over 100 disabilities and conditions which are then summarised for reporting purposes. The statistics which are published in relation to disabilities and conditions relate only to what is described as a claimant's main disabling condition. This is determined by Capita during the PIP assessment process based on information provided by the claimant. Claimants may have one or more disabling conditions.
- 74. Table 6 below shows the top five main disabling conditions³⁶ (summarised) listed in order of the percentage of claims in payment which the condition represents. In order to provide context some examples³⁷ of subcategories are included under each main disabling category.

Main Disabling Condition Category	% of Claims in payment
Psychiatric disorders (mental illness) - for example anxiety and autism spectrum disorders	39
Musculoskeletal disease (general) - for example chronic pain syndrome and inflammatory arthritis	21
Musculoskeletal disease (regional) - for example hip disorders and specific back pain	14
Neurological disease (nervous system disorders) -for example cerebral palsy and epilepsy	10
Respiratory disease - for example asthma and cystic fibrosis	4
Remaining Main Disabling Conditions	12

Table 6: PIP Claims in Payment by Main Disabling Condition Category

³⁶ Not exhaustive

³⁷ Examples provided by the Department's Analytical Services Unit.

- 75. The most common disabling category (in NI) is psychiatric disorders (mental illness). In the corresponding DWP statistics³⁸ the main disabling condition in GB (June 2013 January 2018) was also psychiatric disorders accounting for 35% of PIP claims in payment³⁹.
- 76. It is evidenced⁴⁰ that Northern Ireland has a 25% higher overall prevalence of mental illness than England 1 in 5 adults in NI have a mental health condition at any one time. It is referenced in the Mental Health Foundation (2016) Mental Health in Northern Ireland: Fundamental Facts 2016 that "Evidence suggests that levels of poor mental health are in the upper end of the international scale within Northern Ireland due to the conflict that was experienced by the society" ⁴¹.
- 77. In Chapter 5 the Review sets out the arrangements for the Call for Evidence, design of the questionnaire, responses received and the analysis of over 330 responses.

³⁸ assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/691552/pip-statistics-to-january-2018. pdf

³⁹ Excludes claims in payment assessed under SRTI.

⁴⁰ Taken from – 'Making Life Better – a whole system framework for public health (2013-23)' PDF of which can be found at www.health-ni.gov.uk/publications/making-life-better-strategy-and-reports

⁴¹ Bunting, B.P., Murphy, S.D., O'Neill, S.M., & Ferry,F.R. (2011). Lifetime prevalence of mental health disorders and delay in treatment following initial onset: evidence from the Northern Ireland Study of Health and Stress. Psychol Med 42 (8), 1727–1739. doi: 10.1017/S0033291711002510.

Chapter 5: Call for Evidence

- 78. The Review issued a Call for Evidence to gather information which would help inform the Reviewer's findings and recommendations. The Call for Evidence was launched on 15 January 2018 and closed on 16 March 2018. It was aimed at individuals and organisations that were likely to have information which would be relevant to how the PIP assessment process was working for both new claims and DLA reassessment.
- 79. Information was gathered by way of an on-line questionnaire and a series of meetings with stakeholder groups. Evidence in any other format could also be submitted for consideration. This approach was developed to ensure that individuals and organisations, which had information relevant to the review, were provided with an opportunity to contribute.

Publicising the Call for Evidence

80. The following methods were used to publicise the Call for Evidence:

a. Press Releases

The Call for Evidence was launched by press release in January 2018. It was sent to over 1,700 recipients including media, political parties and stakeholder organisations.

A further press release was issued in February 2018 and was focused on local areas across Northern Ireland. This was in recognition that different areas may encounter different issues with aspects of the PIP assessment process for example, location of assessment centres, access to public transport or access to hospital services.

b. Social Media

The Department used Twitter to promote the review on several occasions. In addition, NI Direct posted details of the review on Facebook, including links to information about the review and how to submit evidence.

c. Reviewer Interviews

The Reviewer undertook interviews with both 'On Your Behalf' (Radio Ulster/Radio Foyle) and 'NVTV' (NI community channel) in which he discussed the Review and encouraged individuals and groups to submit evidence.

d. Leaflets/posters

In addition, the Call for Evidence was advertised in the 35 local benefit offices and the nine Capita assessment centres by way of posters and leaflets. Information was also distributed to 100 libraries and a short message was developed for display on screens in the libraries.

e. Letters to MLAs and Wider Advice Sector Organisations

Letters advising of the Call for Evidence were issued to MLAs and advice sector organisations.

Information Gathering – Questionnaire

- 81. The Call for Evidence questionnaire was made available on the Departmental website with a link to the online version for completion. The questionnaire was also available in easy read and word versions which could be submitted by email or post.
- 82. The structure of the questionnaire was designed to provide responders with an opportunity to express their views of the PIP assessment process.
- 83. The questionnaire was split into two parts. Part 1 for completion by individual claimants, their family members or representatives. Part 2 was for completion by organisations or individuals, with experience of the PIP assessment process. Individuals included both Capita and Departmental staff as well as those providing healthcare to claimants.
- 84. The claimants and organisations that contributed to the Call for Evidence have set out their views based on personal experiences of PIP processes. The Review 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

- 85. In total 333 responses were received as a result of the Call for Evidence. Respondents to the survey accounted for 305 of which 271 were submitted online. A further 34 responses were received electronically or in hard copy.
- 86. Of the 305 responses 265 were received from individuals (who had completed questionnaire Part 1) and 40 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.

- 87. Out of the 40 responses to Part 2, 26 were from organisations in the advice and support sectors. Of the remaining, 14 were individuals or listed as anonymous. A full list of respondents can be found at Annex 1.
- 88. The Review notes that 14 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 position that those respondents were individuals and not representing the views of organisations.
- 89. In addition, 17 organisations, five political parties/representatives and six individuals provided the Review with written submissions in a format other than the questionnaire. These are also listed at Annex 1.

Analysis of Responses - Questionnaire

- 90. Part 1 of the survey questionnaire was structured with initial focused questions, such as "Did you appeal your PIP decision?" which could be answered from a defined list of responses, in this case "Yes/No". There then followed open questions for example "If so, please tell us about your experience of the appeals process", for which a free text box was provided so that the respondent could use their own words to describe their experience.
- 91. The free text, narrative responses were analysed to identify key themes in each response and to identify the frequency of such themes, in order to determine how prevalent they were. This enabled the Review to identify a series of key or recurring themes throughout the responses.
- 92. Part 2 of the survey consisted of 14 open questions, which sought narrative responses. The first two questions related to respondent specific details such as, who they were and/or the organisation they represented. The remaining 12 questions were linked to three categories 'Claimant Experience'; 'Assessment Criteria and Process'; and 'Further Evidence'.
- 93. As the questions in Part 2 sought narrative response, analysis focused on identification of key themes arising.

Evidence Gathering - Meetings

94. The schedule of meetings with stakeholder groups evolved in response to requests from organisations and as initiated by the Review. The aim was to ensure that as wide an audience as possible was reached. The Review sought to ensure that a wide range of organisations from across NI were provided with an opportunity to participate.

- 95. In addition, a series of meetings was scheduled between the Reviewer and those with an interest or 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 from the assessment provider, Capita, again with the aim of understanding the element of the assessment process delivered by the external contractor. Included in these meetings were several visits to assessment centres across Northern Ireland where the Reviewer observed assessments taking place.
- 96. A total of 16 face-to-face meetings with both the advice sector and voluntary and community organisations took place.
- 97. Three meetings took place with representatives from political parties, and individual elected representatives attended some of the meetings referenced above.
- 98. Four meetings (including one teleconference) took place with representatives of professional bodies.
- 99. The schedule of meetings is included at Annex 4. The Review Support Team provided secretariat cover at the majority of meetings, except when the Reviewer observed face-to-face assessments at the Capita assessment centres.

Evidence Gathering – Observations of Assessments

100. The Review undertook observations of assessments at five Capita locations across NI with the agreement of Capita and the claimants involved.

Analysis of Evidence - Written Submissions and Meetings

- 101. The content of each written submission together with the notes of meetings undertaken by the Reviewer were subject to a thematic analysis.
- 102. The evidence gathered from all sources was considered by the Reviewer in forming his findings and recommendations.
- 103. A series of general observations are contained in Chapter 6, which follows. Quotes from evidence received are used to illustrate issues raised.

Chapter 6: General Observations

The Disability Category

- 104. The Review considers it appropriate to contextualise the introduction of PIP, noting comment on the disability category and how perceptions of it have evolved over recent years.
- 105. In an article for Disability & Society, Alan Roulstone⁴² considers 'Personal Independence Payments, welfare reform and the shrinking disability category', drawing on the work of numerous commentators⁴³. In this article he contends that while socially and legally the disability category has been widened in the last 30 years, Government policy, in particular changes to welfare benefits such as Employment and Support Allowance and PIP, has been premised on the idea that too many people have wrongly entered the disability category and are thus receiving benefits not intended for them.
- 106. Whilst the Review does not take a view as to Roulstone's conclusions, his work and the work of those he references, gives an insight into how the reform of DLA is viewed by policy makers, claimants and others. With comments such as those referenced by Roulstone in wide circulation, and when taken together with public statements made by Government Ministers, it can hardly be surprising that claimants, starting upon their PIP assessment process, do so with fear, apprehension and negativity.

"We can now publish caseload assumptions about the impact of PIP. These figures clearly show that PIP will deliver its key objective – focusing support on those with greatest needs. By October 2015 we estimate we will have reassessed 560,000 claimants. Of these 160,000 will get a reduced award and 170,000 will get no award"

(McVey [then Secretary of State for Disabled People] 2012)44

"It is too early to conclude on the Personal Independence Payment programme's overall success and all major programmes run the risk of early operational problems. However, the Department [DWP] did not allow enough time to test whether the assessment process could handle large numbers of claims. As a result of this poor early operational performance, claimants face long and uncertain delays and the Department [DWP] has had to delay the wider roll out of the programme"

(Comment from the National Audit Office regarding the rising volume of negative messages about PIP in GB, National Audit Office 2014)⁴⁵

⁴² Professor of Disability Studies at Leeds University

⁴³ PIP, Welfare Reform and the Shrinking Disability Category, Roulstone (2015) doi.org/10.1080/09687599.2015.1021759

⁴⁴ www.gov.uk/government/speeches/oral-statement-on-personal-independence-payment

⁴⁵ Amyas Morse, Head of the National Audit Office, www.nao.org.uk/report/personal-independence-payments-pip-2/

"The reconsideration was shot down from day dot the system is designed to scrap people of benefits nothing more nothing less." Claimant⁴⁶

Change Management

- 107. Change, and the management of change, has been written about and discussed extensively. The concepts of change management are not confined to organisational structures alone. Much can be gleaned from change management theory and processes which will aid the understanding about and implementation of change across society, such as welfare reform.
- 108. The DABDA model (Denial, Anger, Bargaining, Depression and Acceptance) was devised by Elizabeth Kubler Ross⁴⁷ and represents the stages which people experience during the grieving and loss process. This model has also been applied to change situations⁴⁸. Individual resistance may occur because people fear change, not wanting to lose the security they feel in their present situation. Resentment can occur if the proposed change involves having something removed, or through the application of different rules in a given set of circumstances. In the case of welfare reform, there may be self interest in maintaining the existing situation and perhaps a degree of concern regarding things being worse in the future.
- 109. An important element of change management is awareness raising, clear information and repeated communication surrounding the change. It is apparent from the representations made to the Review that claimants, their family members and some support workers do not have a clear understanding of the PIP assessment process and its purpose. There is a lack of clarity regarding the functional nature of the assessment and the types of information and evidence required to support a claim.

"People are unsure of the process and quite often feel intimidated by the whole thing and the horror stories surrounding the process." Claimant⁴⁹

"In practical terms the assessment includes confusion over what evidence to submit in advance, being rushed for time during the assessment and the wrong information being recorded by assessors"

Positive Life⁵⁰

⁴⁶ PIR227 – Claimant

⁴⁷ Kubler Ross, E (2005) On Grief and Grieving: Finding the Meaning of Grief Through the five Stages of Loss, Simon & Schuster Ltd

⁴⁸ Scire, P (2007) Applying Grief Stages to Organizational Change

⁴⁹ PIR020 – Claimant

⁵⁰ PIR819 – Positive Life

Awareness

should be submitted.

- 110. Whilst it is acknowledged by the Review that efforts have been made to date by the Department, much of which focused on an early advertising campaign, increased engagement is required to both inform and communicate with claimants on what PIP is, to demystify the PIP assessment process, while addressing misconceptions which have grown around PIP and its purpose.
- 111. The introduction of a new benefit such as PIP must be accompanied, both initially and on an ongoing basis, by a targeted awareness raising campaign which sets out clear messages about the purpose and requirements of the new benefit. Any such campaign is unlikely to achieve total saturation in the target population, through an initial burst of advertising and information flow. It is only as the target market, in this case claimants and supporters, are faced with the reality of either being reassessed or making a first-time claim, that the information and messaging becomes more relevant to them.

