

Independent Mechanism for Northern Ireland

Report on the Department for Communities Response to Independent Review of PIP Process and Compliance with Recommendations of the UN CRPD Committee

July 2019



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Summary of Recommendations

The Independent Mechanism for Northern Ireland (IMNI):

- 5.3 recommends that the Department for Communities considers how to ensure continued awareness and education of the PIP system, including application and assessment process at the conclusion of the planned series of events.**
- 5.4 recommends the Department for Communities continues its collaboration with thematic support groups, including disability groups to develop and facilitate ongoing educational awareness, particularly in relation to what constitutes “relevant information”.**
- 5.6 recommends the Department for Communities reviews the terminology used throughout the process, especially terminology used in advice and guidance documents, and does not remain confined to the terms of the research undertaken by the Department for Work and Pensions in this area. IMNI further recommends that the Department’s production of the series of information guides for the Universal Credit system in general is replicated to provide information specific to PIP.**
- 5.8 recommends the Department for Communities commits to further adjustments within the engagement process relating to the use of DLA evidence, including the introduction of paper- and electronic-based advice.**
- 5.9 recommends the Department for Communities monitors and evaluates the continued use of DLA evidence within the process.**
- 5.11 recommends the Department for Communities commits to undertaking its own review, separately to the Department for Work and Pensions, of all written material used throughout the PIP process. The review should determine the accessibility and comprehension of the written material, identify areas where revision is required, and outline steps to improve the accessibility of written material. IMNI further recommends the Department devise concise material in a variety of accessible formats, describing the PIP assessment process in particular.**

- 5.13 recommends the Department for Communities commits to undertaking its own review, separately to the Department for Work and Pensions, of the accessibility and comprehension of the PIP application process. The review should include the consideration of further adjustments to the initial stage of the application process, including the introduction of electronic forms. The Department should further commit to liaising with Capita in delivering enhanced awareness training to staff operating the initial telephone claim desk to ensure awareness of how to engage with claimants have difficulties in using or are unable to use telephone communications due to their disabilities.**
- 5.15 recommends that the Department for Communities commits to reviewing the continued operation of the six months' life expectancy criterion. This ongoing review should include an assessment of the compatibility of this criterion with the rights of the people of NI, especially people with disabilities.**
- 5.17 recommends the Department for Communities reviews the accessibility and comprehension of the PIP2 form and accompanying guidance booklet, in line with its production of a series of information guides for Universal Credit in general. The review should include the consideration of adjustments to the PIP2 stage, including the introduction of electronic and easy read forms. IMNI further recommends the Department undertakes a review of the current four-week deadline for completion of the PIP2 form and examines the feasibility of extending the deadline.**
- 5.19 recommends the Department for Communities undertakes, separately to the Department for Work and Pensions, exploratory research into the development of a "Function First" approach to the PIP assessment process. IMNI further recommends the Department engage with relevant professional medical bodies to devise a process which enables the most effective and time-efficient way to obtain a GP Short Summary Report to support the PIP2 submission. This engagement process should also examine what constitutes "relevant information" and "additional information" regarding a claimant's medical history, condition, and how this may be obtained and included within the GP Short Summary Report.**

- 5.21 recommends the Department for Communities produces concise paper- and electronic based advice for claimants, families, carers and guardians regarding the preferred format and style for the submission of the completed PIP2 form and additional supporting documentation. The advice should also provide information on the process by which Capita receives a completed PIP2 form, including how documents are processed for inclusion in the claimant's case file.**
- 5.23 recommends the Department for Communities reviews the procedure of determining when a face-to-face assessment is conducted, and the process by which this assessment is carried out. The review should include the consideration of adjustments to the initial review carried out by Capita, including the feasibility of alternative means of assessment beyond paper-based and face-to-face assessment. The review should also assess the compatibility of the initial review including its restricted methods of assessment with the rights of the people of NI, especially people with disabilities.**
- 5.25 recommends the Department for Communities undertakes, separately to the Department for Work and Pensions, exploratory research into the process by which requests for home assessments are considered.**
- 5.26 recommends that the Department for Communities consult with thematic support groups, including disability groups, on adjustments which could be made to the assessment process, including the arrangement of assessments, traveling to the assessment, how to take into account the claimant's medication needs and the effects of medication on the claimant, and accessibility of the assessment room.**
- 5.28 recommends the Department for Communities reviews the training currently delivered to assessors. The review should take into account the recent judgment of the High Court of England and Wales in December 2017 and assess the compatibility of the current training with the human rights of the people of NI, particularly people with disabilities.**

- 5.29 recommends the Department for Communities engages in discussion with Capita about developing enhanced training, particularly to consider specialist training for mental health awareness/conditions in line with human rights standards. The development of enhanced training should also consider the implementation of a system whereby claimants with particular medical conditions may request an assessor with enhanced training and knowledge of their conditions, or request a paper-based review.**
- 5.31 recommends the Department for Communities reviews the current framework governing self-representation at the assessment stage, particularly assessing the compatibility of this framework with human rights standards.**
- 5.32 recommends the Department for Communities consults with thematic support groups, including disability groups, and the advice sector to determine the scale of the difficulty faced by claimants to effectively demonstrate their circumstances during the PIP assessment process. The Department should also engage with relevant professional medical bodies, and thematic support groups including disability groups, to examine the extent of the issue of claimants with certain medical conditions and disabilities encountering difficulties in representing themselves.**
- 5.34 recommends the Department for Communities commits, separately to the Department for Work and Pensions, to carrying out a pilot scheme of video recording of assessments.**
- 5.36 recommends the Department for Communities and Capita produce updated advice on the use of informal observations for assessors which should include the advice that informal observations must be factual observations.**
- 5.37 recommends that the Department for Communities and Capita should review the continued use of informal observations within the assessment process. The Department and Capita should undertake a review on the continued inclusion of questions about suicide and self harm in the assessment process. This review should take into account the recent judgment of the High Court of**

England and Wales in December 2017¹ and assess the compatibility of the use of such questioning with the human rights of the people of NI, particularly people with disabilities. IMNI advises this review should consider the introduction of specialist training for mental health awareness/conditions, and consider the development of a system whereby claimants with a history of suicide and/or self-harm may request an assessor with enhanced training and knowledge of mental ill health.

- 5.39 recommends the Department for Communities review current arrangements to allow for the inclusion of a copy of the assessor's report to be made available to claimants along with the decision letter.**
- 5.40 recommends the Department for Communities commits, separately to the Department for Work and Pensions, to undertaking its own review of PIP communications.**
- 5.43 recommends that the Department of Communities undertakes a cumulative impact assessment of the impact of social security reforms in NI, drawing from the Equality and Human Rights Commission's research.**
- 5.52 recommends that the Department for Communities examines the principles-based approach enshrined in a social security charter implemented in Scotland, and further examines the case for adopting a similar approach in NI.**

¹ *R. (on the application of RF) v Secretary of State for Work and Pensions* [2017] EWHC 3375 (Admin).

1.0 Introduction

- 1.1 The Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission jointly perform the role, under Article 33 (2) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), of “Independent Mechanism” in Northern Ireland (IMNI) to promote, protect and monitor the implementation the Convention. Together with the Equality and Human Rights Commission (EHRC) and the Scottish Human Rights Commission (SHRC), we are designated as the United Kingdom Independent Mechanism (UKIM).

- 1.2 This paper examines the operation of the Personal Independence Payment (PIP) system in Northern Ireland (NI), particularly in relation to its assessment process and the impact on the rights of people with disabilities. Section 2 sets out the 2017 concluding observations and 2016 Inquiry recommendations of the United Nations Committee on the Rights of Persons with Disabilities (UN CRPD Committee). Section 3 sets out the recommendations of the Independent Review of the PIP assessment process commissioned by the Department for Communities and compares these with the UN CRPD Committee’s recommendations. Section 4 considers the subsequent response of the Department of Communities and compares these with the UN CRPD Committee’s recommendations. Section 5 sets out the recommendations of the Independent Mechanism in Northern Ireland (IMNI) taking into consideration the interim response of the Department including the Department’s practical steps to the Independent Review. Section 5 further considers, as an example of good practice, the approach adopted in the Scottish social security system, namely the introduction of a principles-based approach to social security as enshrined in a social security charter.

2.0 Recommendations of the UN CRPD Committee

UN CRPD Committee's Concluding Observations

2.1 In its 2017 Concluding Observations, the UN CRPD Committee expressed its concern about the impact of austerity measures and anti-poverty initiatives that were introduced by the UK Government following the 2008-2009 financial crisis, noting these measures resulted in "severe economic constraints" among persons with disabilities and their families.² The Committee stated it was concerned about the negative impact on the standard of living of persons with disabilities arising from the reductions in social support, including independence payments. The Committee noted in particular the introduction of the Personal Independence Payment, which has reduced the number of recipients of disability-related allowances.

UN CRPD, Article 28

2.2 The UN CRPD, Article 28, provides for the adequate standard of living and social protection.³ The UN CRPD Committee issued five recommendations to the UK Government and devolved institutions, to be undertaken working in conjunction with disability organisations.⁴ These recommendations were:

- 1) To introduce, adopt and implement legislative frameworks to ensure that social protection policies and programmes across the State party secure income levels for all persons with disabilities and their families, by taking into account the additional costs relating to disability, and ensuring that persons with disabilities are able to exercise their parental responsibilities;
- 2) To carry out a cumulative impact assessment of the recent and forthcoming reforms of the social protection system for persons with disabilities, and define, implement and monitor measures to tackle retrogression in their standard of living and use the cumulative impact assessment as a basis for policy development;

² CRPD/C/GBR/CO/1, 'UN CRPD Committee Concluding Observations on the Initial Report of the UK of Great Britain and NI', 3 October 2017, at para 58.

³ The right of persons with disabilities to an adequate standard of living and social protection, as provided for by UN CRPD, Article 28, is further reinforced by UN ICESCR, Article 9, which recognises the right of everyone to social security, including social insurance.

⁴ CRPD/C/GBR/CO/1, 'UN CRPD Committee Concluding Observations on the Initial Report of the UK of Great Britain and NI', 3 October 2017, at para 59.

- 3) To repeal the Personal Independence Payment (Amendment) Regulations of 2017 and ensure that eligibility criteria and assessments to access Personal Independence Payments, Employment Support Allowance and Universal Credit are in line with the human rights model of disability;
- 4) To ensure that the budget allocation is sufficient for local authorities to meet their responsibilities regarding assistance for persons with disabilities, and extend support packages to mitigate the negative impacts of social security reform in NI;
- 5) To conduct a review of the conditionality and sanction regimes concerning the Employment and Support Allowance, and tackle the negative consequences on the mental health and situation of persons with disabilities.

UN CRPD Committee's Inquiry Report

2.3 The UN CRPD Committee recommended the UK Government undertake collaborative work with disability organisations across the UK in line with the Committee's 2016 Inquiry Report carried out under Article 6 of the Optional Protocol to the Convention.⁵ In its Inquiry Report, the Committee found evidence that the threshold of grave or systematic violations of the rights of persons with disabilities arising from the implementation of social security reform in the UK was met: specifically, the rights to independent living and to be included in the community, social protection and work and employment.

