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Exploring the impact of the migration from disability living allowance to personal independence payment on claimants with mental health problems

Final Report

**Richard Machin, Fiona McCormack and Chris
Gidlow**

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‘Exploring the impact of the migration from disability living allowance to personal independence payment on claimants with mental health problems’ – Project Report

Executive summary

Introduction

This report summarises the findings of a research project conducted by Staffordshire University and Disability Solutions West Midlands. The research was funded by a grant from the Centre for Health and Development (CHAD). The research explored the impact of the transition from Disability Living Allowance (DLA) to Personal Independence Payment (PIP) on working-age claimants with mental health problems.

Methods

The research project adopted a qualitative methodology. Semi-structured, in-depth interviews were conducted with thirteen service users from Disability Solutions. The research explored participants’ views on their experiences of claiming DLA and PIP, the effectiveness of the migration process and experience of the PIP medical assessment. The research explored the impact of receiving financial support through the payment of a disability benefit.

Findings

The findings of the research can be grouped into three main themes:

1. Overall process led to increased anxiety and uncertainty

- Poor communication with DWP
- Issues created by time-limited awards
- Reluctance to appeal negative decisions

2. Problems with the PIP claims process

- Problems recording complex mental health needs on the Personal Independence claim form
- Issues with the Personal Independence Payment medical assessment
- Feeling judged

3. Positive experiences/elements

- Importance of additional income from disability benefits
- Positive outcomes for some participants
- Importance of professional support

Recommendations

This research has led to six recommendations on a national level and five recommendations at a local level. The national level recommendations include a larger scale review of the impact of the move to PIP on claimants with mental health problems and a range of improvements to be made to the communication between the Department for Work and Pensions (DWP) and claimants. The local level recommendations include local agencies developing a co-ordinated approach to support PIP claimants with mental health problems and to monitor and report the impact of this aspect of welfare reform.

Introduction

This report summarises the findings of a collaborative research project conducted by Staffordshire University and Disability Solutions West Midlands. The study explored the impact of the transition from disability living allowance (DLA) to personal independence payment (PIP) on claimants with mental health problems. The research was funded through a grant provided by the Centre for Health and Development (CHAD), a research centre whose purpose is to contribute to the reduction of health and social inequalities through high quality, translational research. The study is aligned to one of CHAD's principle themes **Health Inclusion**.¹

[Disability Solutions West Midlands](#) is a voluntary organisation and registered charity. As a Disabled People's User Led Organisation (DPULO), Disability Solutions is managed and run by people with a disability, working with people across all disabilities and ages, their carers, families and communities. Disability Solutions exists to remove the barriers that restrict life choices, independence and control for people with a disability and their families by providing accessible, high quality, user-led services to meet the needs of people with disabilities. Disability Solutions encourages disabled people to fully participate and integrate in society and promote/recover positive attitudes towards their life, and healthy life choices. The organisation aims to ensure clients themselves gain a deeper understanding of the health and social care system/landscape and promotes positive health and well-being strategies throughout all service delivery points.

Academic staff from Staffordshire University's Social Welfare Law, Policy and Advice Practice degree worked with research staff from the Centre for Health and Development (CHAD) on the design, data collection and data analysis for this project. Undergraduate students from the Social Welfare Law, Policy and Advice Practice degree assisted with the data collection stage of this study. Research participants were recruited from Disability Solutions via their database of service users who had sought advice about PIP.

¹ This theme focuses on the health and wellbeing of people in Staffordshire and Stoke-on-Trent who may experience complex and multiple needs and/or who may have difficulty accessing universal services. For more information, please visit the website: <https://www.chadresearch.co.uk/health-inclusion/>

The importance of PIP to the well-being and mental health of claimants was explored. This included an examination of how the maintenance and continuity of income from disability benefits affects the health and independence of claimants in a wide range of ways (e.g. ability to interact with family/friends, affordability of care and support services, impact on diet, ability to adequately heat property, ability to afford suitable mobility options). The research also examined the impact of the administrative process associated with the move from DLA to PIP, exploring claimants' views on the quality and timeliness of decision-making, the completion of claim forms, the interaction with medical assessors, the terminology that underpins the administration of PIP and effectiveness of communication with the Department for Work and Pensions (DWP).