Anticipated Outcome:
Claimants, their families and support workers enter the PIP assessment process with a clearer understanding of what is required in terms of relevant information and what is expected of claimants. This is likely to contribute to reducing levels of apprehension and mistrust in addition to decreasing the need for moves to Mandatory Reconsideration and recourse to Appeal.
C e u r c l

Sources of Confusion throughout the PIP Assessment Process

112. Given that the Review's initial recommendation is intended to create greater clarity about PIP generally and the application process in particular, the following sections of the Review Report seek to identify elements of the PIP assessment process which cause confusion and anxiety amongst claimants.

Medical Assessment versus Functional Assessment

- 113. Throughout the PIP literature and guidance materials, both for claimants and for those operating the process within the Department and Capita, there are a number of inconsistencies. These are in regard to the terminology used to describe both the process and those involved in administering it. For example, much emphasis has been placed on the fact that an award for PIP is determined following a functional assessment, as opposed to a medical one. The end-to-end PIP assessment process is intended to determine the claimant's functional ability. However, in official communications and in support material, descriptions of the assessment process give the impression of a pseudo-medical approach.
- 114. The nine Capita locations across Northern Ireland are variously described as Assessment Centres; Clinics; Consultation offices. Signage in the centres titles the rooms as Consultation Rooms. In the interests of clarity, the Capita locations should use the title assessment centre and the room, used by the assessor, should be called an assessment room.

Health Care Professionals

- 115. There is confusion about the nature and purpose of the PIP assessment process, which is generally interpreted, by claimants, to be the stage undertaken by Capita. This narrow interpretation is understandable as the Capita assessment is one of the few parts of the process where the claimant meets 'a person' associated with PIP. Clarity in communicating the nature and purpose of the assessment process is urgently required as is clarity around the roles and responsibilities of staff involved.
- 116. The term 'Health Care Professional' is used in documents and general discussion in an interchangeable way to describe a variety of roles. The term is used to identify nurses, paramedics, occupational therapists and physiotherapists; the sectors from which Capita recruit assessment staff. However, it is evident from the recruitment process that Capita seeks to appoint to a role titled as Disability Assessor. The Review is of the opinion that staff should be referred to as Assessors and that the process undertaken should be identified as the Assessment.

- 117. The health care professional term is also used, across PIP documentation, to describe a range of roles and functions including: doctors, consultants, thematic experts, to name but a few, with whom the claimant may have some contact, or from whom the claimant receives a service.
- 118. These inconsistencies reinforce misconceptions surrounding PIP. The Review believes that greater clarity could be achieved as a result of the Department undertaking an exercise to examine the terminology used to describe roles and functions undertaken throughout the PIP assessment process, with a view to adopting a simple common format. This would aid clarity, manage the expectations and allay the fears of those navigating the process.

Recommendation 2:	Anticipated Outcome:
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 use of clear terminology will ensure a consistent and correct message is delivered to all involved as to the purpose of the assessment and how the PIP assessment process is undertaken.

DLA Evidence

- 119. The Review understands that on each occasion when a claimant rings the PIP claim line to initiate their reassessment from DLA, they are asked if they wish their DLA medical evidence (held by the Department in respect of their current DLA award) to be made available as part of the PIP assessment process.
- 120. It has been indicated to the Review that in more than 90% of DLA reassessment cases claimants ask for their DLA medical evidence to be considered.
- 121. The relevance of DLA evidence to the PIP assessment process is open to debate. The Review has been told that DLA and PIP are two different benefits, with different criteria and assessment processes. For claimants who have been on a lifetime award of DLA, (over 70% across NI) their case file is unlikely to contain up-to-date information. It should also be noted that a claimant's DLA case file will contain information which was gathered for a different purpose.
- 122. The process of transferring the claimant's DLA information to PIP has resource and time implications. The DLA and PIP files are held on two separate computer systems which are not linked, therefore the transfer involves manual intervention. The use of, or reference to, a claimant's DLA medical information is not explicitly included in the PIP Assessment Guide for

Capita assessors. However, following permission given by the claimant at the start of the PIP assessment process, their DLA medical information is included in the case files available to both Capita assessors and Departmental Case Managers. The Review has seen little evidence to indicate that DLA information is regularly taken into consideration as part of the PIP assessment process.

123. It is apparent, from respondents to the Review, that in many cases claimants assume, having agreed to their DLA medical evidence being made available to PIP, that it will form part of their assessment. This is not an unreasonable assumption. It follows therefore, that claimants also assume they will not need to provide more information in support of their PIP claim. This could be to their detriment.

"When I spoke to an operator on the PIP phone line, he asked me what evidence I wanted to be carried across from my DLA claim to my PIP claim. I said all of it, as my condition has been lifelong, and because of this I believed no further evidence was required."

AC, Claimant ⁵¹

124. The Review considers it to be essential to have all the relevant evidence available at the earliest possible point in the PIP assessment process. This increases the likelihood of a correct conclusion being reached during the Capita assessment and later by Departmental Case Managers. The Department should ensure that claimants are fully advised early in the process of what constitutes relevant evidence.

⁵¹ PIR206 – AC (Claimant)

125. The Review has not been in a position to establish, conclusively, the relevance and use of DLA medical evidence during the PIP assessment process, indeed conflicting information on the subject has been obtained. The Review is of the opinion that the relevance, if any, of DLA evidence to the PIP assessment process is questionable. General Practitioners (GPs) have told the Review that the most relevant medical evidence is that which covers the last two years of the claimants condition.

Recommendation 3:	Anticipated Outcome:
The use of DLA evidence to support reassessment cases should cease.	To remove the confusion caused by inclusion of DLA evidence that has questionable relevance to the PIP claim. This will also ensure claimants do not mistakenly rely on this evidence when other, more relevant evidence, is available to them.

126. The Review now moves to consider the PIP assessment process in Chapter 7. A seven stage flow chart is introduced, which helps to focus the analysis contained in the following chapters.

Chapter 7: The PIP Assessment Process

- 127. The Review has considered all elements of the PIP assessment process. The Review observed processes during visits to both Departmental and Capita operational sites and through discussions with staff.
- 128. The Review considers that the PIP assessment process can be grouped into seven broad stages as per the graphic below.

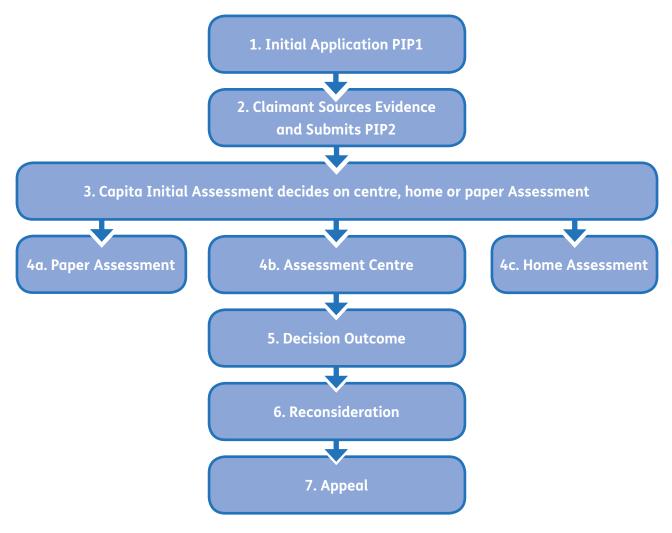


Figure 1: Stages of a PIP Claim

129. It should be noted that these are not formally recognised stages but are presented here to serve as a guideline for the next chapters of this Report and to allow for structured consideration of the process.

130. The Review's understanding of the PIP assessment process comes as a result of an extended period of engagement with Departmental and Capita staff. It included having access to operational sites to witness the process in action. It was only with the benefit of this exploration of PIP, including drilling down into the systems and procedures, that the Review was able to understand the PIP assessment process in its entirety. It is not unreasonable to draw the conclusion that a claimant, who does not have the benefit of such access, would struggle to understand the PIP assessment process.

"There was no way I could of done claim on my own [sic]. I had no energy orconcentration or understanding of the questions" KT, Claimant

"The form is long and intimidating. Even seeing that brown envelope landing on your mat is a source of great anxiety." Claimant⁵²

131. The Review believes that it is necessary to develop straightforward, clear, information materials, in suitable formats, which describe the PIP assessment process. This would assist claimants, family members and support workers in their understanding of the PIP assessment process and its purpose. The material should not assume any prior PIP knowledge on the part of the claimant.⁵³

Recommendation 4:	Anticipated Outcome:
(A) The Department should review written material, particularly (i) the initial letters to claimants and (ii) the subsequent decision letters to claimants, ensuring clarity of message and the avoidance of jargon.	This would assist claimants, family members and support workers in understanding the PIP assessment process and its purpose.
(B) The Department should develop simple straightforward material describing the PIP assessment process.	

132. The opportunity is now taken, in Chapter 8, to consider in-depth the stages of the PIP assessment process starting with applying for PIP; the application of special rules criteria and completing the PIP2 form. The Chapter continues by commenting on further evidence and the Initial Review by Capita.

⁵² PIR820 – KT (Claimant)

⁵³ PIR093 – Claimant

Chapter 8: Applying for PIP

Initial Application - PIP1

- 133. Making a claim to PIP is undertaken in two stages. Initially the claimant is required to call the PIP telephone claim number. It is at this point that some basic eligibility conditions are checked and a PIP1 form is completed. The Review acknowledges the benefits of taking this approach as it removes the need to complete a lengthy application process for those who would fail the basic eligibility test.
- 134. The Review has heard of some frustration and anger, on the part of claimants, that there has been an insistence on speaking to the claimant personally at this initial stage. For some claimants, with a range of medical conditions and particularly for those with hearing or speaking impairment, it is not possible to conduct communication via telephone.
- 135. The Review acknowledges that there are currently provisions in place to allow claimants with communication issues to complete the PIP1. Claimants or their representatives can request a paper copy of the PIP1 either by telephone or in writing. It is the opinion of the Review, that delivery of awareness raising training, to staff operating the initial telephone claim desk is required. This could cover the range of conditions where it may be difficult, or indeed impossible, for an individual to communicate by phone. Clear instruction should be set out regarding how to proceed in such cases, including how to take input from family members, support workers, advocates and others.

"A person with autism and communication difficulties who does not speak to strangers or doesn't use the phone or refuses to. How do they contact by phone! In first instance"

Claimant⁵⁴

"Due to my disability I was unable to hand complete the How my disability affects me form. No format exists for a computer generated form. No help was offered by the department to complete the form when [in] fact I [was] subsequently informed that an outreach officer was available on request."

JR, Claimant⁵⁵

⁵⁴ PIR802 - Claimant

⁵⁵ JR (Claimant)

Re	commendation 5:	Anticipated Outcome:
	That the Department ensures there are suitable, accessible options for those with particular needs such as communication 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.	This will assist those with particular needs in accessing PIP.
	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.	

Claims Made Under Special Rules

- 136. There is provision where a claimant has a short life expectancy, as confirmed by a medical practitioner, to seek to claim PIP under the 'special rules for terminal illness' criterion, also known as special rules. The current arrangements indicate that, where a medical practitioner completes a DS1500 form, confirming the claimant is terminally ill and not expected to live more than 6 months, a Paper-Based Assessment can then be carried out.
- 137. As at May 2018, such assessments, in NI, are being completed within a one week period. It is acknowledged that dealing with terminal illness is sensitive for both claimants and their families. It was represented to the Review that in these circumstances a terminally ill person may find it difficult to accept their life-limiting condition, they may not know or may not wish to know the detail of their condition. An award made under special rules remains in place for a three-year period.
- 138. The Review has listened carefully to the concerns expressed regarding the application of special rules, and the impact the diagnosis of a terminal illness can have. The Review is of the opinion that the determining factor, as to how these sensitive cases are processed, should be the provision of a clinical judgment indicating a terminal condition. This should be sufficient to allow for special rules to be applied.

Recommendation 6:	Anticipated Outcome:
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.	This will lessen pressure, stress and anxiety on claimants and their families at what is an already difficult time.

Completing the PIP2

- 139. Having undertaken the initial telephone conversation which results in the completion of the PIP1 form, the claimant will then receive, by post, the PIP2 form and a guidance booklet on how to complete that form. Receiving the form and booklet can increase stress and anxiety as claimants may not be familiar with, or have experience of, completing such an extensive form, within a four week deadline. Responses to the Call for Evidence indicate that claimants required assistance, in some cases from more than one source, when completing the PIP2.
- 140. Similar to the issues outlined in Paragraph 134 it also has been represented to the Review that many claimants experience difficulty in completing forms where handwriting is required.
- 141. For some claimants this is the point at which they seek assistance from independent advice agencies. Due to resource pressures, appointments with such agencies can take up to three weeks to arrange. There is provision for the claimant to seek a further extension of two weeks in order to complete the PIP2 form.
- 142. The Review has considered the Explanatory Notes to the PIP Regulations (NI) 2016⁵⁶. This states:
 - 10.1 The introduction of PIP does not introduce a statutory burden on business, charities or voluntary bodies. NISSA (Northern Ireland Social Security Agency) will continue to work with charities and voluntary bodies supporting disabled people to help them prepare for the introduction of PIP
 - 10.2 The impact on the public sector is negligible. This measure is part of the welfare reform package that will restore parity with the rest of the UK and contribute towards sustainable finances for the Executive.