2.4 That conclusion was based on the following:

- several measures under the new system had disproportionately and adversely affected rights;
- measures resulting in reduction of support provided to meet the extra cost of disability, denial of reasonable accommodation in assessment procedures and realisation of the right to employment had a discriminatory effect; and
- core elements of the rights to independent living and being included in the community, an adequate standard of living and social protection and their right to employment were affected by the

⁵ CRPD/C/15/R.2/Rev.1, 'UN CRPD Committee Inquiry concerning the UK of Great Britain and NI carried out by the Committee under Article 6 of the Optional Protocol to the Convention Report of the Committee', 6 October 2016.

implementation of social security reform.

The UN CRPD Committee held there was evidence (gathered by Parliament, the independent monitoring framework, universities, research institutes and centres, and independent experts) illustrating adverse and disproportionate effects of measures on persons with disabilities.

- 2.5 The UN CRPD Committee issued several recommendations to the UK Government at the conclusion of its Inquiry Report.⁶ It noted the UK Government had not conducted a human rights-based cumulative impact assessment and recommended for this to be conducted. It recommended the UK Government ensure any intended measure of the social security reform is rights-based, upholds the human rights model of disability and does not disproportionately and/or adversely affect the rights of persons with disabilities. It further recommended the UK Government ensure intended legislation and/or policy measure respect the core elements of the outlined rights. The Committee recommended the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities seeking to avail of such information and services. Lastly, the Committee recommended the establishment of a mechanism and a system of human rights-based indicators to permanently monitor the impact of the different policies and programmes relating to the access and enjoyment by persons with disabilities of the outlined rights.

3.0 The Independent Review of the PIP Assessment Process

- 3.1 The Independent Review found that the current PIP assessment process is fragmented, and viewed with suspicion and distrust by claimants and their families.⁷ 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.⁸

⁶ CRPD/C/15/R.2/Rev.1, 'UN CRPD Committee Inquiry concerning the UK of Great Britain and NI carried out by the Committee under Article 6 of the Optional Protocol to the Convention Report of the Committee', 6 October 2016, at para 114.

⁷ Walter Rader, 'Personal Independence Payment: An Independent Review of the Assessment Process NI' (DfC, 2018).

⁸ Walter Rader, 'Personal Independence Payment: An Independent Review of the Assessment Process NI' (DfC, 2018), at 6.

- 3.2 There were a number of key findings/issues, which caused concern for claimants with disabilities and that negatively affected them. The Independent Review recommended prompt action was taken to rectify the issues identified in its investigation, and to ensure trust in and credibility of the process. It submitted:
- 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.⁹
- 3.3 The Independent Review issued 14 recommendations, which aim to rectify the issues found within the key findings of the investigation.¹⁰ The Independent Review's recommendations do not explicitly comply with the UN CRPD Committee's recommendations, but go some way in reforming the assessment process to empower claimants with disabilities and their families, by ensuring they are better informed of the process. This in turn increases the independence and dignity of claimants with disabilities, in accordance with the UN CRPD Committee's recommendations, to ensure the upholding of a human rights model of disability.
- 3.4 The Independent Review's recommendations provide a foundation for a framework to ensure access to PIP for claimants with disabilities in accordance with the 2017 UN CRPD Committee's Concluding Observations, and would assist in the conduction of a rights-based cumulative impact assessment, in accordance with the UN CRPD Committee's recommendations of both 2016 and 2017. These reforms, taken collectively, could also provide a framework for the creation of a system of rights-based indicators to monitor the accessibility of the PIP process and the impact of same on the access and enjoyment of rights of claimants with disabilities.
- 3.5 The Department for Communities published its Interim Response to the Independent Review in November 2018.¹¹ It details the current position with respect to the recommendations made by the Independent Review

⁹ Walter Rader, 'Personal Independence Payment: An Independent Review of the Assessment Process NI' (DfC, 2018), at 6.

¹⁰ Walter Rader, 'Personal Independence Payment: An Independent Review of the Assessment Process NI' (DfC, 2018), at 8-10.

¹¹ Department for Communities, 'Review of the Personal Independence Payment Assessment Process: Department for Communities' Interim Response' (DfC, 2018).

and, where possible, what the Department and Capita have done, or propose to do, to address the Independent Review's recommendations.

- 3.6 Before examining its response to the recommendations, the Department for Communities noted it had from the outset introduced an additional step in the process, whereby an Outreach Officer will contact reassessment claimants who do not respond to the invitation to claim PIP within four weeks. It explained this would provide an "additional safeguard for vulnerable claimants" when they start the PIP reassessment process. Moreover, it noted the PIP Centre has established a Good Reason team who investigate reasons for non-return of PIP forms or failure to attend an assessment with the claimant in the first instance, before any negative determination is made and payment of benefit stopped.¹²
- 3.7 The Department for Communities noted its Interim Response was prepared in the absence of Executive Ministers with responsibility for devolved functions in NI, including the functions of the Department for Communities. As such, the content of its Interim Response will remain subject to review; it could possibly be changed by an incoming Minister. Moreover, the Department must also operate within the existing statutory framework for the delivery of PIP in NI and the general provisions that a single system of social security should operate in the UK unless a local Executive and Assembly determine otherwise.¹³
- 3.8 The Department for Communities acknowledged a second independent review would be carried out and laid before the Assembly by June 2020.¹⁴

4.0 Evaluation of Findings

- 4.1 There were 14 recommendations issued by the Independent Review. The majority of recommendations related to undertaking awareness raising and information dissemination events to support claimants and their families in understanding the PIP assessment process and purpose, including updating terminology to describe the roles and functions found within the process, using clear language and simplified terms in all material and

¹² Department for Communities, 'Review of the Personal Independence Payment Assessment Process: Department for Communities' Interim Response' (DfC, 2018) at 5.

¹³ Department for Communities, 'Review of the Personal Independence Payment Assessment Process: Department for Communities' Interim Response' (DfC, 2018) at 6.

¹⁴ The Department for Communities did not address whether the second independent review would be laid before Parliament in the event the devolved institutions are not restored by June 2020, or whether the Department itself would receive the review in light of recent legislation which has empowered civil servants in the absence of Executive Ministers; see section 3 of the NI (Executive Formation and Exercise of Functions) Act 2018.

guidance found within the process, and providing training to staff both in the Department for Communities and Capita relating to communication and engagement with people with disabilities and/or impairments which may affecting hearing and speech. One recommendation (Recommendation 10) specifically related to the Department addressing concerns raised by claimants, including but not limited to the scheduling of appointments, the cancellation and rescheduling of appointments and the assessment room itself, concerning the accessibility of the room layout.

4.2 The Department for Communities accepted a majority (11 of 15 taking Recommendation 13 in two parts) of recommendations, accepting seven in full, and partially accepting four. These were recommendations relating to:

- undertaking awareness raising and information dissemination events to support claimants and their families in understanding the PIP assessment process and purpose, including updating terminology to describe the roles and functions found within the process;
- using clear language and simplified terms in all material and guidance found within the process; and
- providing training to staff both in the Department for Communities and Capita relating to communication and engagement with people with disabilities and/or impairments which may affecting hearing and speech.

4.3 Below sets out the findings, recommendations, initial anticipated outcome of the Independent Review, and the interim response of the Department for Communities including the Department's practical steps to the Independent Review. This overview is structured under the headings of the Independent Review and evaluates the Department for Communities' response in line with the UN CRPD Committee's Concluding Observations, and Inquiry recommendations.

Awareness

4.4 **Finding:** Claimants, their family members and some support workers did not have a clear understanding of the purpose of PIP, and the assessment process. There was a lack of clarity regarding the functional nature of the assessment and the types of information and evidence required to support a claim. Increased engagement was found to be needed to both inform and communicate with claimants on what PIP is, explain the assessment process, and address misconceptions of PIP.

- 4.5 **Initial Recommendation 1:** That the Department for Communities, in conjunction with advice and thematic support organisations, coordinates a series of information and outreach events, across NI. 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.
- 4.6 **Initial 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.
- 4.7 **Evaluation of Initial Recommendation:** Initial recommendation 1 would ensure greater understanding and knowledge of the process and enable the claimants to engage more fully in the process. This would fulfil the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability, encouraging participation and inclusivity of people with disabilities including in decision-making relating to their daily lives, condition management, and independence. This in turn acknowledges the human dignity of persons with disabilities. It also fulfils the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.
- 4.8 **Interim response to Recommendation 1:** The Department for Communities accepted this recommendation. It agreed continuous communication of the PIP process was important and so will continue to engage with key stakeholder groups to deliver the outcomes identified by the Independent Review in ensuring claimants fully understand the PIP process and what is required of them.
- 4.9 **Practical steps:** To address Recommendation 1, the Department for Communities noted it is working with thematic support groups and the advice sector to coordinate a series of events to further publicise the nature of the PIP assessment process and what is required of claimants in support of their application. These events will commence in January 2019. In addition, it had developed a series of educational videos relating to

particular stages of the PIP assessment process: explaining what it is; how to apply for it; how to provide information to support the claim; the face-to-face assessment; and the decision. These videos were available on NI Direct from 12 October 2018, and are available in sign language.

4.10 Evaluation of Department's response: The Department for Communities' work with support groups to run a series of events will ensure expert advice is availed of, tailoring events to the needs of claimants with disabilities. The events and videos mark a start in ensuring claimants with disabilities and their families gain a better understanding of the process. These actions mean the Department is beginning to fulfil the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability. The series of events introduced by the Department assists with the fulfilment of the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities. It is important these events are fully accessible for range of medical conditions and disabilities/impairments including for those with visual and auditory impairments.

Confusion around the Assessment Process

4.11 **Finding:** There were inconsistencies within the PIP literature and guidance materials, both for claimants and for those conducting the process in the Department for Communities and at Capita. These inconsistencies were found in the terminology used to describe the process and those delivering it; this was primarily relating to the descriptions of the assessment process giving the impression the assessment process adopted a pseudo-medical approach. Terminology was also an issue with regards to Capita staff delivering the process. 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.

4.12 **Initial Recommendation 2:** That the Department for Communities 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.

4.13 **Initial Anticipated Outcome:** 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.

4.14 Evaluation of Initial Recommendation 2: This recommendation would ensure greater understanding and knowledge of the process and enable the claimants to engage more fully in the process. This would fulfil the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability, encouraging participation and inclusivity of people with disabilities including in decision-making relating to their daily lives, condition management, and independence. This in turn acknowledges the human dignity of persons with disabilities. It also fulfils the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.

4.15 **Interim response to Recommendation 2:** The Department for Communities accepted this recommendation. It agreed it was important that use of terminology was consistent throughout the process.