⁵⁶ PIP Regulations (NI) 2016, 10.1-10.2 https://www.legislation.gov.uk/nisr/2016/217/pdfs/nisrem_20160217_en.pdf

143. The Review notes, as set out in the Explanatory Notes above, there is "no statutory burden on charities or voluntary bodies as a result of the introduction of PIP". However, claimants are seeking help from multiple sources of support. It has been represented to the Reviewer by some advice bodies that around 40% of their case work is linked to PIP. A situation does exist where ensuring claimants can access the relevant information and assistance, is a challenge and is impacting on both the advice sector and thematic support organisations.

"Because of my mental health problems I found filling in the forms very [challenging] and stressful. My mother and sister helped me a lot but it caused lots of conflict between us and I know it hurt them to read about my problems and the traumas I endured as a child and young adult." Claimant⁵⁷

144. The Review has been told that for those in the deaf community, whose first language is not English and who rely on a sign language interpreter being present, the only provision of such a service (by an advice organisation) is in Belfast, and only on a Monday. The Review understands that it is not possible to book an appointment, so prospective users from across NI must turn up and wait to be seen.

"The written application form is both lengthy and unnecessarily elongated. The overarching question replaced by specific questions in each category is unnecessary. We recommend 1 overarching question in each category, with various written prompts to the applicant to clearly show what evidence they are seeking. Greater effort is needed to ensure forms/correspondence are in accessible formats, and that appropriate timelines are extended to ensure applicants have been fully supported to understand everything that is required of them."

North West Forum of People with Disabilities⁵⁸

"The claim form is ridiculous and takes hours to fill out. I had to do it over the course of a week as it was so time consuming and exhausting" Claimant⁵⁹

145. Having considered both the PIP2 form and the accompanying booklet, the Review considers that it is unclear as to what is meant by relevant evidence. Over 90 per cent of reassessment claimants agreed, when asked, to their medical evidence being transferred to PIP. Therefore it is a not unreasonable assumption that only limited additional information is required either on the PIP2 form or by way of attaching relevant information.

⁵⁷ PIR120 - Claimant

⁵⁸ PIR827 – North West Forum of People with Disabilities

⁵⁹ PIR168 – Claimant

Sourcing Further Evidence

- 146. The Review recognises that many claimants hold their GP in high regard and value the service they receive through their local surgery. Given that confusion exists about the PIP assessment process regarding the issue of medical versus functional information, it is understandable that claimants feel more confident in having an input from their GP.
- 147. The Review has been told, both by GPs and their professional bodies, of the need to preserve the GP patient relationship which is the cornerstone of medical services provided to patients through the network of local surgeries. The Review has heard of examples of patients seeking to influence what the GP will write in support of their PIP claim.
- 148. The Review has learnt from both GPs and their professional bodies, that they are not the best source of information in terms of the patient/claimant's daily functionality. On many occasions the GP will not see the claimant undertaking daily living functions and is therefore not in a position to offer meaningful comment on such matters.
- 149. The Review has considered the wording used in the PIP2 Form and its supporting guidance which advises the claimant not to request additional information over and above that which they [the claimant] already have:

"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.

150. Whilst it is welcomed that the claimant is advised to avoid unnecessary expense, numerous representations have been made to the Review stating that Department and Capita have not attempted to get any further evidence from the professionals supporting claimants.

"GPs and consultants are already overworked and it is difficult to get a report as a patient. However it appears capita don't request it direct from these professionals putting further stress on claimants" MM, Claimant⁶⁰

⁶⁰ PIR229 – MM (Claimant)

"I assumed that as I gave permission for the department to access my medical records that there would have been no need to provide further evidence as everything was made available. I then found out that the decision was made without reference to my medical records and history but was based solely on an interview held with a stranger of unknown qualification and experience."

CL, Claimant⁶¹

"My medical professionals were unwilling to write reports or supporting letters for me to submit with my claim, as they expected to be contacted by Capita with requests for specific information. They were not contacted." Claimant⁶²

151. Requests from Capita to GPs for further information, which they believe will help the Department to determine eligibility for a claimant, are currently requested using a form which is known as a GP factual report. Where a GP does complete such a request, it is not unusual to find a number of the sections carrying the comments 'don't know' or 'unable to comment'. This is both frustrating for the claimant and for the GP, as well as being time consuming for GP surgeries already under significant pressures. GPs told the Review that they are unaware if the information they provide to Capita currently is relevant or not.

"On average about 35% of cases would require that there be further GP evidence required. We receive fewer than 10% of these back of which 3% would actually be relevant to the functional capacity during the assessment."

Dr Ian Gargan, Capita Chief Medical Officer⁶³

152. Additionally, the Review has seen evidence of correspondence from GP surgeries to claimants, the Department and others outlining that they are unable to provide any further medical evidence:

"Recently there has been an increase in requests for supporting letters for PIP applications/ appeals...Unfortunately, due to rising pressure within general practice we cannot fulfil these requests and would appreciate it if you would not forward any further requests for PIP reports."⁶⁴

⁶¹ PIR020 – CL (Claimant)

⁶² PIR012 – Claimant

⁶³ Oral Evidence: PIP and Employment and Support Allowance Assessments Q128 data.parliament.uk/writtenevidence/ committeeevidence.svc/evidencedocument/work-and-pensions-committee/pip-and-esa-assessments/oral/75298.pdf

⁶⁴ PIR985 – GP Letters

- 153. A general letter was sent by one surgery to the Departmental Mail Opening Unit as follows: "Re Personal Independence Payment forms: due to the current crisis in general practice in Northern Ireland, the practice is not in a position to divert time from clinical care to completing the new PIP forms. We recommend that you base your decision on patient's entitlement to benefits on the information they [the patient] have already provided ..."⁶⁵
- 154. The Review acknowledges that the GP is not always the best person to contact about the claimant's functionality. This may not be a view held by the patients/ claimants; however, it is a reality. As the primary function of the PIP assessment is to determine the claimant's daily functionality, the Review is of the opinion that the focus should be placed on gathering relevant information relating to the claimants functionality.
- 155. The Review readily accepts that a claimant's medically diagnosed conditions, and associated medications, will impact on their functionality. The Review has been told by medical professional bodies, and GPs, that basic medical information has an important function in the PIP assessment process. In order to obtain the most relevant information, medical professional bodies and GPs suggested that it would be more appropriate for the Department/Capita to arrange for the provision of a brief GP Short Summary Report, which could be made available by practices.
- 156. The Review is of the opinion that obtaining a GP Short Summary Report, at the start of the PIP assessment process for each claimant, alongside the completed PIP2, would introduce consistency in terms of establishing the claimant's medically diagnosed conditions and medication, both of which are likely to impact on the claimant's functionality and communication.
- 157. The Review understands that provision of a Short Summary Report would be significantly more achievable for GP practices than completing the current free text pro forma. The Review understands that the short report would contain a medical history including existing conditions, medication and hospital referrals over the last two years. Thus it would contain brief, up-to-date relevant information, which could dispense with the need for DLA medical evidence to be transferred for reassessment claims. Not only would it ensure that relevant medical information is available at the start of the assessment, but consistency of approach would follow through to the Tribunal, where medical evidence is considered.
- 158. Focused evidence regarding a claimant's daily functionality may best come from family or friends who see the person on a regular basis; care providers may also be well placed to

⁶⁵ PIR985 – GP Letters

provide information; similarly, physiotherapists, occupational therapists and social workers may also be able to contribute an informed view. However, due to resource pressures, the Review is aware that managers in a range of support services are directing that priority should not be given to providing letters of support or completing forms related to the PIP assessment process.

- 159. Further clarification is urgently required regarding what constitutes relevant information and where and how it may be obtained.
- 160. The introduction of obtaining the Short Summary Report, at the start of the PIP assessment process, would bring consistency in terms of establishing the claimant's medically diagnosed conditions and associated medication.
- 161. It is clear from what has been represented to the Review that there is either a breakdown in the sourcing of evidence by the Department and Capita for numerous claimants, or

Recommendation 7:	Anticipated Outcome:
So that the 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 to obtain a GP Short Summary Report to support the PIP2 submission. This should be requested for every claim.	This should allow GPs to provide relevant medical evidence to the Department and Capita in a timely fashion which is both useful to assessors and Departmental Case Managers.

that the literature claimants receive does not contain clear advice. The net effect is that decisions are being made at various points of the process without access to all the relevant information.

Receipt of Further Evidence

- 162. Based on observation of the assessment process, the Review is concerned that all the relevant information may not be available at key times in the assessment and decision-making process.
- 163. Once a PIP2 form, together with any relevant information, has been returned by the claimant, it is routed via the Department's Mail Opening Unit before it is sent to Capita for consideration.
- 164. The Review acknowledges the realities of the Department receiving large volumes of information, arriving by post, at the central Mail Opening Unit. Many hundreds of

thousands of items of PIP mail are received a year comprising almost six million pages of information which must be scanned. The Review notes that further information can also be sent in, by the claimant, at different points during the assessment process, without the advance knowledge of the Department or Capita. Whilst there are additional arrangements in place for handling these items, the challenge is to ensure that all such additional items of information are identified, properly indexed and placed electronically in the claimant's PIP case file at the earliest opportunity.

- 165. The electronic scanning system located in the Mail Opening Unit deals with all incoming items received by post. This Unit services several benefits and in respect of PIP the bulk of the work relates to the PIP2 form and further information sent by the claimant, at the start of the process. The scanning system is programmed to identify specific forms with a common layout, such as the PIP2. The system is less likely to identify other documents, which do not conform to a recognised layout. Documents not identified by the electronic scanning process will require manual intervention to sort, index and place the documents in the claimant's electronic case file.
- 166. Understandably the manual process takes time, not dissimilar to more conventional post sorting. This means that the documents requiring manual intervention may take longer to be indexed and placed electronically in the claimant's case file, than those routed automatically. This can result in a less than complete case file being available to Capita and Departmental staff.
- 167. In addition to the scenarios set out above, it has been represented to the Review that, Capita may have undertaken the initial review of a claim and proceeded to a face-to-face assessment, before further evidence has been received, sorted, indexed and placed in the claimants electronic case file. This may well have been evidence that could have altered the decision. It should be noted for clarity that, in such instances, Capita may have no indication that further evidence is pending for the case and thus have proceeded unaware of its existence. It has further been represented to the Review that Capita is contractually obliged to progress a case within a given time period. The Review notes that there is a section of the PIP2 form where a list of the additional documents, submitted with the form, can be set out. Every effort should be made to encourage claimants to complete this box when they submit further information.
- 168. The Review has witnessed Departmental Case Managers reviewing the date on which further information has been received and added to a case file. In doing this it has been

possible for a Case Manager to determine if a particular piece of information was received after a decision was made.

169. In these circumstances, the Review has witnessed Case Managers referring the matter back to Capita so that the more recently received information can be taken into account. There are therefore a series of checks and balances in the PIP assessment process, which the Review regards as positive. The delay in receiving information is not ideal but is symptomatic of the challenge in managing PIP claims within defined timescales where additional information may be submitted at several points.

Initial Review by Capita

170. When the claimant's PIP2, along with any supporting information, reaches Capita, an

Recommendation 8:	Anticipated Outcome:
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.	This should ensure those involved move forward in the process with the most relevant information available to them, and that additional remedial steps are not required later in the process.

Initial Review is carried out to consider what type of assessment is appropriate. If there is sufficient relevant information available at this point to enable Capita to complete an assessment on the claimant's functionality, the claim will then be progressed as a Paper-Based Review.

- 171. Relevant information provided with the PIP2 form can enable Capita to complete a Paper-Based Review without the need to see a claimant face-to-face. Currently this happens in around 9.4% of cases⁶⁶.
- 172. If Capita considers that there is insufficient information available at this point to carry out a Paper-Based Review then a face-to-face assessment is selected. It is at this stage that Capita will request additional evidence if it is deemed to be required. The case then moves on for an assessment appointment to be scheduled, either at an assessment centre or the claimant's home.

⁶⁶ Based on Departmental records, figures supplied by Department for Communities Commercial Services branch

- 173. The Review has been told of instances where claimants, or their representatives, have engaged with Capita at this early point in an attempt to demonstrate that they would not be able to participate in a face-to-face assessment due to the severity or nature of their conditions.
- 174. The Review understands that, while the nature of a claimant's condition can impact on the type of assessment offered, the main consideration behind Capita deciding if they can conduct a Paper-Based Review, is whether they are in possession of sufficient relevant information at Initial Review stage to adequately assess a claimant's functionality. Recommendation 7, if implemented, should go some way to improving the information available at this stage of the process.
- 175. The assessment is considered in Chapter 9, and reference is made to assessors. The chapter then moves to the matter of accuracy of reports and includes reference to informal observations. The chapter concludes with an analysis of questions regarding self harm and suicide and the effectiveness of the assessment.