4.16 **Practical steps:** To address Recommendation 2, the Department for Communities noted it has commenced reviewing the terminology used throughout the process to ensure it corresponds with the recommended terms of the Independent Review. The Department for Work and Pensions has announced its intention to commission independent research to support improvements to the PIP2 questionnaire and the Department for Communities committed to ensuring any recommendations arising from this are considered when reviewing any revised literature. As of July 2019, the Department for Communities published a series of information guides relating to Universal Credit. This series of information guides outlines the purpose of Universal Credit, and the process for applications in a clear and concise manner.¹⁵ One document in the series is an "easy read" guide, and another document provides a "step-by-step" guide to applying for Universal Credit. This series applies only to Universal Credit; it does not focus on PIP.

¹⁵ See Department for Communities, 'Universal Credit – What you need to know' (DfC, 2019); 'Universal Credit & You' (DfC, 2019); 'Universal Credit and You – Easy Read' (DfC, 2019); 'Universal Credit – Questions and Answers' (DfC, 2019); 'A Step by Step guide to making and maintaining a Universal Credit claim online' (DfC, 2019). All guides are available at <https://www.communities-ni.gov.uk/publications/universal-credit-customer-information>

4.17 Evaluation of Department's response: The announcement from the Department for Communities that it has commenced reviewing terminology used throughout the process marks a start towards fulfilling the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability, encouraging participation and inclusivity of people with disabilities including in decision-making relating to their daily lives, condition management, and independence. The Department for Communities' announcement of a review process in addition to the commitment to consider any recommendations arising from the Department for Work and Pensions' research assists with the fulfilment of the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities. The publication of a series of information guides for Universal Credit which are written in an accessible and comprehensive manner is welcome. It is hoped that similar guides will be produced for PIP, in line with the recommendation of the Independent Review and as accepted by the Department in its Interim Response. The guides do not however provide sufficient information on the assessment process for Universal Credit, and it does not reference the assessment process specific to PIP. PIP is briefly referenced in an information guide within the series, but no specific guidance about the process is provided; readers are instead referred to the NI Direct website.¹⁶ The literature available to download from the NI Direct website has not been subject to revision or updating.¹⁷

DLA Evidence

4.18 Finding: Claimants are asked if they wish their DLA medical evidence to be made available as part of the PIP assessment process. It was found that for claimants who have been on a lifetime award of DLA (over 70 per cent across NI) their case file was unlikely to contain up-to-date information. In addition, it appeared no one considered that a claimant's DLA case file contains information obtained for a different purpose and may not be suitable for a PIP assessment. Moreover, there was an assumption from claimants who requested their DLA case file being made available that it

¹⁶ Department for Communities, 'Universal Credit: What you need to know' (DfC, 2019), at 14.

¹⁷ As of 2 July 2019, the only PIP literature available to download from the NI Direct website dates from May 2016; see Department for Communities, 'Personal Independent Payment' (DfC, 2016) available at <https://www.nidirect.gov.uk/publications/personal-independence-payment-leaflet>

would form part of their assessment – which is not always the case – and therefore would assume they do not need to provide additional supportive information – potentially to their detriment. It was therefore essential all relevant evidence should be made available at the earliest possible point, with the Department for Communities ensuring claimants are fully advised and informed early in the process as to what constitutes “relevant evidence”.

- 4.19 **Initial Recommendation 3:** The use of DLA evidence to support reassessment cases should cease.
- 4.20 **Initial Anticipated Outcome:** 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.
- 4.21 Evaluation of Initial Recommendation 3:** This would omit ongoing confusion and streamline the process. This would enable better accessibility of the process, including for claimants who wish to protect their independence. It also fulfils the UN CRPD Committee’s recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.
- 4.22 **Interim response to Recommendation 3:** The Department for Communities did not accept this recommendation. It accepted the relevance of DLA evidence to PIP claims varies on a case-by-case basis, but submitted this evidence had proven to be relevant in a proportion of cases. It said it could see no reason to move from the current position of offering claimants the option of having their DLA evidence considered as part of their PIP assessment.
- 4.23 **Practical steps:** The Department for Communities did acknowledge that some claimants may overly rely on DLA evidence, and as such has strengthened its call scripts to advise claimants that the inclusion of this evidence does not guarantee a PIP award equivalent to their current DLA award, and that they should still provide any further relevant evidence they currently hold in support of their PIP claim.

4.24 Evaluation of Department's response: The Department for Communities could do more to ensure better accessibility of the process: strengthening call scripts is a first step but this new advice must be given in a variety of formats including in paper form and in guidance documentation, particularly given the findings of the Independent Review that claimants with hearing impairments / who are Deaf will not be able to engage in telephone communication and so will not be provided with advice under the new arrangement. Further adjustments are necessary in order for the Department to fully adhere to the recommendation of the UN CRPD Committee for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.

The PIP Assessment Process

4.25 **Finding:** The assessment process was found to be complex and had required a thorough exploration through engagement with the Department for Communities and Capita for the Independent Review to fully understand the entire process. It was felt a claimant who would not have the opportunity for this engagement, would find it difficult to understand the process. It was found it was necessary for the development of clear and concise information materials in suitable formats to describe the process in an accessible manner. Such materials should not assume a claimant has prior knowledge of the process.

4.26 **Initial Recommendation 4:** (A) The Department for Communities 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 for Communities should develop simple straightforward material describing the PIP assessment process.

4.27 **Initial Anticipated Outcome:** This would assist claimants, family members and support workers in understanding the PIP assessment process and its purpose.

- 4.28 Evaluation of Initial Recommendation 4:** This recommendation would ensure greater understanding and knowledge of the process and enable the claimants to engage more fully in the process. It fulfils the UN CRPD Committee’s recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities. This would also fulfil the UN CPRD Committee’s Inquiry Report recommendation of upholding a human rights model of disability, encouraging participation and inclusivity of people with disabilities including in decision-making relating to their daily lives, condition management, and independence. This in turn acknowledges the human dignity of persons with disabilities.
- 4.29 **Interim response to Recommendation 4:** The Department for Communities accepted this recommendation. It agreed clear communications were important and that it was vital that claimants were well informed when making a claim, throughout the assessment process, and when receiving their final decision. The clarity of materials advising and informing claimants of the PIP process is central to achieving this aim.
- 4.30 **Practical steps:** The Department for Communities noted the Department for Work and Pensions are currently reviewing the PIP application process to identify and implement improvements. The Department for Communities will be a key stakeholder in any amendments to literature stemming from this work and will ensure the recommendations of the Department for Work and Pensions’ review are considered when considering any revised literature.
- 4.31 Evaluation of Department’s response:** The Department for Communities did not commit to undertaking its own review of the written material used in the process. The Department has confirmed it is conducting a review of terminology used to describe roles and functions throughout the PIP assessment process; this could be widened to include a review of all written material used in the process. It could undertake its own review separately to the Department for Work and Pension’s examination to ensure claimants with disabilities and their families can access the material, understand fully the process, and can provide an informed response. A separate review conducted by the Department for Communities would assist towards fulfilling the UN CRPD Committee’s recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal

procedures in relation to social security fully accessible to people with disabilities.

Application Process

4.32 **Finding:** Claimants, namely with certain medical conditions and those with speech and/or hearing impairments, found it frustrating that the initial stage of the application process required telephone communication. There are provisions to complete the PIP1 in paper copy which can be requested via telephone or in writing. However, there is no provision for an electronic format which is preferred by those claimants who cannot complete the form by hand. It was found that there was a need for awareness training for staff operating the initial telephone claim desk to raise awareness of how to engage with claimants with conditions, impairments etc. which restrict or hinder telephone communication.

4.33 **Initial Recommendation 5:** (A) That the Department for Communities 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 for Communities 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.

4.34 **Initial Anticipated Outcome:** This will assist those with particular needs in accessing PIP.

4.35 Evaluation of Initial Recommendation 5: This recommendation would ensure greater understanding of the needs of claimants with disabilities, resulting in a more comfortable process that facilitates them, and acknowledges the human dignity of persons with disabilities. It would fulfil the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability, by ensuring the process is accessible and inclusive of people with disabilities. It also fulfils the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal

procedures in relation to social security fully accessible to people with disabilities.

- 4.36 **Interim response to Recommendation 5:** The Department for Communities accepted this recommendation. The Department agreed it was important those with specific communications needs do not face unnecessary obstacles in applying for PIP, and when communicating with the Department and Capita.
- 4.37 **Practical steps:** The Department for Communities noted it would soon implement a Video Relay Service that users of sign language can avail of when making a claim. It further noted its primary method for claimants applying for PIP is via telephone; there is also a text phone service available. There is an option to request a paper claim form. Alternatively, a claimant can provide consent, either verbally or in writing, for a nominated person to make a claim to PIP on their behalf and undertake telephone communication. The Department committed to reinforcing with telephony staff the various options that are available to support the accessibility options that are in place. Capita has also enhanced its use of interpreters by ensuring they are all fully trained sign language interpreters. It was noted that the Department for Work and Pensions has carried out a small-scale pilot for online PIP applications; the Department will track any digital development in the Department for Work and Pensions with respect to providing an online claim facility.
- 4.38 Evaluation of Department's response:** Ensuring greater understanding of the needs of claimants with disabilities, resulting in a more comfortable process that facilitates them, and acknowledging the human dignity of persons with disabilities would fulfil the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability. The Department for Communities has acknowledged a nominated person may claim on behalf of the claimant with disabilities, but this does not take into account people who may not have someone close to them to nominate. The introduction of a Video Relay Service is welcomed by IMNI, however the Department could also do more to support those who may experience difficulties with completing hand-written forms; an electronic form could be considered to ensure greater facilitation. A review/pilot of this could be undertaken independently from the Department for Work and Pensions. Introducing additional supportive services, forms etc. would assist with the fulfilment of the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all

information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.

Claims made under Special Rules

- 4.39 **Finding:** There is provision for claimants with a short life expectancy as confirmed by a medical practitioner to claim PIP under the “special rules for terminal illness” criterion. 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 six months, a paper-based assessment can then be carried out. Such assessments are completed within one week. The requirement of a completed assessment form following the completion of a DS1500 form by a medical practitioner in order to avail of “special rules” has been considered insensitive.
- 4.40 **Initial 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 six months life expectancy criterion should be removed.
- 4.41 **Initial Anticipated Outcome:** This will lessen pressure, stress and anxiety on claimants and their families at what is an already difficult time.
- 4.42 Evaluation of Initial Recommendation 6:** This recommendation would respect the dignity of claimants with terminal illnesses and would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CRPD Committee’s Concluding Observations.
- 4.43 **Interim response to Recommendation 6:** The Department for Communities cannot implement this recommendation. The Department noted the provision in PIP mirrors the provision that has been in place in Attendance Allowance and DLA since the 1990s; these arrangements underwent a consultation process both in Great Britain and NI in 2010 and the Westminster Government response noted a majority of respondents indicated the “special rules” should remain the same. Social security law is maintained in parity with provision brought forward by the Department for Work and Pensions unless the NI Executive and NI Assembly determine otherwise.

- 4.44 **Practical steps:** The Department for Communities submitted this was a matter for incoming Executive Ministers to consider, including determining if a review of the current arrangement in place for the “special rules” in NI should be held.
- 4.45 **Evaluation of Department’s response:** It could be worth examining whether the recent Westminster legislation empowering civil servants in the absence of devolved government in NI would enable a review of the current arrangement for the operation of “special rules” in NI to be held.¹⁸ In the event that civil servants lacked the power to instigate such a review, there could be scope for them to plan for such a review. There could be scope for the Department for Communities to launch a public consultation and invite stakeholders to submit their views in preparation for such a review. Removing the six months life expectancy criterion would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CRPD Committee’s Concluding Observations; it would therefore be worthwhile for the Department to consider what it could do.

Completing the PIP2

- 4.46 **Finding:** Following the initial telephone conversation, the claimant will receive by post a paper copy of the PIP2 form and a guidance booklet on how to complete same. It was found that claimants reported feeling stress and anxiety at having to complete an extensive form within a four-week deadline; it was noted claimants had required assistance and sometimes from more than one source when completing the form. Claimants may face difficulty completing a form by hand depending on their medical conditions/impairments. Claimants seek assistance from advice bodies; due to demand appointments may take up to three weeks to arrange with some advice bodies estimating around 40 per cent of their case work is linked to PIP. For those claimants in the deaf community who require a sign language interpreter in seeking advice for the form, the only service available is in Belfast and only on a Monday. It is not possible to book an appointment so prospective users from across NI must just turn up and wait. Finally, it was found the form and booklet are unclear in terms of what they mean by “relevant evidence”.

¹⁸ NI (Executive Formation and Exercise of Functions) Act 2018, at section 3.

- 4.47 **Initial Recommendation:** No recommendation was provided by the Independent Review.
- 4.48 **Initial Anticipated Outcome:** No anticipated outcome was provided by the Independent Review.
- 4.49 Evaluation of Initial Recommendation:** It is disappointing that no recommendation was provided by the Independent Review on the issues raised regarding completion of the PIP2. From the findings of the Independent Review, it would appear that it is necessary for the process of completing the PIP2 form to be reviewed. The Department for Communities should consider revising the language and terminology used in the form and the accompanying booklet, to ensure clear and simplified language is consistently used. This would make the process more accessible and understandable for claimants, their families and support workers, and they would be able to more confidently complete the form. The four-week deadline should also be reviewed by the Department, particularly in light of the difficulties faced by claimants with disabilities seeking advice from advice bodies. It is suggested that it would allow for additional time which would be of great benefit to claimants with particular disabilities and impairments who require support from advice bodies. This is likely to contribute to reducing levels of apprehension. Taking such action would fulfil the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability, encouraging participation and inclusivity of people with disabilities including in decision-making relating to their daily lives, condition management, and independence. This in turn acknowledges the human dignity of persons with disabilities. It also fulfils the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.
- 4.50 **Interim response to Recommendation:** There was no response to the finding of the Independent Review from the Department for Communities.
- 4.51 **Practical steps:** There were no practical steps provided by the Department for Communities.
- 4.52 Evaluation of Department's response:** It is disappointing that there has been no interim response to the issues raised in the Independent Review

regarding completion of the PIP2. Given that the Department for Communities had accepted previous recommendations relating to revision of language and terminology proposed by the Independent Review, it appears likely the Department would accept revision of language and terminology used in the PIP2 form. However, it appears unlikely that the Department would accept a recommendation suggesting it review the four-week deadline; it is anticipated the Department would cite the volume of casework required in the PIP process and the need to process claims and paperwork quickly, which would be delayed in the event of an extension to the deadline. If the Department accepted the recommendation to revise the language and terminology used in the PIP2 form, it would mark progress in the fulfilment of the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities. It is important the Department consider the difficulties experienced by claimants with particular disabilities and/or impairments which require additional support, including when seeking advice from an independent advice agency. The Department must ensure the PIP process, including completion of forms, is fully accessible. In light of the Department's recent publication of a series of information guides providing an overview of Universal Credit including the application stage in a concise manner, it is hoped this is replicated for the PIP system, and would include an information guide for the PIP2 form.

Sourcing Further Evidence

4.53 **Finding:** GPs and their professional bodies have argued they are not the best source of information in terms of the claimant's daily functionality, as in general the GP will not see the claimant undertaking daily living functions. It was noted the PIP2 Form and its supporting guidance booklet advise claimants not to request additional information if they do not already have it, stating the Department for Communities and Capita would request additional evidence themselves if they required it. However, claimants have alleged the Department and Capita have not attempted to source further evidence from professionals supporting them. When Capita has requested additional information from GPs, GPs have said they are unaware if the information they provide is relevant or not. Moreover, some GP surgeries in correspondence with claimants and the Department have expressed their inability to provide additional information due to rising pressure in general practice. It was felt that decisions are being made

throughout the process without access to all the relevant information. Again, it was noted that clarification was required in relation to what constitutes relevant information, and where/how it may be obtained.

- 4.54 **Initial Recommendation 7:** So that the relevant up-to-date medical information is available early in the PIP assessment process, the Department for Communities 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.
- 4.55 **Initial Anticipated Outcome:** This should allow GPs to provide relevant medical evidence to the Department for Communities and Capita in a timely fashion which is both useful to assessors and Departmental Case Managers.
- 4.56 **Evaluation of Initial Recommendation 7:** This recommendation would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CRPD Committee's Concluding Observations.
- 4.57 **Interim response to Recommendation 7:** The Department for Communities partially accepted this recommendation. The Department accepted that, ideally, all relevant information should be available as early as possible in the process. It noted the recommendation of the second Gray Review¹⁹ – the independent review of the PIP assessment carried out in England and Wales that is the equivalent to the independent review carried out in NI by Walter Rader - that assessments should begin with gathering a functional history, not a medical history, which the Department for Work and Pensions had accepted.²⁰
- 4.58 **Practical steps:** The Department for Communities said it was monitoring the exploratory work of the Department for Work and Pensions in developing a "Function First" approach. Once discussions around the feasibility of obtaining GP Short Summary Reports have been progressed the Department will need to carry out a cost-benefit analysis of the

¹⁹ Paul Gray, 'The Second Independent Review of the Personal Independent Payment Assessment' (Department for Work and Pensions, 2017), at para 37.

²⁰ Department for Work and Pensions, 'Government's response to the Second Independent Review of the Personal Independence Payment Assessment' (Department for Work and Pensions, 2017), at 15-16.

proposal. The Department submitted any final decision was a matter for the incoming Minister.

4.59 Evaluation of Department's response: Devising a GP Short Summary Report would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CRPD Committee's Concluding Observations. The Department for Communities could independently of the Department for Work and Pensions undertake its own exploratory work as to how to devise and adopt a "Function First" approach to the PIP assessment process.

Receipt of Further Evidence

4.60 **Finding:** It appeared that all relevant information may not be available at key times during both the assessment and decision-making process, particularly given the process by which Capita receives a completed PIP2 form: it is routed via the Department for Communities' Mail Opening Unit, which receives large volumes of mail and relies upon an electronic scanning system to sort through the mail. The scanning system is programmed to identify specific forms with a common layout, such as the PIP2; it is less likely to identify other documents and so 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, which is time consuming and could result in an incomplete case file being made available to Capita and Department staff.

4.61 **Initial Recommendation 8:** The Department for Communities 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.

4.62 **Initial Anticipated Outcome:** 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.

4.63 Evaluation of Initial Recommendation 8: This recommendation would ensure the eligibility criteria and assessments to access PIP is in line with a

human rights model of disability, in accordance with the recommendation of the UN CRPD Committee's Concluding Observations.

- 4.64 **Interim response to Recommendation 8:** The Department for Communities accepted this recommendation. It agreed it was important that Capita should know as early as possible whether there was any additional information to consider. The Department acknowledged automatic routing of post is preferable and quicker, and this is in place for a large number of the forms and letters PIP receives. The Department said it was not possible to do this in all instances as the Department has no control over the style and format of all post it receives.
- 4.65 **Practical steps:** The Department for Communities has now implemented a revised process where documents submitted with the PIP2 form are linked to arrive simultaneously. This was implemented in early October.
- 4.66 Evaluation of Department's response:** The implementation of the revised arrival process is a welcome measure but more could be done to ensure Capita are made aware as early as possible in the process regarding the receipt of additional evidence. The main issue appears to be the style and format of post received by the Department for Communities; the Department could advise claimants, their families, advice support staff etc. on the Department's preferred format and style to enable a system of automatic routing of post which would ensure the faster recipient of additional evidence by Capita. This advice could be trialled during the series of educational and awareness events the Department has committed to undertake, or in a future series of events.

Initial Review by Capita

- 4.67 **Finding:** If, after receiving a claimant's PIP2 form, Capita considers there is insufficient information to conduct a paper-based review, a face-to-face assessment is conducted in lieu. Claimants have engaged with Capita to demonstrate they would not be able to participate in a face-to-face assessment due to the nature or severity of their medical condition and/or impairments. Claimants and their families noted the stress, anxiety, and fear which claimants had experienced, both when being informed of having to participate in a face-to-face assessment and participating in same.
- 4.68 **Initial Recommendation 9:** The Department for Communities 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.

4.69 **Initial Anticipated Outcome:** 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.

4.70 **Evaluation of Initial Recommendation 9:** This recommendation would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CRPD Committee's Concluding Observations. It also fulfils the Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.

4.71 **Interim response to Recommendation 9:** The Department for Communities partially accepted this recommendation. It agreed working to ensure the initial review addresses cases where a paper-based review is appropriate is vitally important but noted it was a legislative requirement that the appropriate descriptor must be chosen for every activity; this is set out in regulations. As Departmental Case Managers need full, comprehensive evidence in order to make accurate decisions about entitlement, the Department submitted it would not be in the best interest of claimants to place limitations on the evidence gathering process. It submitted exempting claimants from face-to-face assessments based on one condition may disadvantage them if a face-to-face assessment would be most appropriate to determine the total impact their other conditions or disabilities have on their daily life. It stressed Capita only conducts a face-to-face assessment where there is insufficient evidence, or they have not received evidence in a timely manner.

4.72 **Practical steps:** The Department for Communities and Capita have examined how the initial review is conducted. The decision-making matrix has been enhanced and will be discussed with stakeholders at the Disability Consultative Forum. The Department considered this forum to be the appropriate group to consider the revised approach adopted in response to this recommendation.

4.73 **Evaluation of Department's response:** The Department for Communities is consulting with the Disability Consultative Forum is a welcome measure. However, the Department did not consider the sincerely-held concerns of claimants as captured by the Independent Review that they cannot participate in a face-to-face assessment in lieu of a paper-based review due to the nature or severity of their medical condition and/or impairments. The Department has not considered the possibility of an alternative means of assessment outside of the paper-based review and face-to-face assessment. It is important that the process is be tailored for the needs of claimants with disabilities to ensure accessibility to the process and to prevent a negative impact on their social protection or a violation of their rights. Consideration of additional alternative assessments would assist with the fulfilment of the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.