Chapter 9: The Assessment

The Assessment

- 176. As outlined in the previous chapter, the assessment can take place in three ways
 - i) a Paper-Based Review
 - ii) face-to-face at an assessment centre
 - iii) face-to-face at a claimant's home
- 177. This is determined by Capita during the Initial Review of the claimant's case file. If, following the Initial Review, a Paper-Based Review is not considered appropriate, an appointment is sent to the claimant for a face-to-face assessment, which can be carried out either at an assessment centre or at the claimant's home. The decision on whether a home visit is appropriate is made by Capita.
- 178. For the purposes of clarity from this point on in Chapter 9 the term assessment refers to faceto-face assessments.
- 179. The assessment element of the wider PIP assessment process prompted the most comment from respondents. Even from early analysis of responses it was apparent, from the sheer volume of issues raised, that the assessment is the most contentious part of the overall PIP assessment process.
- 180. A common theme reported to the Review was that claimants provide information indicating either that they cannot attend an assessment, or that they have particular requirements to allow them to attend, and yet the Review has been told that Capita do not appear to take this into consideration.
- 181. Often claimants, due to the nature of their conditions require several hours of preparation time to ready themselves for their assessment. During two of the assessments observed by the Reviewer, the accompanying person indicated that the claimant had slept in the clothes they were wearing to the assessment. It was stated this was the only option in order to make an early appointment time.
- 182. The Review has heard from both GPs and individuals that a claimant's medication needs to be taken into account in determining appointment times. A side effect of medication may be that the person is less able to represent themselves fully and clearly at certain times of the day. GPs have explained to the Review that the effect of some medicines, taken at night, may last well into mid-morning of the following day, which could make answering questions difficult.

183. The use of public transport to get to assessments has been drawn to the attention of the Review. The frequency and proximity of public transport can be problematic. The Review has seen some of the travel directions provided to claimants and would not view them as appropriate, or that they take into consideration the conditions the claimant may have included on their PIP2 form.

"I felt that all the information sent in had not been read as the professionals had not been contacted first and my daughter was asked to go for a face to face at 8 o'clock in the morning which was totally inappropriate if they had read about her complex needs."

KA, Claimant⁶⁷

"I was expected to be at my appointment at 8am, as a person who is disabled this would mean I would have to be up at 5am as the meeting was approx., 30 Miles away... " Claimant⁶⁸

"I [completed] my [PIP] claim form in detail and enclosed substantial evidence to back up my claim. I also enclosed a letter confirming I had a hospital admission but date of Face to Face assessment was scheduled for that week. I was really upset as I felt that my claim had not been read. I rang Capita and was told the computer allocated appointments. This made it even worse as all the info I have read states that you may not require a face to face if [there] is enough info. I ended up having to cancel my urgent hospital admission."

RM, Claimant⁶⁹

⁶⁷ PIR085 – KA (Claimant)

⁶⁸ PIR239 - Claimant

⁶⁹ PIR127 - RM (Claimant)

"I received a [text] message on the Thursday that I was to attend the assessment centre the following Tuesday. The following day I received a letter from Capita with the direction to the centre. I was to walk 0.9 miles to the bus service in [named town] which would take me 18 minutes and get a bus to Belfast. I was then required to walk from Bedford [St] to the centre which would take me 4 minutes. I phoned Capita and told them I could not walk that far I asked could I not get a home visit. The answer from one of the staff was no that I could attend appointments I was to go to the assessment. I asked the girl [where] the car parking spaces were around the centre I was told there [were] 2 spaces but could I might get one. My son was going to take me and I was borrowing a wheelchair as my walking is very bad. Through my MLA I got a home visit instead on the Tuesday. It was a very stressful weekend with a lot of tears. I felt who ever read my claims forms should have been able to realise I could hardly walk and they [didn't] wait to receive the form back from my GP which asked for a home visit for me"

Claimant⁷⁰

184. Securing a home visit or scheduling of an assessment taking account of their needs does not necessarily mean claimants will not encounter difficulties with their appointment. The Review has been told of times when appointments are cancelled with little warning, sometimes on multiple occasions. There have been occasions where it has been reported that the assessor arrived at a different time than expected. By contrast claimants are afforded only a single opportunity to reschedule an appointment.

"In my case on two occasions the assessor failed to turn up without notice. The follow up assessment was extremely rushed and was recorded to have lasted just 15 minutes to consider over 12 documents of evidence." JR, Claimant⁷¹

"Sign Language Users have booked time off work for a scheduled assessment, but either the interpreter or the assessor has not arrived to the appointment. This has happened to claimants on numerous occasions, with one person having booked time off for their 4th appointment, to have no-one turn up yet again. They later discovered that a voice mail had been left informing them that the appointment was cancelled. Given that Deaf people cannot hear or comprehend speech, a voice mail is not fit for purpose and other means of informing Deaf people should be used" British Deaf Association⁷²

⁷⁰ PIR187 - Claimant

⁷¹ PIR008 – JR (Claimant)

⁷² PIR240 – British Deaf Association

Reviewer's Observations of Assessments

- 185. The Review undertook observations of assessments at five Capita locations across NI with the agreement of Capita and the claimants involved. Of the locations visited all had street-level access. In some locations it may have been necessary to 'set down' the claimant at the front door of the assessment centre and park the vehicle a short distance away. This could cause difficulties if the driver of the car is also the only person accompanying the claimant.
- 186. In the Belfast City Centre location, set down from public transport is some distance away. In other locations, dependent on local public transport services, it may not be possible to guarantee set down close to the assessment location. Claimant's reported using taxis to ensure they were set down close to the assessment centre. In the Belfast location provision was over two floors (ground and first with lift access to the upper floor). In the other locations the assessment centre was on the ground floor. The Review notes that travel costs incurred in attending the assessment can be reclaimed.
- 187. The assessors conducted assessments in a room identified by signage as 'Consulting Room'. In each consulting room there was a medical-style examination couch. The desk was set at a 90° angle to a wall or window, with the assessor's chair closest to the door. The claimant's chair, and a chair for the accompanying person, was located on the opposite side of the desk to the Assessor.
- 188. During the observed assessments the assessor set the scene for the process in their own style. The assessor pointed out that they would be typing throughout the assessment in order to capture the answers given by the claimant. Each claimant was asked if they were ready to proceed. Several claimants mentioned their apprehension about the process and some displayed signs of stress, anxiety and concern. Whilst the observed assessments followed a similar pattern, the process varied in length from 30 minutes to 80 minutes.
- 189. Of the nine assessments observed one claimant was unaccompanied, with the remainder accompanied by a relative or friend. In one case a support group representative attended.
- 190. As a result of the nine observed assessments the Review formed the opinion that one claimant (who was accompanied by a friend 'for moral support') was able to adequately represent their multiple medical conditions and the functional impact on their daily life. One unaccompanied claimant, in the early years of life changing diagnosed conditions, showed signs of considerable stress and anxiety, in addition to challenges with speaking and swallowing. The remaining seven claimants, (who had a variety of mental health conditions, in addition to some physical disabilities) were not, in the opinion of the Reviewer, in a position to adequately communicate their conditions, nor the impact on their daily living. Each required input form their accompanying person.

- 191. The Reviewer observed one occasion, where the claimant was using a wheel chair and the assessor had to physically move the desk so that the wheelchair had access between the desk and the examination couch. The claimant became anxious as furniture was moved and they were placed behind the desk, in what was an area of restricted space. Such was the limited space available that only the claimant's wheelchair could be located behind the desk and the person accompanying the claimant had to sit at the side of the desk with the back of their chair pushed against the examination couch.
- 192. The layout of each location gives the impression of what might be found in a doctor's waiting room. Whilst the Capita reception staff were welcoming, the obvious anxiety and stress experienced by claimants negated any initial attempt to de-stress the situation.
- 193. The Review did not establish any evidence to indicate that the examination couch is used in the muscular skeletal test undertaken by each claimant. On a practical note the examination couch takes up a considerable amount of space in often small consulting room areas.

Regarding Assessments

- 194. The Review acknowledges the inherent difficulty in designing a system to assess how a person's disability or illness impacts on their functionality on a daily basis. As a result of observing several assessments, the Review is aware of the challenges involved in producing a report covering a claimant's daily functionality drawn primarily from a relatively short interview. The assessment report is required to adhere to a prescribed and audited format, set down in advance by two administrative organisations (the Department and Capita).
- 195. Based on the information submitted by respondents, it is no surprise to the Review, that claimants view the assessment with distrust and apprehension. During the observed assessments, the Reviewer was aware of people being physically sick; panic attacks occurring; difficulties with swallowing and breathing being exacerbated; feelings of disorientation when away from familiar environments.
- 196. The Review has heard from respondents who challenged how this relatively short assessment process can gain an understanding of the realities of their daily lived experience. This was particularly relevant where their condition fluctuates. Such fluctuations can occur within the space of an hour. Respondents set out the realities of their lived experience which may have taken them, their family and those they receive care from, a substantial amount of time to come to terms with, if indeed they have.

"I have gotten past my difficulties a long time ago, but for this process I had to reexamine every aspect of my daily life and try to see all the problems. All with the thought in mind that if I don't give the interviewer, in our 20 minute chat, with a person who seemed to know very little about how an amputee such as myself would navigate life, every aspect of how my life is different, I get "rewarded" by having my weekly financial support cut."

ER, Claimant⁷³

197. The Review has been told by family, representatives and supporting organisations of times when, perhaps due to the claimant's condition, the claimant's attendance at a face-to-face assessment has either had no effect on the outcome or it may have made carrying out the assessment more difficult.

"Our constituent was called to a face-to-face assessment, despite having an IQ of 46, a physically debilitating condition and engagement with state services from birth. His mother, his carer and Appointee, despite explaining all of this to Capita, had to take him to a face to face assessment at 8am. At the Assessment the young man couldn't fully understand the questions and was incorrectly affirming that he could do tasks independently. His mother has invested much time into building confidence up in her son throughout his life but to ensure the assessor had a correct understanding of her son's situation she had to correct him and in her words 'run him down in front of a stranger'. As a result, our constituent has tried to carry out every-day tasks to prove he can do them, even though they pose a safety risk to him and others around him. This all could have been avoided by the Department for Communities if a paper-based assessment had been carried out."

SDLP74

"Law Centre is assisting a client who stated on her PIP2 claim form that her conditions included schizophrenia. The client's GP returned a report to Capita noting that the claimant suffered from paranoid schizophrenia and chronic acute psychosis. The GP report also noted that the claimant had no insight and was in denial of her illness, was resistant to all therapy and suffered from on-going delusions and hallucinations. Despite the medical evidence, a face-to-face assessment was arranged."

Law Centre NI⁷⁵

⁷³ PIR084 - ER (Claimant)

⁷⁴ PIR950 - SDLP

⁷⁵ PIR935 – Law Centre NI

- 198. It has been represented to the Review by respondents that attendance at face-to face assessments is neither possible nor practical for claimants with certain conditions. Furthermore, requiring some claimants to attend is having a negative effect on their health, contradictory to the very intent of PIP.
- 199. In some instances, the value of the claimant attending the assessment was not apparent as any interaction with the assessor was limited. The Review does not see the value in compelling people to attend an assessment in in particular where they provide no input and no additional information is gleaned from their presence above that contained in their initial PIP2 application, whilst the process exacerbates their condition(s).

Recommendation 9:	Anticipated Outcome:
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.	This will ensure that claimants who cannot practically attend or represent themselves at an interview are not required to. This will reduce stress and anxiety for these claimants and their families and supporters. This will result in more efficient and effective assessments taking account of the realities of the conditions of claimants.

200. The above recommendation has the aim of alleviating the requirement for face-toface assessments for those for whom it is not appropriate. There will however still be a requirement for face-to-face assessments. For those that will undergo such an assessment the issues raised in this chapter will remain. The Review would stress the seriousness of the matters set out above and the need for prompt action.

Recommendation 10:

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

Anticipated Outcome:

This will move to address the issues raised by numerous claimants. The goal being to reduce stress and anxiety while ensuring the process is considerate of claimant's needs. This seeks to address the mistrust and fear claimants have for the process.

Assessors

201. The role of assessors features prominently in respondents' submissions to the Review. The main issue raised was that claimants would prefer an assessor qualified to comment on, or a specialist in, their condition. The Review has been told many times of assessors displaying a basic lack of understanding of claimant's conditions and an inability to perceive, even with the benefit of questioning, the full impact of the conditions on the claimant's life. Respondents told the Review that they felt that the assessor was not familiar with their case and had not read the PIP2 and supporting evidence. 202. Another area of concern raised by respondents about the conduct of assessors was that they seemed disengaged with the claimant and focused more on their computers. Claimants state that the assessors rarely looked at them or acknowledged the information being relayed to them. Overall there is a sense of disconnection which does not engender trust or confidence in either the assessor or the process.