The Assessment

4.74 **Finding:** The sheer number of issues raised during the Independent Review indicated the assessment was the most contentious part of the overall process. Claimants said they have provided information to Capita that they cannot attend an assessment or they had particular requirements which needed to be met before they could attend an assessment, but Capita did not appear to consider this information. GPs submitted claimants' medication needs had to be taken into account in determining appointment times: there may be side effects which result in claimants not being able to represent themselves clearly and in full at certain times of the day. Travel directions that tend to rely on the use of public transport were not considered appropriate and did not take into account needs and conditions claimants had outlined on their PIP2 form. There were occasions when Capita cancelled home visits/assessments without advanced notice, which sometimes happened multiple times; this proved particularly

inappropriate for people who are Deaf and/or require a booked sign language interpreter. People who are Deaf reported receiving a voicemail informing them of their cancelled appointment. There were occasions where an assessor arrived to homes earlier than expected. In contrast, claimants are only allowed one opportunity to reschedule an appointment. Of the assessments observed by the Independent Review, the majority (7 from 9) of claimants were considered not to be in a position to adequately communicate their conditions nor the impact on their daily lives, particularly as a result of heightened stress and anxiety in conjunction with their respective medical conditions. The layout of the assessment room also caused difficulties for one claimant who used a wheelchair due to restricted space. Claimants stated the relatively short assessment and the use of a prescribed and audited format could not possibly gain an understanding of the realities of their daily lives and conditions. There were reports of claimants with acute special educational needs and claimants with acute mental ill-health including diagnosis of schizophrenia still having to attend a face-to-face assessment despite their needs and conditions being listed on their PIP2 form with supporting medical evidence from their GPs.

- 4.75 **Initial Recommendation 10:** The Department for Communities should urgently address the issues raised by claimants. This includes but is not limited to: a) How appointments are scheduled – this should include reasonable adjustments, taking account of claimants’ conditions and the practicalities of attending appointments; b) 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; c) 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.
- 4.76 **Initial 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.
- 4.77 Evaluation of Initial Recommendation 10:** This recommendation would ensure greater understanding of the needs of claimants with disabilities, resulting in a more comfortable process that facilitates them, and acknowledges the human dignity of persons with disabilities. It would fulfil the UN CRPD Committee’s Inquiry Report recommendation of upholding a

human rights model of disability, by ensuring the process is accessible and inclusive of people with disabilities. It would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CRPD Committee's Concluding Observations. It also fulfils the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.

4.78 **Interim response to Recommendation 10:** The Department for Communities accepted this recommendation. The Department agreed appointments should be scheduled, where possible, with due consideration given to the requirements of claimants.

4.79 **Practical steps:** The Department for Communities said the recommendation of the Independent Review had been considered and the system of appointment scheduling had been enhanced to allow for more flexibility for front line Capita staff to reschedule appointments. If reasonable adjustments, e.g. a request for an interpreter, are identified at the initial review stage, Capita will put these in place and an appointment letter will be issued to the claimant. Moreover, if a claimant requires a particular time for their appointment, or is unavailable for certain dates, the appointment can now be subject to enhanced manual scheduling by Capita staff, bypassing the scheduling system. The Department appreciated that claimants may have to make significant efforts to attend their assessment. The Department is aware of a review to be undertaken by the Department for Work and Pensions into how requests for home assessments are dealt with; it will monitor this. It has commenced discussions with Capita to consider assessment room layout improvement, investigating removing any unnecessary items from the rooms.

4.80 **Evaluation of Department's response:** The Department for Communities must ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CRPD Committee's Concluding Observations. The Department further must ensure it undertakes all necessary adjustments that would make information, communications and administrations relating to PIP fully accessible to all people with disabilities. It did not give due consideration to the difficulties faced by claimants: it did not address the concerns raised that it assumed claimants

could readily avail of public transport when this was not always the case. It also did not address the concerns raised by GPs and claimants with regards to side effects of medication particularly at certain times of the day which could impact on their assessment. In addition, the Department could undertake its own exploratory work in relation to how requests for home assessments are considered, independently of the Department for Work and Pensions. The Department must ensure with Capita that the assessment room layout is accessible; it is not about there being enough room through removing “unnecessary items” but rather ensuring there is room so that the claimant and accompanying members if relevant are comfortable.

Assessors

- 4.81 **Finding:** Claimants said they believed their assessor was not familiar with their case, had not read their PIP2 form or supporting evidence, and displayed a lack of understanding of their conditions and an inability to perceive the full impact these conditions had on the claimants’ lives. Claimants said their assessors did not fully engage with them during the assessment, rarely looked at them or acknowledged claimants’ responses. There appeared to be a lack of understanding of a range of complex medical conditions and needs, and it was noted an assessor working in a general healthcare role would not be equipped to understand all specific conditions arising during assessments, including mental health.
- 4.82 **Initial Recommendation 11:** The Department for Communities 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.
- 4.83 **Initial Anticipated Outcome:** 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.

4.84 Evaluation of Initial Recommendation 11: This recommendation would ensure greater understanding of the needs of claimants with disabilities, resulting in a more comfortable process that facilitates them, and acknowledges the human dignity of persons with disabilities. It would fulfil the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability, by ensuring the process is accessible and inclusive of people with disabilities. It would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CPRD Committee's Concluding Observations.

4.85 Interim response to Recommendation 11: The Department for Communities did not accept this recommendation. The Department accepted that it was important that disability assessors have the most appropriate training to allow them to deliver the assessment effectively but added the assessment is not a clinical assessment involving diagnosis of conditions or the recommendation of options for treatment. It considered that whether a health professional is a specialist in a given area or not, this should not affect their ability to carry out a functional assessment. The Department noted all PIP assessors in NI are health professionals - occupational therapist, nurse, physiotherapist, paramedic or doctor - with specialist training in conducting functional assessments. The Department considers assessors appropriately trained to carry out the PIP functional assessment, given the extensive training received by assessors, and the continual learning and auditing of the assessors.

4.86 Practical steps: The Department for Communities did not outline any practical steps it had taken/would consider taking as it stated it considered assessors to be appropriately trained.

4.87 Evaluation of Department's response: It is disappointing the Department for Communities did not acknowledge there are a variety of conditions and needs presented at assessments; it did not acknowledge in particular the lack of mental health specialists. Whilst it has ensured training has been tailored locally to include specific content relating to victims and survivors, it has not tailored training to consider the high levels of mental ill health in NI. Whilst the assessment is not a clinical assessment, a key element of the assessment is the understanding of medical conditions and how they impact on the daily lives of claimants with disabilities. The Department must consider ensuring assessors can increase their understanding of needs of claimants with disabilities and

enable the assessment to facilitate them in line with a human rights model of disability. It would be worthwhile for the Department to engage in discussion with Capita about the potential for enhanced training, in light of the findings of the Independent Review and particularly to consider specialist training for mental health awareness/conditions. This is particularly relevant following the judgment of the High Court of England and Wales in December 2017 that regulations introduced by the UK Government in March 2017 “blatantly discriminated” against claimants with mental ill health²¹: the regulations meant assessors were required to disregard claimants with certain mobility problems who were unable to travel independently due to their “psychological distress” rather than other medical conditions. The Department of Work and Pensions later confirmed they would not appeal the judgment.²² Consequently, the judgment ensures the recognised need for access to mental health experience when claimants with mental ill health are undergoing the assessment process.

Effectively Demonstrating Circumstances during the PIP Assessment Process

4.88 **Finding:** It was apparent for claimants to fully engage with the assessment process they must have a wide variety of knowledge and skills including: an understanding of the process; an understanding of the required relevant information and how to obtain it; well-developed written and oral communication skills; organisational ability; self-confidence to communicate about their conditions and functionality. If a claimant does not have these skills, they would struggle to effectively represent themselves; due to certain medical conditions claimants may not possess these skills.

4.89 **Initial Recommendation:** No recommendation was provided by the Independent Review.

4.90 **Initial Anticipated Outcome:** No anticipated outcome was provided by the Independent Review.

²¹ *R. (on the application of RF) v Secretary of State for Work and Pensions* [2017] EWHC 3375 (Admin), at para 59.

²² Secretary of State for Work and Pensions, ‘Written Statement: Welfare – HCWS414’, 19 January 2018. The Department for Work and Pensions committed to undertaking a review of approximately 1.6 million existing PIP claims. Around 220,000 claimants with disabilities including an estimated 164,000 claimants with mental health-related conditions are expected to receive increased PIP payments as a result of this decision (latter statistic taken from Disability Rights UK, ‘DR UK welcomes Govt decision not to appeal PIP psychological distress judgment’, 19 January 2018).

4.91 Evaluation of Initial Recommendation: It is disappointing that no recommendation was provided in response to the Independent Review’s finding regarding effectively demonstrating circumstances during the PIP assessment. It is a cause for concern that claimants may struggle to represent themselves, considering the detrimental impact on their social security and independence in the event their claim is unsuccessful. It is apparent the assessment process is not fully accessible, especially for claimants with certain medical conditions and disabilities. The Department of Communities should engage with disability organisations and advice support groups to determine whether claimants with disabilities are disproportionately affected by the requirement of certain skills to engage fully in the assessment process. The Department should determine whether there is scope to launch a public consultation on the issue. Both steps would assist with the development of an inclusive, human rights compliant assessment framework. These actions would ensure greater understanding and knowledge of the process and enable the claimants to engage more fully in the process, particularly those with more complex needs. This would fulfil the UN CRPD Committee’s Inquiry Report recommendation of upholding a human rights model of disability, encouraging participation and inclusivity of people with disabilities including in decision-making relating to their daily lives, condition management, and independence. This in turn acknowledges the human dignity of persons with disabilities. It also fulfils the UN CRPD Committee’s recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.

4.92 Interim response to Recommendation: There was no response to the finding of the Independent Review from the Department for Communities.

4.93 Practical steps: There were no practical steps provided by the Department for Communities.

4.94 Evaluation of Department’s response: It is disappointing that no interim response was provided by the Department for Communities regarding the Independent Review’s finding on effectively demonstrating circumstances during the PIP assessment process. The Department should engage with disability organisations and advice groups, and determine the scale of the issue. In the absence of a Minister, the Department should

also commission research to establish the extent of the issue regarding claimants with certain medical conditions and disabilities struggling to adequately represent themselves. These actions would assist with full implementation of the UN CRPD Committee's recommendation of co-operation with disability organisations to ensure the assessment process is more understanding of claimants with disabilities. This would also mark progress in the fulfilment of the UN CRPD Committee's recommendation for the introduction of all necessary adjustments that would make all information, communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities.

Accuracy of Reports

4.95 **Finding:** Concern was expressed by claimants, those supporting them, and support organisations about the accuracy of assessment reports. In addition those accompanying claimants shared accounts of having their input blocked by the assessor which restricted the information being shared. The Independent Review felt it would be helpful to have an audio-visual recording in place which could be consulted: it would assist the assessor in writing their report and could enable greater interaction between the assessor and claimant. The Independent Review was told of occasions when an assessor's report contained conclusions seemingly based on visual observations. The Independent Review stressed observational methods must be undertaken with caution.

4.96 **Initial Recommendation 12:** The Department for Communities should introduce audio-visual recording of assessments in both home and assessment centre locations.

4.97 **Initial Anticipated Outcome:** 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.

4.98 **Evaluation of Initial Recommendation 12:** This recommendation would ensure greater understanding and knowledge of the process and enable the claimants to engage more fully in the process. This would fulfil the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability, encouraging participation and inclusivity of

people with disabilities including in decision-making relating to their daily lives, condition management, and independence. This in turn acknowledges the human dignity of persons with disabilities. It would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CPRD Committee's Concluding Observations.

4.99 Interim response to Recommendation 12: The Department for Communities partially accepted this recommendation. The Department noted the PIP Assessment Guide confirms the assessor's report is not intended as a verbatim record of what was discussed at the assessment. Claimants may audio record their face-to-face assessment if they provide appropriate equipment. The equipment must generate two copies at the end of the assessment: one for the claimant, the other for Capita.

4.100 Practical steps: It was noted the Department for Work and Pensions is intending to pilot video recording of assessments; the Department for Communities is both tracking these developments and will carry out a pilot of audio recording in NI.

4.101 Evaluation of Department's response: Whilst the Department for Communities has not committed to piloting or rolling out audio-visual recording of assessments, it is still welcome it has committed to carrying out a pilot of audio recording. This would ensure greater understanding and knowledge of the process and enable the claimants to engage more fully in the process. This would fulfil the UN CRPD Committee's Inquiry Report recommendation of upholding a human rights model of disability, encouraging participation and inclusivity of people with disabilities including in decision-making relating to their daily lives, condition management, and independence. In addition, the fact that the Department for Communities will undertake this pilot independent of the Department for Work and Pensions' pilot illustrates that it can conduct independent research into the various issues raised by the findings of the Independent Review, such as conducting home assessments.

Informal Observations and Questions Regarding Self-Harm and Suicide

4.102 Finding: Claimants said they were offended and upset at the inclusion of questions around self-harm and suicide in the assessment which was also noticed in the observed assessments. The Independent Review was 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 – but the Independent Review did not hear this point being put to claimants during the observed assessments. It was considered an inadequate response. It was noted that to disclose a reference to suicide included in a claimant’s PIP2 form during assessment in front of someone who was not aware of the claimant’s history could be a breach of confidentiality particularly as the claimant has no indication from the form this line of questioning may be followed.

4.103 Initial Recommendation 13: (A) The Department for Communities, 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 for Communities 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.

4.104 Initial 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.

4.105 Evaluation of Initial Recommendation 13 (A) and (B): This recommendation would ensure greater understanding of the needs of claimants with disabilities, resulting in a more comfortable process that facilitates them, and acknowledges the human dignity of persons with disabilities. It would fulfil the UN CPRD Committee’s Inquiry Report recommendation of upholding a human rights model of disability, by ensuring the process is accessible and inclusive of people with disabilities.

4.106 Interim response to Recommendation 13 A: The Department for Communities accepted this recommendation. It acknowledged that it is critical that these informal observations are factual observations and not opinions.

4.107 **Interim response to Recommendation 13 B:** The Department for Communities partially accepted this recommendation. The Department appreciated the questioning carried out during an assessment must be conducted in a sensitive manner. It acknowledged that the issues of mental health, and in particular suicidal ideation and self-harm, are particularly sensitive. The Department emphasised any information shared with the Department, for the purposes of a claim for support, is handled appropriately and in line with data protection regulations. The Department did not consider discussing information contained in the PIP2 a breach of confidentiality in this context. It considered an appropriate approach would be to review communications from the Department and Capita, to ensure it is clear that information in the PIP2 is likely to be discussed in the assessment.

4.108 **Practical steps:** The Department for Communities will continue to use informal observations as part of the PIP assessment process. Departmental Case Managers have since been advised to challenge the observations, if they deem them unjustified, to ensure their correct application. The Department has discussed with Capita how questions regarding suicide and self-harm should not be asked unless raised by the claimant in the assessment or included on the PIP2 questionnaire. Capita has since completed a review of its processes for observing both the mental and cognitive state of claimants where suicidal intent or self-harm may be relevant to their daily living or mobility components. This resulted in updated guidance to assessors to ensure that the subjects of suicide and self-harm are only addressed where it is relevant and that this is done in a sensitive and professional manner. The delivery of training on this revised guidance commenced on 1 October 2018.

4.109 Evaluation of Department's response: Informal observations can result in an uncomfortable environment for claimants with disabilities; they may feel that the process does not facilitate them and they could feel their dignity is compromised or undermined. It is important informal observations are conducted in a manner which includes the claimant with disabilities. This would ensure inclusivity and would operate in line with a human rights model of disability. The Department for Communities and Capita should extend advice to assessors, not just Case Managers that informal observations cannot be mere opinions. In addition, this advice should also form part of the training process. Whilst Capita has updated guidance so subjects of suicide and self-harm are asked only when

relevant and in a professional manner, it must be noted assessors do not benefit from mental health-focused training or awareness training, or counselling training. Again, it illustrates the need for enhanced training of assessors on mental health awareness and conditions, further to paragraph 4.87.

The Assessor's Report

- 4.110 **Finding:** Claimants stated they would benefit from seeing their assessment report either before the decision is made or alongside their decision notification. This in addition with audio-visual recording would enhance openness and transparency in the process and increase trust in the process.
- 4.111 **Initial Recommendation 14:** The Department for Communities should put in place arrangements for a copy of the assessor's report to be made available to claimants along with the decision letter.
- 4.112 **Initial Anticipated Outcome to Recommendation 14:** 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.
- 4.113 **Evaluation of Initial Recommendation 14:** This recommendation would ensure greater understanding and knowledge of the process and enable the claimants to engage more fully in the process. This would fulfil the UN CPRD Committee's Inquiry Report recommendation of upholding a human rights model of disability, encouraging participation and inclusivity of people with disabilities including in decision-making relating to their daily lives, condition management, and independence. This in turn acknowledges the human dignity of persons with disabilities. It would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CRPD Committee's Concluding Observations.
- 4.114 **Interim response to Recommendation 14:** The Department for Communities did not accept this recommendation. The Department did not see the need to issue more paperwork with the decision letter in large numbers of cases where claimants are content with the decision they have

received. It noted how the Independent Review itself acknowledged how claimants can be intimidated by the amount of literature they must read when applying for PIP.

4.115 Practical steps: The Department for Communities noted the Department for Work and Pensions had already undertaken to improve PIP communications to clearly highlight to everyone that they can request a copy of their assessment report should they wish to. Changes to the Department for Work and Pensions' notifications are normally carried through into Department for Communities' notifications unless there is reason not to follow suit; the Department for Communities expected it will also have updated notifications clarifying the availability of the report to claimants. Once it has improved the PIP communications to clearly highlight to all that they can request their report the Department for Communities believes those claimants who want to see their report will do so.

4.116 Evaluation of Department's response: The Department for Communities has attempted to explain its decision to not provide copies of the assessor's report to claimants as part of the process on the grounds there is too much paperwork disseminated already; arguably claimants with disabilities would rather receive a copy of the Report as part of the process than numerous guidance booklets. However, the arrangement to ensure a copy may be made available on request is an improvement and would ensure the eligibility criteria and assessments to access PIP is in line with a human rights model of disability, in accordance with the recommendation of the UN CRPD Committee's Concluding Observations. Moreover, the Department could commit to undertaking its own review of PIP communications including notifications to claimants independently of the Department for Work and Pensions.

5.0 Conclusions and Recommendations

5.1 The Department for Communities accepted the majority of the UN CRPD Committee's 2016 and 2017 recommendations. However, acceptance does not equate to explicitly complying with these recommendations. There have been some concrete steps to reform the PIP assessment process, for the purpose of informing and empowering claimants with disabilities and their families. This is a step in the right direction in terms of upholding a human rights model of disability, ensuring all information,

communications, administrations and legal procedures in relation to social security fully accessible to people with disabilities, and increasing independence and dignity of claimants. Yet, there is still a long way to go in terms of the Department for Communities fully and effectively implementing the UN CRPD Committee's 2016 and 2017 recommendations.

Awareness

5.2 The Independent Review found that claimants, their family members and in some instances, support workers did not have a clear understanding of the purpose of PIP, and the assessment process. In particular, it was found that there was a lack of clarity regarding the functional nature of the assessment and the types of information and evidence required to support a claim. This lack of clarity has resulted in confusion as claimants progress further into the process, especially in relation to "relevant" and "additional" information required for their applications. It is evident increased engagement is essential to better inform claimants, their family, carers, guardians about the PIP process.

5.3 IMNI recommends that the Department for Communities considers how to ensure continued awareness and education of the PIP system, including application and assessment process at the conclusion of the planned series of events.

5.4 IMNI recommends the Department continues its collaboration with thematic support groups, including disability groups to develop and facilitate ongoing educational awareness, particularly in relation to what constitutes "relevant information".

Confusion around the Assessment Process

5.5 The Independent Review found that there were inconsistencies within the PIP literature and guidance materials, both for claimants and for those conducting the process in the Department for Communities and Capita. Such inconsistencies were present in the terminology used to describe the process and those delivering it. It is essential that clarity in communicating the nature and purpose of the assessment process is provided to claimants. The production and publication of the series of information guides pertaining to Universal Credit is welcome, and it is hoped this is replicated for the PIP system in due course. PIP is briefly referenced in an

information guide within the series, but no specific guidance about the process is provided; readers are instead referred to the NI Direct website.²³ This brief reference to PIP within one of the Universal Credit information guides should be built upon in order to display commitment to making all necessary adjustments to ensure the accessibility of the PIP system. It is not sufficient to refer potential claimants and their carers/family members to a website page, especially when it does not provide in-depth guidance on the PIP2 form, or assessment process. Moreover, the literature available to download from the NI Direct website has not been subject to revision or updating.²⁴

5.6 IMNI recommends the Department for Communities reviews the terminology used throughout the process, especially terminology used in advice and guidance documents, and does not remain confined to the terms of the research undertaken by the Department for Work and Pensions in this area. IMNI further recommends that the Department's production of the series of information guides for the Universal Credit system in general is replicated to provide information specific to PIP.

DLA Evidence

5.7 The Independent Review found that for some claimants (those who have been on a lifetime award of DLA) their case file was unlikely to contain up-to-date information. There appears to be omissions in consideration in this area: i) no consideration that a claimant's DLA case file contains information obtained for a different purpose and may not be suitable for a PIP assessment; ii) no consideration that claimants assume if they request their DLA case file being made available, it would form part of their assessment which is not always the case. It is therefore essential all relevant evidence should be made available at the earliest possible point. Claimants are also not fully aware as to what constitutes "relevant evidence" and again this may prove detrimental to their claim.