"The person conducting the process failed to acknowledge the information I was relaying to her. There were several instances of [where] the assessor completely ignored my response to the questions. In the report sent to me there were references to my physical abilities which were not assessed on the day." BD, Claimant⁷⁶

"Had she looked up from her laptop, she would have seen that I was in fact quite anxious, tearful and sweating profusely from the distress of the whole degrading process. This process only served to exacerbate my [symptoms]." Claimant⁷⁷

"the interviewer commented at one stage that my son's condition was just like normal teenage behaviour, an insult to someone with [Autistic Spectrum Disorder]." CS, Claimant ⁷⁸

"I was asked how long I had my condition. Surely a so called medic should know that [Congenital Heart Defect] is a birth defect." Braveheart⁷⁹

"I will use an example of a case [the Alliance Party] dealt with: the client has epilepsy and the medically trained assessor commented that "the first I became aware of epilepsy was in an episode of EastEnders a few weeks prior to the assessment" – this would not fill you full of confidence." Alliance Party⁸⁰

- 78 PIR025 CS (Claimant)
- ⁷⁹ PIR900 Braveheart NI

⁷⁶ PIR266 – Claimant

PIR177 – Claimant

⁸⁰ PIR944 – Alliance Party

"it just shows what an absolute disgrace that assessor is for failing to see what that person is suffering in their head. ...when it comes to PIP, mental health issues and poor communication skills are ultimately brushed aside because assessors don't take those issues seriously enough nor realise how important they are."

AC, Claimant⁸¹

"I have attended a number of assessment interviews with patients. In my experience, most assessors are unable to get to grips with the idea of a fluctuating condition. It just appears to be a box-ticking exercise. The assessors ask the questions, but they don't relate to the individual in front of them. What has being able to tie your shoes, got to do with living with epilepsy? There is no room for flexibility to uncover the issues for people and the impact epilepsy has on people's daily lives." Epilepsy Action⁸²

- 203. Having observed a number of assessments the Reviewer acknowledges the complex role assessors have to perform. The Review understands that the preconceptions of the assessment itself may colour the claimant's views of the assessor, however, the number of representations from respondents cannot be ignored.
- 204. The Review formed the opinion that effective conducting of the face-to-face assessment relies on the assessor having, in addition to their professional experience, a number of wide-ranging skills including:
 - Well developed interpersonal skills with the ability to put people at ease
 - Advanced communication skills in order to be able to explain the complex process in straightforward terms without the use of jargon
 - Well developed computer skills and a sufficient typing speed to maintain the flow of the assessment without unnecessary delays whilst notes are typed
 - An ability to frame questions and provide time for the claimant to respond
 - An ability to involve the accompanying person to provide relevant evidence
 - Having had time prior to the assessment to fully consider the case files of the person to be assessed

⁸¹ PIR208 – AC (Claimant)

⁸² PIR951 – Epilepsy Action

- 205. The Review, in considering the training delivered to assessors has had discussions with professional representative bodies of various disciplines to ascertain their views regarding training, skill sets and relevant experience. In addition to this the Review notes that the Department's PIP statistics⁸³ provide information on the main disabling conditions of claimants, and the number of broad groupings of these conditions, which runs into the hundreds. The Review has formed the opinion that to expect an assessor to develop a working knowledge of such a range of conditions is ambitious under the current training regime.
- 206. With regard to specific conditions, it has been represented to the Review that, understanding areas such as mental health conditions, would require specific knowledge, background experience and training in that area. The Review has further heard that working in a general health care role does not necessarily equip a person to be able to understand all specific conditions with which they may be confronted during a PIP assessment. The Review has been told that if one were a nurse, but not currently a mental health nurse, it would be very difficult to cross over into working in the mental health discipline without significant retraining.
- 207. The Review is of the opinion that in order to effectively assess a claimant's functionality an assessor requires, for certain conditions such as mental health, or for less commonly known conditions, additional training in these areas. Moreover, claimants who indicate that they are affected by one of these conditions should be afforded the opportunity to see an assessor with enhanced training relevant to their condition. Such is the range of conditions classified by the Department that the Review believes it would be challenging for an assessor to have an advanced working knowledge of every condition.

Recommendation 11:	Anticipated Outcome:
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.	This should allow Assessors to have more familiarity with the conditions they are dealing with and allow them to report more accurately on the functional impacts of these conditions. It would increase the confidence of claimants in the ability of the assessor to report on their functionality effectively giving due cognisance to their conditions.

⁸³ www.communities-ni.gov.uk/articles/personal-independence-payment-statistics

Effectively Demonstrating Circumstances during the PIP Assessment Process

- 208. For the PIP assessment process to perform effectively a number of elements must be in place. Two such elements are the skills required for both the claimant and the assessor. Alignment of these two elements of the process enhances the likelihood of delivering an accurate decision. The Review is of the opinion that for the claimant to fully participate in the assessment process they, or those supporting them, require a range of knowledge and skills including:
 - An understanding of the PIP process in order to participate effectively
 - An understanding of the relevant information required and at what point that information should be submitted
 - An understanding of where to obtain the relevant information
 - The cooperation of those holding the relevant information to provide it in the required format
 - Well developed written communication skills together with organisational ability to make the initial telephone contact, subsequently complete the PIP2 Form, assemble and present the relevant information for submission
 - Well developed oral communication skills and a level of self confidence to communicate, with the assessor, about the claimant's functionality in each of the 12 designated descriptors, during the face-to-face assessment
- 209. If the claimant, does not have the skills and understanding outlined above the Review considers that they will struggle to effectively represent themselves during the PIP assessment process. Findings from the Call for Evidence strongly indicated that claimants find it difficult to identify where to obtain the wide ranging support they need.
- 210. The Review is of the opinion that, at the start of the PIP assessment process, claimants should be signposting to sources of independent advice and support. This would complement Recommendation 4.

Accuracy of Reports

211. The Review received 72 representations, as a result of the Call for Evidence survey alone, expressing deep concern about the accuracy of assessment reports. Respondents, and those who accompanied the claimant during the assessment process, felt that the Assessment Report did not reflect the reality of their assessment, nor accurately set out the information provided by them. These concerns were echoed by submissions from support organisations. "I have had chest and mental health problems all my life and I had bitten holes in my hands while waiting and cried in the interview - the questions were re asked in a different manner multiple times and I wasn't awarded one point - the report stated I was confident and maintained eye contact - this obviously wasn't the case!" AO, Claimant⁸⁴

"The assessment was very stressful for me and I cried the whole way through, but they assessed me as stable"

LC, Claimant⁸⁵

"Pip assessor who was a paramedic lied on their report to [the Department for Communities]. Says things that were completely untrue and said things that did not happen."

Claimant⁸⁶

- 212. Respondents told the Review of perceived inaccuracies which they attributed to assessors confusing individual claimant's notes, omitting details or copying and pasting between reports.
- 213. The Review has observed assessors in circumstances where it proved difficult for them to get clear answers to questions. In an attempt to bring clarity to an answer, the assessor sought to sum up the limited information given by saying, ".... So what you are saying is ... ". The Review can therefore understand that the answer which appears in the report may not reflect the claimant's recollection of the process.
- 214. The Review has been told by respondents of times that the assessor blocked input by the person accompanying the claimant, thus restricting the flow of information during the assessment. If this were the case it could lead to a report being seen as inaccurate by a claimant and their accompanying person.

"The assessor who came out to me for the face to face, did not listen to me nor my wife spoke over the top of me and did not know anything about my conditions or medication" GT, Claimant⁸⁷

⁸⁴ PIR078 – AO (Claimant)

⁸⁵ PIR218 – TB (Claimant)

⁸⁶ PIR227 – Claimant

⁸⁷ PIR133 – GT (Claimant)

- 215. The Review has heard from assessors regarding home assessments during which they felt uncomfortable due to the tone of language or behaviour directed at them; the presence of several people attending the home assessment; family pets being loose in the room; the assessor having their exit blocked.
- 216. The Review acknowledges the strongly held views and opinions expressed on the matters of the assessment and the assessor. However, it has not been possible for the Review to substantiate what actually took place in these cases.
- 217. In the interests of openness, transparency and natural justice it would be helpful to have a point of reference which could be consulted to determine what was, or was not, said. Such a record could assist the assessor in later writing their report, after having conducted several consecutive assessments. This could also take pressure off the requirement for detailed note taking during the assessment, allowing for more interaction between the assessor and claimant.
- 218. An audio-visual record would provide protection for all parties, the claimant, and their accompanying person, the assessor, Capita and the Department. Access to an audio-visual record could also help to identify training requirements, in addition to lessening the need for Mandatory Reconsideration and perhaps appeal, thus streamlining the PIP assessment process.
- 219. The Review understands DWP intend to introduce video recording of assessments as standard⁸⁸ and that this will be piloted with a view to rolling this out across GB. The Review would encourage the Department to maintain parity with developments in GB.

Recommendation 12:	Anticipated Outcome:
The Department should introduce audio-visual recording of assessments in both home and assessment centre locations.	This will provide an accurate record of what was said during the assessment. This will protect all parties, support training and, it is hoped, lessen disputes and improve confidence and trust in the PIP assessment process. Further benefits of audio-visual recording would include having evidence available to support the observations referenced by the assessor and to indicate a claimant's ability.

PIP: Written Statement – HCWS733 www.parliament.uk/business/publications/written-questions-answers-statements/ written-statement/Commons/2018-06-05/HCWS733/

Informal Observations Made by Assessors during the Assessment

220. The Review has been told of occasions when an assessor's report contains conclusions which it would appear have been based on visual observations. These are alleged to have been made by the assessor, during the assessment or at a time when the claimant was in the assessment centre. The Review acknowledges the benefit of inclusion in the assessment of well documented and justified observations. However, the Review notes the concerns regarding observations. If during the assessment conclusions are drawn as a result of observations undertaken these need to be fully explained and justified.

"I had a client who dropped out of university because of crippling anxiety, applied for PIP and was awarded the standard rate daily living and mobility. She is currently appealing the PIP decision because we think she should get the enhanced rate. The PIP medical assessor noted that because she had been at university, she had no cognition problems and therefore presumably would not suffer from mental health issues which would affect her daily life!"

National AIDS Trust⁸⁹

"My assessor's report was a combination of incoherent self-contradiction (as in some of the sentences made no grammatical sense at all) and outright lies. They accused me of faking difficulty standing up. They said that because I was overweight I couldn't be struggling to eat regularly. I have hypermobility and they said that because I was playing with a scarf tassel during the interview I couldn't possibly have difficulty using my hands. They said I used too many intellectual words to have cognitive problems. It was absolutely offensive and ridiculous." VC, Claimant⁹⁰

"In the assessment and the subsequent appeal, I was told that I couldn't possibly have difficulty preparing a meal because I was so fat that it was obvious I was overeating. This is despite medical evidence from my GP that my weight gain was recent, and caused by underactive thyroid, and despite the fact that I provided evidence that I did have difficulty preparing meals and was reliant on family to help me." Claimant⁹¹

⁸⁹ PIR947 – National AIDS Trust

⁹⁰ PIR201 – VC (Claimant)

⁹¹ PIR012 – Claimant

"The decision says 'At assessment you were dressed appropriately and appeared well nourished! YES because his family ensure that he is as he lives at home with his parents!!!!! AND 'You were relaxed and calm for assessment...made good eye contact!!!!! oh yes and what does that tell anyone!!!!!!!! He was raised to be mannerly and respectful particularly to visitors in his home, does that deny the fact that he is physically disabled!!!! What does any of that have to do with a physical disability? So, improvements [to the assessment] well..... observations relating to the physical condition under examination and not how many hairs were combed on someone's head might be more relevant to an assessment!" KB, Claimant⁹²

221. The use of observational methods must be undertaken with caution. Such an approach requires skill, experience, and an awareness of both the short observational period of the assessment and the potential subjective nature of observations. To draw conclusions from observations that are not then fully justified, in the assessment report, jeopardizes the credibility of both the assessor and the PIP assessment process.

Questions Regarding Self Harm and Suicide

222. The Review has noted respondents who were either offended or upset by the inclusion of questions regarding self harm and suicide in the assessment. During the observed assessments the Reviewer noted that questions were raised by assessors about suicidal ideations. The Reviewer observed additional stress experienced by claimants when the subject was raised. In one case, the accompanying person (a friend), had not been aware of the claimant's thoughts about suicide.

"Our constituent suffers from PTSD as a result of sexual and other abuse in her life. She was re-traumatised by this experience and feels the PIP assessment has contributed to a further deterioration in her mental health. Likewise, the claimant in question was asked very pointed questions about suicide, for example, she was asked if she had ever attempted to take her own life." SDLP⁹³

"The assessor did not seem to know that my condition was a birth defect, and asked me when I was diagnosed with it, even though she said she was a nurse. When I said I had anxiety around my weak bladder, she asked if I was suicidal, which seemed very inappropriate."