5.8 IMNI recommends the Department for Communities commits to further adjustments within the engagement process relating to the

²³ Department for Communities, 'Universal Credit: What you need to know' (DfC, 2019), at 14.

²⁴ As of 2 July 2019, the only PIP literature available to download from the NI Direct website dates from May 2016; see Department for Communities, 'Personal Independent Payment' (DfC, 2016) available at <https://www.nidirect.gov.uk/publications/personal-independence-payment-leaflet>

use of DLA evidence, including the introduction of paper- and electronic-based advice.

5.9 IMNI recommends the Department for Communities monitors and evaluates the continued use of DLA evidence within the process.

The PIP Assessment Process

5.10 It is evident the PIP assessment process is complex. Given the intensive engagement and research required by the Independent Review to fully comprehend the entire process, it appears unrealistic that the average claimant could be expected to confidently understand the process. In addition, the Department for Communities and Capita should not assume a claimant has prior knowledge or understanding of the process. There is a lacuna of accessible, concise information explaining the process for claimants.

5.11 IMNI recommends the Department for Communities commits to undertaking its own review, separately to the Department for Work and Pensions, of all written material used throughout the PIP process. The review should determine the accessibility and comprehension of the written material, identify areas where revision is required, and outline steps to improve the accessibility of written material. IMNI further recommends the Department devise concise material in a variety of accessible formats, describing the PIP assessment process in particular.

Application Process

5.12 The application process was found to be lacking in accessibility, which has resulted in claimants with disabilities including certain medical conditions and those with speech and/or hearing impairments, encountering difficulties at the initial stage of the application process. These difficulties have included the requirement for telephone communication, and the lack of provision for an electronic-based PIP1 form, which is preferred by those claimants who cannot complete the paper-based form by hand.

5.13 IMNI recommends the Department for Communities commits to undertaking its own review, separately to the Department for Work and Pensions, of the accessibility and comprehension of the PIP application process. The review should include the consideration of

further adjustments to the initial stage of the application process, including the introduction of electronic forms. The Department should further commit to liaising with Capita in delivering enhanced awareness training to staff operating the initial telephone claim desk to ensure awareness of how to engage with claimants have difficulties in using or are unable to use telephone communications due to their disabilities.

Claims made under Special Rules

5.14 The requirement for a claimant with a short life expectancy to complete an assessment form following the completion of a DS1500 form by a medical practitioner in order to avail of “special rules for terminal illness” was considered insensitive.

5.15 IMNI recommends that the Department for Communities commits to reviewing the continued operation of the six months’ life expectancy criterion. This ongoing review should include an assessment of the compatibility of this criterion with the rights of the people of NI, especially people with disabilities.

Completing the PIP2

5.16 The Independent Review highlighted that claimants reported feeling stress and anxiety at having to complete the extensive PIP2 form within a four-week deadline. Claimants may face difficulty completing a form by hand depending on their medical conditions/impairments. Again, there is an issue regarding lack of clarity within written material, as both the PIP2 form and accompanying booklet are unclear in terms of what they mean by “relevant evidence”. It appears to be necessary for the process of completing the PIP2 form to be reviewed, however the Independent Review did not issue a recommendation on this. It is also disappointing the Department for Communities did not recognise there is an issue which requires addressing. In light of the Department’s publication of a series of information guides providing an overview of Universal Credit including the application stage in a concise manner, it is hoped this is replicated for the PIP system. A series of information guides providing a clear overview of and assistance for the PIP application stage including the PIP2 form would ensure enhanced accessibility and clarity for claimants.

5.17 IMNI recommends the Department for Communities reviews the accessibility and comprehension of the PIP2 form and accompanying guidance booklet, in line with its production of a series of information guides for Universal Credit in general. The review should include the consideration of adjustments to the PIP2 stage, including the introduction of electronic and easy read forms. IMNI further recommends the Department undertakes a review of the current four-week deadline for completion of the PIP2 form and examines the feasibility of extending the deadline.

Sourcing Further Evidence

5.18 It appears that the current system governing the sourcing of further evidence is confusing and convoluted for claimants, and burdensome for GPs, whose submissions on the subject have seemingly not been addressed by the Department for Communities. It is concerning that decisions may be made during the PIP process without access to all relevant information. The Independent Review found the PIP2 Form and its supporting guidance booklet advise claimants not to request additional information if they do not already have it, stating the Department for Communities and Capita would request additional evidence themselves if they required it. However, claimants have alleged the Department and Capita have not attempted to source further evidence from professionals supporting them. When Capita has requested additional information from GPs, GPs have said they are unaware if the information they provide is relevant or not. It is important this stage in the PIP assessment process is subjected to a review.

5.19 IMNI recommends the Department for Communities undertakes, separately to the Department for Work and Pensions, exploratory research into the development of a "Function First" approach to the PIP assessment process. IMNI further recommends the Department engage with relevant professional medical bodies to devise a process which enables the most effective and time-efficient way to obtain a GP Short Summary Report to support the PIP2 submission. This engagement process should also examine what constitutes "relevant information" and "additional information" regarding a claimant's medical history, condition, and how this may be obtained and included within the GP Short Summary Report.

Receipt of Further Evidence

5.20 It is concerning that all relevant information may not be available at key times during both the assessment and decision-making process, largely due to a convoluted process for the receipt of completed PIP2 forms and accompanying additional evidence/information.

5.21 IMNI recommends the Department for Communities produces concise paper- and electronic based advice for claimants, families, carers and guardians regarding the preferred format and style for the submission of the completed PIP2 form and additional supporting documentation. The advice should also provide information on the process by which Capita receives a completed PIP2 form, including how documents are processed for inclusion in the claimant's case file.

Initial Review by Capita

5.22 The Independent Review found that claimants have engaged with Capita to demonstrate they would not be able to participate in a face-to-face assessment due to the nature or severity of their medical condition and/or impairments. Claimants and their families have endured stress, anxiety, and fear after being informed of having to participate in a face-to-face assessment and participating in same.

5.23 IMNI recommends the Department for Communities reviews the procedure of determining when a face-to-face assessment is conducted, and the process by which this assessment is carried out. The review should include the consideration of adjustments to the initial review carried out by Capita, including the feasibility of alternative means of assessment beyond paper-based and face-to-face assessment. The review should also assess the compatibility of the initial review including its restricted methods of assessment with the rights of the people of NI, especially people with disabilities.

The Assessment

5.24 The sheer number of issues raised during the Independent Review indicated the PIP assessment was the most contentious part of the overall

process. It is apparent there is a lack of consideration of claimants with disabilities including speech and hearing impairments, and no consideration of how best to ensure accessibility for these claimants.

5.25 IMNI recommends the Department for Communities undertakes, separately to the Department for Work and Pensions, exploratory research into the process by which requests for home assessments are considered.

5.26 IMNI recommends that the Department for Communities consult with thematic support groups, including disability groups, on adjustments which could be made to the assessment process, including the arrangement of assessments, traveling to the assessment, how to take into account the claimant's medication needs and the effects of medication on the claimant, and accessibility of the assessment room.

Assessors

5.27 The Independent Review found that there was a lack of understanding of a range of complex medical conditions and needs, including mental health. The Department for Communities did not acknowledge there currently is an outstanding gap in the knowledge and understanding of assessors of particular medical conditions including mental health, nor did it acknowledge the importance of enhanced training for assessors.

5.28 IMNI recommends the Department for Communities reviews the training currently delivered to assessors. The review should take into account the recent judgment of the High Court of England and Wales in December 2017 and assess the compatibility of the current training with the human rights of the people of NI, particularly people with disabilities.

5.29 IMNI recommends the Department for Communities engages in discussion with Capita about developing enhanced training, particularly to consider specialist training for mental health awareness/conditions in line with human rights standards. The development of enhanced training should also consider the implementation of a system whereby claimants with particular medical conditions may request an assessor with enhanced

training and knowledge of their conditions, or request a paper-based review.

Effectively Demonstrating Circumstances during the PIP Assessment Process

5.30 The PIP process, particularly the application process, is lengthy and complex. It requires a range of skills, not least the comprehension of the process itself. The Independent Review identified that claimants who did not have this knowledge and/or skillset would struggle to effectively represent themselves. This is especially the case for claimants with certain medical conditions. The Independent Review did not issue a recommendation to the Department for Communities, and the Department itself did not provide a response to this issue or outline any practical steps to address it. This is despite previous findings of the Independent Review that the written material provided by the Department must be reviewed, and that there must be greater engagement and awareness of the PIP process undertaken by the Department.

5.31 IMNI recommends the Department for Communities reviews the current framework governing self-representation at the assessment stage, particularly assessing the compatibility of this framework with human rights standards.

5.32 IMNI recommends the Department for Communities consults with thematic support groups, including disability groups, and the advice sector to determine the scale of the difficulty faced by claimants to effectively demonstrate their circumstances during the PIP assessment process. The Department should also engage with relevant professional medical bodies, and thematic support groups including disability groups, to examine the extent of the issue of claimants with certain medical conditions and disabilities encountering difficulties in representing themselves.

Accuracy of Reports

5.33 Concern was expressed by claimants, those supporting them, and support organisations about the accuracy of assessment reports. Concern was also expressed about the incidents when an assessor's report contained conclusions seemingly based on visual observations. The commitment from

the Department for Communities to pilot video recording of assessments is welcome but it appears there is a reasonable case to be made as to the necessity of video recording of assessments.

5.34 IMNI recommends the Department for Communities commits, separately to the Department for Work and Pensions, to carrying out a pilot scheme of video recording of assessments.

Informal Observations and Questions Regarding Self-Harm and Suicide

5.35 The Independent Review found that claimants were upset and offended at the inclusion of questions around self-harm and suicide in the assessment and the manner in which the questions were asked. It is evident there is a lack of consideration of the sensitivities involved in engaging with claimants with mental health conditions. This is particularly pertinent given the lack of enhanced training on mental health for assessors.

5.36 IMNI recommends the Department for Communities and Capita produce updated advice on the use of informal observations for assessors which should include the advice that informal observations must be factual observations.

5.37 IMNI recommends that the Department for Communities and Capita should review the continued use of informal observations within the assessment process. The Department and Capita should undertake a review on the continued inclusion of questions about suicide and self harm in the assessment process. This review should take into account the recent judgment of the High Court of England and Wales in December 2017²⁵ and assess the compatibility of the use of such questioning with the human rights of the people of NI, particularly people with disabilities. The IMNI advises this review should consider the introduction of specialist training for mental health awareness/conditions, and consider the development of a system whereby claimants with a history of suicide and/or self-harm may request an assessor with enhanced training and knowledge of mental ill health.

²⁵ *R. (on the application of RF) v Secretary of State for Work and Pensions* [2017] EWHC 3375 (Admin).