AC, Claimant⁹⁴

⁹² PIR235 – KB (Claimant)

⁹³ PIR950 - SDLP

⁹⁴ PIR206 – AC (Claimant)

- 223. Based on the current PIP Assessment Guide, the Review understands questions regarding suicide are asked to determine what level of functional ability a claimant has in the daily living areas *Making Food*, *Managing Therapy* and in the mobility area *Going Out*.⁹⁵
- 224. The Review has heard from support organisations, trained professionals and regulatory bodies that the raising of the subject of self harm and suicide in the context of a relatively short, wide-ranging assessment process is at best unhelpful and at worst potentially dangerous. The assessor may ask the questions but is then not involved in dealing with any possible consequences of the issue having been raised.
- 225. The Review has been informed that the assessor will ask the claimant, in the case where they indicate they have suicidal ideations, if they are content this information is shared with their GP. The Review did not hear this point being put to claimants during the observed assessments, nor does the Review regard this as an adequate response to such a serious matter.
- 226. With particular regard to the disclosure of reference to suicide which was contained in the claimant's PIP2 form; this has been described to the Review as a breach of confidentiality if mentioned in front of others who may be unaware of the claimant's ideations. The claimant has no indication from the PIP2 form that this line of questioning may be pursued.
- 227. The Review questions raising the subject of self harm and suicide in the context of an assessment which is both relatively short, and conducted by an assessor who has not previously had engagement with the claimant. The five week training provided to assessors cannot be expected to equip them to deal with matters such as suicidal ideations. Trained professionals have indicated to the Review that they would not approach this matter until they had developed trust with a patient or person they were counselling over a significant period of time, and that to do so, in the context of a relatively short one-off assessment, when others may be present, would border on the unethical.
- 228. The Review is of the opinion that the subject of self harm and suicide is something that should not be included in an assessment.

⁹⁵ PIP Assessment Guide – Part 2 Assessment Criteria paragraph 2.2.11 et seq, Section 2.4 Mobility Activities.

Recommendation 13:

- (A) The Department, in conjunction with the assessment provider Capita, should remove or revise the use of informal observations to support assessor's reports. If revised, assessors should be required to justify the conclusions which they have drawn from their observations.
- (B) 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.

Anticipated Outcome:

- (A) To ensure that inaccurate conclusions are not included in Assessor's Reports by inappropriate use of informal observations. This would be assisted by the introduction of audio-visual recording.
- (B) To ensure that unnecessary distress or harm is not caused by inappropriate discussions of suicide and self harm and that the Assessor does not breach the confidentiality of the claimant in discussing such matters.

Effectiveness of the Assessment

- 229. The Review considers the Assessment to be a key element of the overall process. It was the area of the PIP assessment process which drew the most concerns from respondents, both individually and organisationally. Similar concerns were referenced in Gray's first Review Report, so it is not solely an NI issue.
- 230. The Review makes recommendations about the assessment and urges the Department to place priority on addressing these matters. The assessment, coming as it does early in the process must be open, transparent and trusted. Currently it is a source of anxiety, stress, anger and frustration. This needs to change.
- 231. Chapter 10, which follows, gives consideration to PIP Decisions.

Chapter 10: PIP Decisions

Making a PIP Decision

- 232. When the assessor's report is signed off, which may include internal Capita auditing processes, it is then sent to Departmental Case Managers with the other supporting documents, for them to make a decision on entitlement. For the avoidance of doubt the Review would stress that it is the Departmental Case Manager who makes the decision on entitlement, award rate and period of award. This decision is made using all the available evidence including, but not limited to, the assessor's report.
- 233. The Review has had the opportunity to meet Case Managers and observe their work. The Review has witnessed Case Managers challenge the content of assessment reports, where sufficient justification has not been set out in relation to the conclusions reached, based on the information available in the case file.
- 234. The Review has witnessed these 'key points' throughout the PIP assessment process, when there is a 'challenge function'. This is based on consideration of evidence contained in the case file, when it is judged that more detailed justification is required for the conclusions drawn. At this point the Department can refer the report back to Capita for clarification or amendment.
- 235. It is also possible that, when a Case Manager examines a case, more evidence has been received which was not available to the assessor at the time of their report writing. In this scenario the Case Manager will refer the new evidence to the assessor, who will consider if it would change the outcome of their report. If changes to the assessor's report are required a supplementary report is produced and forwarded to the Case Manager.
- 236. The Review can understand why, when such apparent changes are highlighted later in the process, claimants and their representatives will question why such changes have been made. The Review considers that there needs to be a clear way of recording the justification for such changes made to reports and any adjustments to decisions.

Decision Notifications

237. When the Departmental Case Manager makes their decision they will also put the claim into payment if an award has been made. The claimant will subsequently receive a notification advising them of the outcome of their claim. The Review has seen examples of decision notifications and has concerns as to how clear they would be to a claimant who is not well versed in PIP processes.

The Assessor's Report

238. It is apparent from representations made to the Review that claimants feel they would benefit from seeing their assessment report either before the decision is made or along with their decision notification.

"I was unsure but did not realise that information would be used and reported so inaccurately. It would have been fairer to allow claimants to have sight of report before any decision made so that inaccuracies could have been discussed changed etc. This would be good practice."

PM, Claimant⁹⁶

239. The Review believes that for openness, transparency and in the pursuit of natural justice, claimants should have sight of their assessment report. This would allow for a better understanding of how the decision was arrived at. This would also allow them to consider, from a more informed position, if they disagree with the decision and wish to dispute it. This along with audio-visual recording would enhance the openness and transparency of the process, thus increasing trust.

Recommendation 14:	Anticipated Outcome:
The Department should put in place arrangements for a copy of the Assessor's Report to be made available to claimants along with the decision letter.	This would allow for a better understanding of how the decision was arrived at and allow claimants to consider if they wish to dispute the decision from a more informed position. Provision of the report should also improve claimant trust in the integrity of the decisions being made if they can see the basis for those decisions.

240. Disputed decisions are discussed in Chapter 11 as are appeals. Consideration is set out regarding Medical Evidence.

⁹⁶ PIR173 – PM (Claimant)

Chapter 11: Disputed Decisions

Mandatory Reconsiderations

- 241. The introduction of a requirement to have a Mandatory Reconsideration of any decision on benefit entitlement, prior to a claimant lodging an appeal, was included in the *Welfare Reform Order (NI) 2015*. Where the Case Manager makes a decision the claimant has the right to ask the Department to explain the decision further or have their decision looked at again, this is known as a Mandatory Reconsideration. This must be requested within one month of the date of the initial decision and can be made by telephone or in writing.
- 242. As part of evidence gathering the Reviewer spent time with Mandatory Reconsideration Case Managers in the PIP operations branch observing how they work.
- 243. Within the Mandatory Reconsideration process:
 - The Mandatory Reconsideration will be assigned to a different Case Manager than that who made the original decision.
 - A decision can be reconsidered with or without further evidence being supplied.
 - The different Case Manager looks at all evidence currently available and any additional evidence provided. If they consider it to be relevant, the case will be referred back to Capita for consideration and advice.
 - Capita will respond with either a no change report or details of the areas within the original report that should be changed. In both cases Capita will provide justification for their response.
 - Once the supplementary assessment report is completed, details will be returned to the Department to progress.
- 244. As part of the Call for Evidence the Review has heard that the levels of stress, anxiety, fear and apprehension, experienced by claimants during the PIP assessment process, has meant that they could not face either asking for Mandatory Reconsideration or undergo further stress and anxiety which could result from the process.
- 245. Additionally, for those claimants who had been awarded PIP, the fear of losing part or all of, their award, meant that they were unwilling to request a Mandatory Reconsideration.

"I didn't [because] I had no physical or mental energy to cope. Plus was too afraid the whole claim would be denied."

KT, Claimant⁹⁷

⁹⁷ PIR820 – KT (Claimant)

"[I was] told if I did appeal would loose what award I already had." SO, Claimant⁹⁸

246. Respondents who indicated that they had disputed the outcome of their claim commented that the process was not only stressful and complex but, in those cases where the original decision had been upheld, there was a belief that additional information had not been taken into consideration.

"Only done. [But] this just adds to a family's stress and work load I have to take my wife to 2 sometimes 3 appointments every week and I do not need extra form filling." AC, Claimant⁹⁹

"I had to get help from citizens advice, I had no idea what to do, I didn't understand what I needed to do, I found it so stressful I couldn't even think clearly, the reconsideration process again very very complex." Claimant¹⁰⁰

"I asked for a mandatory reconsideration. I received a letter back stating the exact same assessment as the original rejection. I felt that my comments had not been considered at all. I felt part of a process to rid the benefits system of claimants, degraded and embarrassed and that my condition is not genuine." DG, Claimant¹⁰¹

Appeals

- 247. The right of appeal to an Independent Tribunal arises only after the Mandatory Reconsideration has taken place. This is where a claimant is still dissatisfied with the decision. Claimants have one month from the date of their Mandatory Reconsideration decision to lodge an appeal directly with The Appeals Service.
- 248. The claimant is advised of their appeal rights when they are notified of the outcome of the Mandatory Reconsideration by way of two copies of the Mandatory Reconsideration Notice. The claimant is required to submit one copy of the Mandatory Reconsideration Notice to The Appeals Service with their appeal, as confirmation that a Mandatory Reconsideration has been completed.
- 98 PIR159 SO (Claimant)
- 99 PIR238 AC (Claimant)
- ¹⁰⁰ PIR195 Claimant

¹⁰¹ PIR245 – DG (Claimant)

249. The Review notes that of 4,665 PIP appeal disposals¹⁰² at the end May 2018, 3,654 appeals were heard. Of these 47% (1,709) confirmed the original award, 52% (1,917) overturned the original award and resulted in a more advantageous outcome for the claimant.

Medical Evidence used at Appeal

- 250. It is not for this Review to comment on the operation of the Appeal Tribunal. The Review is aware of the priority, placed by the Tribunal, on the availability of the claimant/appellant's medical notes held by their GP. The Appeals Service will ask if the appellant wishes to have their medical notes made available to the Tribunal and to sign consent in this regard. The appellant's medical notes are then considered by the Tribunal, alongside the response to the appeal which is submitted by the Department.
- 251. The Review observes that in arriving at its decision, the Tribunal considers the appellant's medical notes as provided by the GP. The Review is aware that medical notes are not regularly sought earlier during the PIP assessment process and therefore are not available to the assessor or the Departmental Case Managers as a matter of course.
- 252. The Review considers that the current arrangements are inconsistent as the Tribunal has access to medical notes which are not available earlier in the process. This could be resolved by the availability of the GP Short Summary Report linked to Recommendation 7.

"My mental health deteriorated to such a degree that the deadline had passed and it was too late for me to appeal. My family basically had me under suicide watch all over the Christmas holiday period and I had no will to live never mind appealing a PIP decision just to be called a liar and rejected yet again. I am about to send in new evidence to have PIP reconsider my daily living needs since my needs are greater now than ever before, partly due to the ESA/PIP claim processes." Claimant¹⁰³

¹⁰² Figures provided by The Appeals Service Northern Ireland

¹⁰³ PIR120 – Claimant

"With the aid of Citizens advice I had two tribunal APTS the first was deferred due to new evidence which [the Citizens Advice Bureau] had sent and the tribunal felt they hadn't enough time to look at it. I was accompanied by a [Citizens Advice Bureau] representative at both APTS. The tribunal was daunting and thorough and awarded me STD care and STD mobility. The overall claim took more than a year, without [Citizens Advice Bureau] support I would have given up after reconsideration stage."

DA, Claimant¹⁰⁴

"I asked for an appeal and am still waiting hear when this will be held. It will be nearly a year since I originally put in my claim for PIP." NH, Claimant¹⁰⁵

"Yes - but now more than 6 months later we still await a response and a date for an appeal hearing. Enquiries to the Appeal Service on 6 March 2018 indicate that [the Department for Communities] has still to provide its submissions to the Appeals Service to enable the start of the process for fixing the hearing date. It is difficult to understand why [the Department for Communities] is given so much leeway by the Appeals Service to provide their submission. Justice delayed is justice denied; but the long delay by the [the Department for Communities] and Appeal Service (who blame [the Department for Communities] is detrimental financial consequence for us as users of the Motability car scheme. The appeal was submitted on 25 August 2017. But the long delay has meant we were forced to return the car to Motability on 9 December 2017. It is wholly unacceptable that claimants are forced to make decisions about car purchase before their appeals are heard."