The Assessor's Report

5.38 The Independent Review noted claimants stated they would benefit from seeing their assessment report either before the decision is made or alongside their decision notification. The Department for Communities did not accept the recommendation to provide a copy of the assessor's report for claimants on the grounds that claimants already were in recipient of a large volume of literature. Arguably claimants with disabilities would rather receive a copy of the Report as part of the process than the other written material. This is especially given that the Independent Review issued several recommendations for the written material including terminology within same to be reviewed and revised. The distribution of a copy of the assessor's report would enhance transparency in the process.

5.39 IMNI recommends the Department for Communities review current arrangements to allow for the inclusion of a copy of the assessor's report to be made available to claimants along with the decision letter.

5.40 IMNI recommends the Department for Communities commits, separately to the Department for Work and Pensions, to undertaking its own review of PIP communications.

Cumulative Impact Assessment

5.41 In its Interim Response, the Department for Communities did not commit to undertaking a rights-based cumulative impact assessment, in accordance with the UN CRPD Committee's recommendations of both 2016 and 2017. It did not commit to examining the possibility of establishing a mechanism and a system of rights-based indicators to permanently monitor the accessibility of the PIP process and the impact of same on the access and enjoyment of rights of claimants with disabilities. It also did not commit to examining the possibility of introducing and implementing legislative frameworks to ensure that social protection policies and programmes secure income levels for all persons with disabilities and their families. These are likely to remain unfulfilled in the continued absence of the devolved institutions and of a Minister with responsibility for the functions of the Department for Communities. However, following the findings of the Independent Review, it is apparent that the implementation of the recommendations are necessary.

5.42 In 2017, the Equality and Human Rights Commission, commissioned research which examined how to establish a social security system based on legally-grounded definitions of dignity and respect within the Scottish jurisdiction.²⁶ This provides an evidenced based approach to policy making.

5.43 IMNI recommends that the Department of Communities undertakes a cumulative impact assessment of the impact of social security reforms in NI, drawing from the Equality and Human Rights Commission’s research.

Social Security Charter

5.44 An additional measure that is worth considering, that the Department for Communities did not include in its interim response is examining the approach adopted in the social security system in Scotland - namely the introduction of a principles-based approach to social security, as enshrined in a social security charter – as a case of good practice particularly for the protection of the rights of people with disabilities. Further to this, the Scottish approach may be examined with regards to the possibility of the future implementation of a similar principles-based approach in NI, including adopting the principle of social security as a human right, in accordance with UN ICSECR, Article 9, and necessary to the access and enjoyment of other human rights.

5.45 The 2017 research report commissioned by the Equality and Human Rights Commission noted that international treaties which provide rights to social security and/or an adequate standard of living have not been incorporated into UK law and suggested the UK Parliament could impose a requirement on the Scottish Parliament to comply with these international treaties; the report held this appeared unlikely to happen.²⁷ However, the report further noted that primary legislation was “the best means” of defining and protecting dignity and respect, stating:

if access to social security and an adequate standard of living are crucial to the protection of dignity, then the incorporation of relevant provisions of human rights law into Scottish law forms a stepping stone towards a system based on dignity and respect. The UK’s Human Rights Act 1998 is the strongest model for protecting these rights. A similar Act could require public

²⁶ Mark Simpson, Gráinne McKeever and Anne Marie Grey, ‘Social security systems based on dignity and respect’ (Equality and Human Rights Commission, 2017).

²⁷ Mark Simpson, Gráinne McKeever and Anne Marie Grey, ‘Social security systems based on dignity and respect’ (Equality and Human Rights Commission, 2017) at 8.

authorities to ensure their actions are compatible with and courts to interpret legislation in such a way as to be compatible with social rights provisions unless prevented from doing so by primary legislation. The Scottish Parliament itself would be expected, but not obliged, to ensure legislation complies with the same set of rights.²⁸

5.46 The report recommended the Scottish Government considered incorporating the European Social Charter and/or International Covenant on Economic, Social and Cultural Rights into domestic legislation, modelled on the Human Rights Act 1998.²⁹ The report further recommended the creation of a statutory Charter of Social Security Rights and Responsibilities to ensure that laws protecting dignity are followed. It was suggested the Charter would include principles for social security in Scotland, relevant human rights provisions and any additional rights, responsibilities or commitments agreed through consultation.³⁰ Further recommendations of the research report commissioned by the Equality and Human Rights Commission included that: Scottish people including existing and potential users of the social security system should be involved in the development of social security policy and systems;³¹ the Scottish Government explore in conjunction with service users, options for greater personalisation of disability benefits;³² and the assessment process for disability benefits is closely monitored and subject to an early, independent review.³³

5.47 The Social Security (Scotland) Act 2018 enshrined into law cardinal features of the Scottish social security system, including setting out the Scottish “social security principles”³⁴. The social security principles include

²⁸ Mark Simpson, Gráinne McKeever and Anne Marie Grey, ‘Social security systems based on dignity and respect’ (Equality and Human Rights Commission, 2017) at 8.

²⁹ Mark Simpson, Gráinne McKeever and Anne Marie Grey, ‘Social security systems based on dignity and respect’ (Equality and Human Rights Commission, 2017) at 9.

³⁰ Mark Simpson, Gráinne McKeever and Anne Marie Grey, ‘Social security systems based on dignity and respect’ (Equality and Human Rights Commission, 2017) at 9.

³¹ Mark Simpson, Gráinne McKeever and Anne Marie Grey, ‘Social security systems based on dignity and respect’ (Equality and Human Rights Commission, 2017) at 10.

³² Mark Simpson, Gráinne McKeever and Anne Marie Grey, ‘Social security systems based on dignity and respect’ (Equality and Human Rights Commission, 2017) at 11.

³³ Mark Simpson, Gráinne McKeever and Anne Marie Grey, ‘Social security systems based on dignity and respect’ (Equality and Human Rights Commission, 2017) at 11.

³⁴ Social Security (Scotland) Act 2018, Part 1, section 1. The identified social security principles are: (a) social security is an investment in the people of Scotland; (b) social security is itself a human right and essential to the realisation of other human rights; (c) the delivery of social security is a public service, (d) respect for the dignity of individuals is to be at the heart of the Scottish social security system; (e) the Scottish social security system is to contribute to reducing poverty in Scotland; (f) the Scottish social security system is to be designed with the people of Scotland on the basis of evidence; (g) opportunities are to be sought to continuously improve the Scottish social security system in ways which— i) put the

the recognition that social security is a human right, “essential to the realisation of other human rights”,³⁵ respect for the dignity of individuals is at the heart of the social security system,³⁶ and that the social security system is designed with the people of Scotland, on the basis of evidence.³⁷ The 2018 Act further requires the creation of a Scottish social security charter, which will lay down standards for the provision of social security in Scotland that are aligned with the Scottish social security principles.³⁸

5.48 Further to the enshrining of social security principles, the Social Security (Scotland) Act 2018 provides for the practical application of these principles. The 2018 Act requires Scottish Ministers to promote take-up of the Scottish social security system.³⁹ Further to this, the 2018 Act requires Scottish Ministers to have regard to the importance of both inclusive communication⁴⁰ and accessible information,⁴¹ in the promotion of take-up, stipulating that information must be provided in a way that is accessible for individuals who “have a sensory, physical, or mental disability”.⁴² The 2018 Act also includes a duty on Scottish Ministers to have regard to the importance of independent information, advice and advocacy.⁴³

5.49 The social security principles enshrined within the Social Security (Scotland) Act 2018 also apply to the assessment process. The 2018 Act provides for a restriction of assessments of applicants’ physical and mental health by individuals who not acting in the course of employment by a public body.⁴⁴ Scottish Ministers are required to ensure assessors are suitably qualified to conduct assessments.⁴⁵ Moreover, an assessment is only to be conducted when it is the only practicable means to obtain the information required to determine what assistance the individual is eligible for,⁴⁶ and the individual’s preferences for how and where the assessment

needs of those who require assistance first, and ii) advance equality and non-discrimination; and (h) the Scottish social security system is to be efficient and deliver value for money.

³⁵ Social Security (Scotland) Act 2018, Part 1, section 1, subsection (b).

³⁶ Social Security Scotland Act 2018, section 1, subsection (d).

³⁷ Social Security Scotland Act 2018, section 1, subsection (f).

³⁸ [Social Security \(Scotland\) Act 2018, Part 1, sections 15-19.](#)

³⁹ Social Security (Scotland) Act 2018, Part 1, section 3.

⁴⁰ Social Security (Scotland) Act 2018, Part 1, section 4.

⁴¹ Social Security (Scotland) Act 2018, Part 1, section 5.

⁴² Ibid, at subsection (1).

⁴³ Social Security (Scotland) Act 2018, Part 1, section 6.

⁴⁴ Social Security (Scotland) Act 2018, Part 1, section 12.

⁴⁵ Social Security (Scotland) Act 2018, Part 1, section 13.

⁴⁶ Social Security (Scotland) Act 2018, Part 1, section 14, subsection (a).

is conducted must be considered by Scottish Ministers.⁴⁷

5.50 The provision for social security principles within the 2018 Act does not explicitly comply with the UN CRPD Committee's recommendations, but by recognising social security as a human right, which is also essential to the realisation of other human rights, it therefore ensures a rights-based approach to social security.⁴⁸ This, and the further recognition that respect for the dignity of individuals is to be at the centre of social security,⁴⁹ ensures the access and enjoyment of rights of claimants with disabilities, in accordance with the UN CRPD Committee's recommendations, thereby upholding a human rights model of disability.

5.51 The 2018 Act provided for the preparation and publication of a Scottish Social Security Charter⁵⁰, with the preparation requiring Scottish Ministers to consult persons with a physical and/or mental impairment⁵¹, and in receipt of social security payments.⁵² The Act provides for reporting requirements on Scottish Ministers and for the establishment of a Scottish Commission on Social Security in order to periodically assess the extent to which the expectations set out in the Social Security Charter are being fulfilled.⁵³ The Social Security Charter,⁵⁴ published in 2019, outlines what can be expected of Social Security Scotland, the Scottish Government, and of customers. These expectations include: a commitment from the Scottish Government to develop policy that seeks to advance the human right to social security, as well as equality, non-discrimination as defined in laws, treaties and guidance and to publicly challenge the myths and stereotypes about social security so as to reduce stigma and negativity; to respect the dignity of people using the service; and to generally promote a more positive view of social security.

5.52 IMNI recommends that the Department for Communities examines the principles-based approach enshrined in a social security charter implemented in Scotland, and further examines the case for adopting a similar approach in NI.

⁴⁷ Social Security (Scotland) Act 2018, Part 1, section 14, subsection (b).

⁴⁸ Social Security (Scotland) Act 2018, Part 1, section 1, subsection (b).

⁴⁹ Social Security (Scotland) Act 2018, Part 1, section 1, subsection (d).

⁵⁰ Social Security (Scotland) Act 2018, Part 1, section 15.

⁵¹ Social Security (Scotland) Act 2018, Part 1, section 16, subsection (3).

⁵² Ibid, at subsection (4).

⁵³ Social Security (Scotland) Act 2018, Part 1, section 18.

⁵⁴ Social Security Scotland, 'Our Charter' (SSS, 2019).