JC, Claimant¹⁰⁶

"As mentioned above, the appeal process I feel was deliberately complicated and I read it on numerous occasions with the intention of appealing. Every time I read it, it put me off and I thought I'll sit down and properly read this when I can concentrate on it properly. Unfortunately I never got the chance to do this and missed the deadline to appeal. Even looking at the last two questions, I'm not sure what the difference was between reconsideration process and appeals process." Claimant¹⁰⁷

¹⁰⁴ PIR207 – DA (Claimant)

¹⁰⁵ PIR814 – NH (Claimant)

¹⁰⁶ PIR818 – JC (Claimant)

¹⁰⁷ PIR186 – Claimant

"This was a total disaster. The months of waiting and then at my appeal the first question asked to me was "was I prepared to risk losing my award by continuing with the appeal meeting" this made me feel worthless. No updates were provided of the process and the time it took had a massive impact on my condition due to the stress caused"

L, Claimant¹⁰⁸

"I have an appeal in at present. Had a date for court which on the morning of the meeting I received a phone call to cancel as there had been a problem with the paperwork. The stress I have been through from the start of the PIP process has been awful....my anxiety levels are through the roof. My date for review of my PIP is for 2020. My condition is not going to get better and there is no cure so I will have to go through this whole stressful process in 2 years again" Claimant¹⁰⁹

253. The next chapter discusses support, training and positive developments.

¹⁰⁸ PIR129 – L (Claimant)

¹⁰⁹ IR010 – JB (Claimant)

Chapter 12: Support, Training and Positive Developments

Support and Training for Welfare Reform

- 254. The Review notes that as part of the Fresh Start Agreement, £8 million funding was committed over a four year period, to put in place additional independent advice services to support people through the introduction of welfare reform. A number of initiatives have been funded through the independent advice sector and other key organisations.
- 255. The Review has been made aware that Welfare Reform Awareness Sessions have been delivered to 1,500 people who work with impacted claimants. This included elected representatives, statutory bodies, and constituency office staff together with voluntary and community organisations. A project to assist claimants with the tribunal representation has been introduced in the Law Centre NI.
- 256. Since November 2016 the Department has funded an additional 37 welfare reform faceto-face advisers across Northern Ireland. New services include support and Tribunal representation for claimants appealing the impact of the welfare changes on their benefit entitlement. The Welfare Reform Front-Line Advisor Training Programme included information regarding PIP form completion.

Departmental Support during the PIP Assessment Process

- 257. Where reassessment claimants do not respond to the invitation to claim PIP within four weeks (following several contact) a referral process exists. This is undertaken by Outreach Officers from the Department's Make the Call Wraparound Service. Known as non-compliance visits, the Outreach Officer will contact the claimant in order to arrange a suitable time for a home visit.
- 258. At the home visit the Outreach Officer will speak with the claimant to understand why they have not made contact with the Department to make their claim to PIP. If the claimant wishes to proceed with their claim to PIP the Outreach Officer will encourage the claimant to contact the Department, or they will ring PIP on the claimant's behalf and complete the PIP1 together. From April 2017 to March 2018, over 1,600 referrals for non compliance visits were sent by PIP to the Make the Call Wraparound Service.

- 259. The Make the Call Wraparound Service provides advice and assistance to claimants regarding their potential entitlement to benefits and other Government supports. The service is delivered via the 'Make the Call' telephony service and by Community Outreach Officers who, as well as carrying out information sessions, have also received over 1,800 referrals (including those from PIP staff) to help claimants complete PIP2 forms via home visits.
- 260. The aim of these supporting actions are to ensure that all possible efforts have been made to assist claimants during the PIP assessment process.

Engagement with Support Organisations

- 261. The Department has worked with the British Deaf Association and the Advice Sector to develop a programme of initiatives to support claimants with hearing impairment. This programme delivered six PIP road shows across NI to customers with hearing impairment. The Reviewer attended one of the road show sessions and noted the positive reaction.
- 262. In addition, the Review has heard of several initiatives involving Capita, the Department and thematic support organisations. These initiatives have served to raise awareness and improve understanding of a number of medically diagnosed conditions, which have far reaching impacts on individuals, including fluctuating conditions. Some of the initiatives have taken the form of one or two meetings, whilst others involve a series of on-going exchanges of information. The Review notes that Capita has put in place a mental health champion.
- 263. In January 2017, a process for sharing information held by the Victims and Survivors Service, in relation to individuals known to be in receipt of DLA Care Component as a result of their Conflict/Troubles-related injuries, was agreed. This is viewed as a strong and positive working relationship between Victims and Survivors Service and Departmental staff. The Review commends this approach.
- 264. The Reviewer attended a community arts initiative which explored the PIP assessment process using case studies and which was followed by an open discussion. This approach to awareness raising and communication with claimants, families and supporter networks provides an additional opportunity to engage with communities.

Informative Support Videos

265. The Review notes that DWP has recently produced (Spring 2018) several information videos, following recommendations in the Gray Report. The short films cover key aspects of PIP and include sign language interpretation. It is understood that the Department is preparing NI versions of the videos which is to be welcomed.

266. The Law Centre NI has a well developed, web-based, digital guide which contains a number of information films. These short films introduce and explain aspects of the PIP process in a clear and concise way. It is of particular value that the Tribunal is clearly explained for those who may not have experience of that process. The digital guide is a well used resource and an effective method of communication.

Department for Communities and Capita Engagement

- 267. The Review has been made aware that a series of meetings have been arranged between Departmental and Capita staff. The meetings are designed to provide a platform for the exchange of views, addressing matters arising from operational experience, increasing understanding between staff from the various parts of the PIP process who might not otherwise meet each other, improving understanding about functions and enhancing information flow. The Review considers that this level of meeting is to be encouraged as outcomes can include improvements to process and systems.
- 268. The final chapter considers the response to this Review and the subsequent Review scheduled for 2020.

Chapter 13: Moving Forward

Response to this Report

269. As indicated in the foreword, in presenting this Independent Review Report, the Reviewer cannot set out a clear process by which the contents, including the recommendations will be considered, in the absence of The Executive and an Assembly. The Review would urge the Department for Communities to set out a timescale within which a response will be forthcoming. The Review encourages urgent and positive action, by the Department, to address the issues raised in this Report; issues which are impacting negatively on the PIP assessment process in addition to reducing trust and confidence.

Second Independent Review

- 270. By the year four review, due in 2020, PIP will have had significantly more time to establish itself and the reassessment of the DLA caseload is expected to be completed. This First Review considers that there are several areas which merit examination during the Second Review. An update on progress against the recommendations in this Report would of course be considered essential.
- 271. A robust analysis of the outcomes of the DLA reassessment is required; as such an analysis was not possible due to the unavailability of data at the time of writing this report. As the caseload will have had time to mature, an examination of how the award review process is conducted would be appropriate.
- 272. Furthermore, given the understandable focus on reassessment cases in this report, it would be appropriate to examine the process for first-time claimants to PIP. The Review understands that more new claimants disengage with the process than with reassessment cases¹¹⁰ and the reasons for this, and the new claimant journey, should be examined.
- 273. Any further developments across the UK PIP landscape should be considered, in particular the implementation of the changes resulting from the recent High Court Ruling affecting PIP¹¹¹.

¹¹⁰ Table 5 and paragraph 69 et seq.

¹¹¹ Paragraph 44 et seq



Annex 1:

Contributors to the Review

Responses to the Online Questionnaire

Serial	Name	Serial	Name	Serial	Name
PIRO01	VK (Claimant)	PIR101	Action Deaf Youth	PIR201	VC (Claimant)
PIROO2	Northern Health & Social Care Trust	PIR102	CP (Claimant)	PIR202	SR (Claimant)
PIR003	Claimant	PIR103	Claimant	PIR203	SF (Claimant)
PIR004	L (Claimant)	PIR104	TN (Claimant)	PIR204	VM (Claimant)
PIR005	Claimant	PIR105	Claimant	PIR205	ST (Claimant)
PIR006	Claimant	PIR106	Claimant	PIR206	AC (Claimant)
PIR007	SR (Claimant)	PIR107	RD (Claimant)	PIR207	DA (Claimant)
PIR008	JR (Claimant)	PIR108	Claimant	PIR208	AC
PIR009	GD (Claimant)	PIR109	SW (Claimant)	PIR209	JM (Claimant)
PIR010	JB (Claimant)	PIR110	Claimant	PIR210	Claimant
PIR011	LM (Claimant)	PIR111	GL (Claimant)	PIR211	AS (Claimant)
PIR012	Claimant	PIR112	HM (Claimant)	PIR212	RO (Claimant)
PIR013	GC (Claimant)	PIR113	Claimant	PIR213	Claimant
PIR014	CG (Claimant)	PIR114	Claimant	PIR214	EQ (Claimant)
PIR015	Citizens Advice Fermanagh	PIR115	Claimant	PIR215	VC (Claimant)
PIR016	National Autistic Society NI	PIR116	Bangor Physiotherapy	PIR216	Claimant

PIR017	ML (Claimant)	PIR117	Anonymous	PIR217	NK (Claimant)
PIR018	SP (Claimant)	PIR118	TM (Claimant)	PIR218	LC (Claimant)
PIR019	Claimant	PIR119	CM (Claimant)	PIR219	Tuberous Sclerosis Association
PIR020	CL (Claimant)	PIR120	Claimant	PIR220	Claimant
PIR021	DC (Claimant)	PIR121	WM (Claimant)	PIR221	SA (Claimant)
PIR022	Citizen's Advice Mid Ulster	PIR122	Claimant	PIR222	GA (Claimant)
PIR023	LP (Claimant)	PIR123	MC (Claimant)	PIR223	LN (Claimant)
PIR024	Claimant	PIR124	DB (Claimant)	PIR224	LD (Claimant)
PIRO25	CS (Claimant)	PIR125	MM (Claimant)	PIR225	Southern Health and Social Care Trust
PIR026	SM	PIR126	HT (Claimant)	PIR226	Claimant
PIR027	Anonymous	PIR127	RM (Claimant)	PIR227	Claimant
PIR028	Claimant	PIR128	Claimant	PIR228	Action for M.E.
PIR029	Claimant	PIR129	L (Claimant)	PIR229	MM (Claimant)
PIR030	Claimant	PIR130	EN (Claimant)	PIR230	GO (Claimant)
PIR031	Claimant	PIR131	EM (Claimant)	PIR231	Claimant
PIR032	PF (Claimant)	PIR132	RS (Claimant)	PIR232	Anonymous
PIR033	Citizens Advice Bureau	PIR133	GT (Claimant)	PIR233	FM (Claimant)
PIR034	AM (Claimant)	PIR134	GT (Claimant)	PIR234	SY (Claimant)
PIR035	PM (Claimant)	PIR135	CE (Claimant)	PIR235	KB (Claimant)
PIR036	GH (Claimant)	PIR136	Claimant	PIR236	Claimant
PIR037	JD (Claimant)	PIR137	NG (Claimant)	PIR237	Claimant
PIR038	Claimant	PIR138	Claimant	PIR238	AC (Claimant)

PIR039	Claimant	PIR139	Claimant	PIR239	Claimant
PIR040	CO (Claimant)	PIR140	Willowbank Community Resource Centre	PIR240	British Deaf Association
PIRO41	CA (Claimant)	PIR141	CM (Claimant)	PIR241	RM (Claimant)
PIR042	Claimant	PIR142	WM (Claimant)	PIR242	BC (Claimant)
PIR043	Claimant	PIR143	Claimant	PIR243	JS (Claimant)
PIR044	DY (Claimant)	PIR144	Claimant	PIR244	IH
PIRO45	TH (Claimant)	PIR145	Claimant	PIR245	DG (Claimant)
PIRO46	KO (Claimant)	PIR146	Anonymous	PIR246	Cystic Fibrosis Trust
PIR047	Anonymous	PIR147	JG (Claimant)	PIR247	FW (Claimant)
PIR048	TH (Claimant)	PIR148	JW(Claimant)	PIR248	Support and Recovery Community Team
PIR049	KM (Claimant)	PIR149	Claimant	PIR249	Disability Action
PIR050	Claimant	PIR150	JM (Claimant)	PIR250	PW (Claimant)
PIR051	Sarah Kay Neighbourhood Development Association	PIR151	NM (Claimant)	PIR251	TB (Claimant)
PIR052	HW (Claimant)	PIR152	AJ (Claimant)	PIR252	M (Claimant)
PIR053	Claimant	PIR153	AM (Claimant)	PIR253	PG (Claimant)
PIR054	Claimant	PIR154	MW (Claimant)	PIR254	PL (Claimant)
PIR055	SC (Claimant)	PIR155	Claimant	PIR255	DF (Claimant)
PIR056	KN (Claimant)	PIR156	Anonymous	PIR256	Claimant
PIR057	RM (Claimant)	PIR157	Anonymous	PIR257	MJ (Claimant)
PIR058	Claimant	PIR158	T (Claimant)	PIR258	Claimant
PIR059	MS (Claimant)	PIR159	SO (Claimant)	PIR259	SF (Claimant)

PIR060	MH (Claimant)	PIR160	LM (Claimant)	PIR260	ZK (Claimant)
PIR061	AG (Claimant)	PIR161	JB (Claimant)	PIR261	Claimant
PIR062	AO (Claimant)	PIR162	Rathgill Community Association	PIR262	Claimant
PIR063	Claimant	PIR163	DP (Claimant)	PIR263	MM (Claimant)
PIR064	Claimant	PIR164	Claimant	PIR264	PM (Claimant)
PIR065	Claimant	PIR165	SM (Claimant)	PIR265	Claimant
PIR066	Claimant	PIR166	Claimant	PIR266	BD (Claimant)
PIR067	GS (Claimant)	PIR167	Claimant	PIR267	AD (Claimant)
PIR068	EM (Claimant)	PIR168	Claimant	PIR268	SF (Claimant)
PIR069	Citizens Advice Bureau	PIR169	Claimant	PIR269	Claimant
PIR070	CO (Claimant)	PIR170	Claimant	PIR270	Claimant
PIR071	Claimant	PIR171	Claimant	PIR271	Claimant
PIR072	FS (Claimant)	PIR172	GB (Claimant)		
PIR073	HW (Claimant)	PIR173	PM (Claimant)		
PIR074	TS (Claimant)	PIR174	DC (Claimant)		
PIR075	JC (Claimant)	PIR175	PM (Claimant)		
PIR076	AM (Claimant)	PIR176	Claimant		
PIR077	MM (Claimant)	PIR177	Anonymous		
PIR078	AO (Claimant)	PIR178	Anonymous		
PIR079	FP (Claimant)	PIR179	Claimant		
PIR080	Claimant	PIR180	MG (Claimant)		
PIR081	Claimant	PIR181	Claimant		
PIR082	FM (Claimant)	PIR182	SH (Claimant)		
PIR083	NB (Claimant)	PIR183	CB (Claimant)		
PIR084	ER (Claimant)	PIR184	JR (Claimant)		

PIR085	KA (Claimant)	PIR185	JL (Claimant)	
PIR086	Claimant	PIR186	Claimant	
PIR087	JC	PIR187	JT (Claimant)	
PIR088	MG (Claimant)	PIR188	MC (Claimant)	
PIR089	Claimant	PIR189	JL (Claimant)	
PIR090	Claimant	PIR190	BM (Claimant)	
PIR091	FD (Claimant)	PIR191	AM (Claimant)	
PIR092	HW (Claimant)	PIR192	SM (Claimant)	
PIR093	Claimant	PIR193	KQ (Claimant)	
PIR094	DC (Claimant)	PIR194	RG (Claimant)	
PIR095	Claimant	PIR195	Claimant	
PIR096	MG (Claimant)	PIR196	JK (Claimant)	
PIR097	CC (Claimant)	PIR197	IM (Claimant)	
PIR098	JM (Claimant)	PIR198	JR (Claimant)	
PIR099	EW (Claimant)	PIR199	PM (Claimant)	
PIR100	Claimant	PIR200	KT (Claimant)	

Paper and Email Responses to the Questionnaire

Serial	Name
PIR800	Claimant
PIR801	Claimant
PIR802	Claimant
PIR803	TB (Claimant)
PIR804	SH (Claimant)
PIR805	SH (Claimant)
PIR806	LS (Claimant)
PIR807	Claimant
PIR808	NH (Claimant)
PIR809	WW (Claimant)
PIR810	Claimant
PIR811	ОМ
PIR812	CC (Claimant)
PIR813	Royal College of Psychiatrists in Northern Ireland
PIR814	Mindwise and Mental Health Money Advice Service
PIR815	GD (Claimant)
PIR816	SM (Claimant)
PIR817	Parkinson's UK
PIR818	JC (Claimant)
PIR819	Positive Life
PIR820	KT (Claimant)
PIR821	Relatives for Justice
PIR822	Brain Tumour Charity
PIR823	National AIDs Trust
PIR824	Wave Trauma Centre
PIR825	AC (Claimant)

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PIR826	MS Society NI
PIR827	North West Forum of People with Disabilities
PIR828	Claimant
PIR829	PH (Claimant)
PIR830	Calms
PIR831	Omagh Support & Self Help Group
PIR832	South East Fermanagh Foundation
PIR833	SJ (Claimant)

Organisations / Individuals which provided written submissions other than the Call for Evidence questionnaire

Written submissions Area	Source
Advice Sector and Support Groups	Advice NI
	Arthritis Care
	Bravehearts NI
	British Deaf Association
	Citizens Advice Bureau
	Commission for Victims and Survivors for NI
	Cystic Fibrosis
	Disability Action
	Family Fund
	Huntington's Disease Association NI
	Law Centre NI
	MacMillan Cancer Support
	Marie Curie
	NIPSA
	Participation and the Practice of Rights
	Trussell Trust
	Victims and Survivors Group
Elected Representatives / Political Parties	Alliance Party
	Democratic Unionist Party
	SDLP
	Sinn Fein
	Ulster Unionist Party
Letters from Individuals	Six letters received from individuals

Annex 2:

Review Recommendations

Recommendation 1:

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.

Recommendation 2:

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.

Recommendation 3:

The use of DLA evidence to support reassessment cases should cease.

Recommendation 4:

- (A)The Department should review written material, particularly
 - (i) the initial letters to claimants and
 - (ii) the subsequent decision letters to claimants, ensuring clarity of message and the avoidance of jargon.
- (B) The Department should develop simple straightforward material describing the PIP assessment process.

Recommendation 5:

- (A)That the Department ensures there are suitable, accessible options for those with particular needs such as communication 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.
- (B)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.

Recommendation 6:

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.

Recommendation 7:

So that the 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 to obtain a GP Short Summary Report to support the PIP2 submission. This should be requested for every claim.

Recommendation 8:

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.

Recommendation 9:

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.

Recommendation 10:

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

Recommendation 11:

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.

Recommendation 12:

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

Recommendation 13:

- (A)The Department, in conjunction with the assessment provider Capita, should remove or revise the use of informal observations to support assessor's reports. If revised, assessors should be required to justify the conclusions which they have drawn from their observations.
- (B) 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.

Recommendation 14:

The Department should put in place arrangements for a copy of the assessor's report to be made available to claimants along with the decision letter.

Annex 3:

Independent Scrutiny Group

- Professor Madeleine Leonard (Chair) Professor of Sociology at Queen's University Belfast. Academic Director for the Social Welfare Summer School. First Class degree in Sociology and politics and a PhD examining informal work strategies among the long-term unemployed in Belfast.
- William Gamble Private consultant specialising in conflict transformation and the economy. Previously a Senior Civil Servant until 2007, with responsibility for policy covering equality, good relations, regional development, victims and survivors and children and young people. Formerly the Private Secretary to the then Deputy First Minister Seamus Mallon and currently Commissioner with the Equality Commission.
- **Brendan McKeever** Non-Executive Director of the Health and Social Care Board. User Consultant at Queen's University Belfast and University of Ulster. Previous work includes supporting projects to improve the care of people with disabilities. Assists widely on these matters and assists organisations that provide and develop services for users and carers.
- Siobhan Rooney A trained nurse who has held senior positions in the Health Service. Has experience as a General Nurse, Midwife, Community Midwifery Sister and a Specialist Public Health Community Nurse. Previously a Non-Executive Director of the Blood Transfusion Service. Trustee of the Motor Neurone Disease Association NI, member of the NI Motor Neurone Disease Association branch committee, Association Visitor NI Motor Neurone Disease Association, member of the NI Neurological Charities Alliance. Currently a Non-Executive Director of the Southern Health and Social Care Trust.

The Terms of Reference for the Scrutiny Group are as follows. The Scrutiny Group shall 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
- Ensure the Reviewer maintains his independence throughout the review, acting as a sounding board and providing challenge where necessary

The Scrutiny Group met on three occasions during the Review. The initial meeting agreed the Terms of Reference and discussed the Call for Evidence and progress of the Review. Subsequent meetings discussed and tested the Reviewer's findings, conclusions and recommendations.

Annex 4: Meetings attended by the Reviewer

Voluntary and Advice Sector	Date
Disability Consultative Forum	17.01.18
Cystic Fibrosis Trust	01.02.18
Citizen's Advice Bureau	08.02.18
North Belfast Advice Partnership	13.02.18
Disability Action	15.02.18
Advice NI	16.02.18
Multiple Sclerosis Society	16.02.18
Citywide Tribunal Service	22.02.18
British Deaf Association	22.02.18
North Down Community Network	23.02.18
Law Centre	27.02.18
Fermanagh Trust	02.03.18
Rural Community Network (Cookstown)	02.03.18
Derry / Londonderry advice groups including RNIB, Disability Action, North West Forum	15.03.18
British Deaf Association workshop	16.03.18
Survivors of Suicide	09.04.18
Autism NI	09.04.18

Elected Representatives	Date
DUP MLA attended Vol & Advice Sector meeting	23.02.18
Green Party	27.02.18
SDLP	16.03.18
Sinn Fein	16.03.18

Capita (Assessment Provider)	Date
Initial Meeting	18.01.18
Observe assessments	Belfast 26.02.18
	Derry / Londonderry and Coleraine 12.03.18
	Newry and Dungannon 26.03.18
Capita Chief Medical Officer	26.02.18
Visit to Dunmurry office and Head Office	06.03.18

Department for Communities Staff	Date
Overview with Branch Manager / Telephony staff	09.01.18
Decision making / Mandatory Reconsideration process within PIP	13.03.18
Appeals / Customer Service / Quality team within PIP	27.03.18
Department for Communities Health Assessment Advisor	09.04.18
Make the Call Team	12.04.18
Mail Opening Unit	27.04.18

Professional Bodies	Date
British Medical Association (Dr Black)	29.03.18
Royal College of GPs (NI)	09.05.18
Royal College of Occupational Therapists (phone call)	18.05.18
Royal College of Nurses	29.05.18

Glossary of Terms

Assessment Provider	Carries out assessments for PIP on behalf of the Department for Communities. The assessment provider for PIP in Northern Ireland is Capita.
Assessor	A health professional employed by Capita to carry out the assessment. Also known as 'Disability Assessors'.
Assessment	When a claim is assessed either by a face-to-face consultation or by a Paper-Based Review in order to gather factual information about the functional effects of a claimant's condition. Also referred to as a Disability Assessment.
Appeal	Following a Mandatory Reconsideration a claimant can appeal to an independent tribunal if they are still unhappy with the decision.
Claim	An application made to PIP.
Claims in Payment	Where an award has been made and PIP is being paid to the claimant. This includes awards made following a Mandatory Reconsideration or an Appeal.
Claimant	Individual making a claim to PIP. Also referred to as customer.
Cleared / Clearance	Claims where an initial decision has been made by the Departmental Case Manager
The Department	For the purposes of this document refers to the Department for Communities. The Department for Communities is responsible for administering PIP in Northern Ireland.
Disability Living Allowance (DLA)	DLA is a tax-free benefit for people with disabilities who need help with mobility or care needs. From June 2016 no new claims to DLA can be made for people ages 16-64.
Face-to-Face Assessment	A consultation carried out by an Assessor, either at a centre or at a claimant's own home.
Further Evidence	Additional information used to support a claim.

Initial Decision	The decision made by the Case Manager, following the assessment, to either award or not award PIP to the claimant. The Case Manager will consider all the information available when
	making their decision.
Mandatory Reconsideration	Where a claimant asks Department to explain the decision further or have their decision looked at again.
New Claims	Claims to PIP made by those who are not currently receiving DLA
Paper-Based Review	Claims that are assessed using only the written information provided by the claimant in the PIP2 and additionally (in some cases) further evidence.
Personal Independence Payment (PIP)	PIP is a non-means tested benefit which helps towards some of the extra costs arising from having a long-term health condition or disability. PIP replaced DLA in Northern Ireland in June 2016 for people aged between 16-64 years.
PIP1	This part of the claim is where initial evidence is gathered in order to make a claim for PIP.
PIP2	This form allows the claimant to explain how their condition affects them in their own words and is issued following completion of the PIP1.
(PIP) Case Manager	Departmental staff that make the decision to award or not award PIP to the claimant. Also known as 'Decision Makers'.
(PIP) Case Worker	Departmental staff who deal with the PIP application and any subsequent claimant queries via telephone.
Reassessment Claims	Claims to PIP by those currently in receipt of DLA. These claimants will be invited to claim PIP by the Department.
Registrations	Registered claims to PIP.
Special Rules for Terminal Illness (SRTI) also known Special Rules	Special rules that allow people who are terminally ill to get help quickly when they claim PIP.
The PIP Assessment Process	An umbrella term used to describe the various steps involved in the PIP process from the initial application through to Appeal.

Abbreviations

DfC	Department for Communities
DLA	Disability Living Allowance
DWP	Department for Work and Pensions
ESA	Employment and Support Allowance
GB	Great Britain
NI	Northern Ireland
PIP	Personal Independence Payment
SRTI	Special Rules for Terminal Illness
UK	United Kingdom

Available in alternative formats.