Background

Personal Independence Payment (PIP) is replacing Disability Living Allowance (DLA) for claimants of working age and is intended to assist with costs associated with disability or long-term health conditions. Eligibility is determined by an individual assessment; claimants are required to complete a claim pack and in the majority of cases are asked to attend a medical assessment with an approved healthcare professional. All awards are subject to periodic review. PIP was introduced for new claimants from April 2013, and the transition from DLA to PIP is underpinned by a change in philosophy on who should qualify for working age disability benefits. Under DLA there was an emphasis on 'disablement' but the move to PIP has been accompanied by a focus on 'limited ability' to complete a range of daily living and mobility tasks. This is of significance to a study of the social determinants of health. It is the government's aim that disability benefits such as PIP should address health inequities by providing a level of financial assistance for those suffering disadvantage as a result of ill health or disability. Critics of the administration of disability benefits (e.g. Roulstone, 2015) argue that the opposite is true, and that inadequate resourcing of benefits and inappropriate assessment methods exacerbate health inequalities.

The government believe that an overhaul of the Disability Living Allowance system was necessary to provide more targeted support for disabled people in genuine need with decisions based on medical evidence and a transparent points-based system (see section 2.3 below for further details on the rules of entitlement). At the beginning of the transition process it was anticipated that the full roll-out of PIP would result in

600,000 fewer disability benefit claimants with treasury savings of £2.5 billion per year. At the start of 2019 the Office for Budget Responsibility (OBR) has revised this estimate and now assess that modifications to the PIP eligibility criteria as a result of multiple legal challenges and the high number of appeals pursued by claimants will create an overspend of at least £1.5 billion.

The uncertainties created by the move from DLA to PIP are of concern for many people with mental health problems as anxieties arise about the new assessment process and the potential for the loss of a significant amount of benefit income. For other people the new system creates opportunities for their mental health problems to be more accurately assessed and acknowledged by a comprehensively revised social security system. This research project analysed these issues through the lived experience of local people and made connections between academic staff and the local community. It explored the links between theoretical concepts and the practical impact of government policy on people living in North Staffordshire.

The above issues have been the subject of considerable national and international debate. Concerns about the impact of the roll-out of PIP led to an inquiry by the United Nations Committee on the Rights of Persons with Disabilities (2016). The inquiry concluded that recent changes to the benefit system have had a disproportionate impact on disabled people, that advice and guidance to disabled people about their rights to disability benefits was limited, and that recent policy developments have led to a negative media portrayal of disabled people (Machin 2017).

There are well established links between health inequalities and income inequalities (Rowlingson 2011; Wilkinson and Pickett 2010). The Department for Work and Pensions assert that PIP will help to reduce these inequalities by providing financial support to enable disabled people to live more independent and active lives (DWP, 2012). There are a number of significant political and economic factors which potentially reduce the likelihood of these aims being achieved. The Social Mobility and Child Poverty Commission (SMPCP, 2015) found that people experiencing persistent poverty (having less than 60 per cent of current median income for at least three of the previous four years) are often living with a long-term disability or illness. DWP statistics (2013/14) highlight the reliance that disabled people in the UK have on state

welfare – 83% of families with at least one disabled adult in the household were in receipt of state benefits.

All the participants in this research were from the Stoke-on-Trent and wider North Staffordshire area. In Stoke-on-Trent approximately 14,000 people are being migrated from DLA to PIP. Each PIP claim is subject to a medical assessments which in this area are carried out by approved medical practitioners employed by Capita. Final decisions about entitlement rest with the DWP. A significant policy development arose during the course of this research. In March 2017 the government changed the rules of entitlement for the enhanced rate of the mobility component of PIP to exclude claimants experiencing psychological distress. In December 2017 the High Court ruled that this amendment was 'blatantly discriminatory against those with mental health impairments and cannot be objectively justified'. The DWP decided not to challenge the High Court's decision and is now undertaking a review of every person who is receiving PIP. In total approximately 1.6 million claims will be reviewed at a cost of around £3.7 billion. 220,000 people are expected to receive additional payments of PIP as a result of the review (Machin, 2018). This research was conducted against this quickly changing, and often unsettling backdrop, for those experiencing mental health problems who are claiming disability benefits.

[The rules of entitlement for Personal Independence Payment](#)

Personal Independence Payment is a non-means tested benefit for adults (aged 16-64) which is intended to help with the extra costs associated with an illness, disability or mental health condition. PIP has a daily living and mobility component and uses a points-based system to determine entitlement. Claimants may qualify for one or both of these two PIP components.

The assessment focuses on a claimant's ability to undertake a range of ten daily living activities and two mobility activities and does not focus on an individual's condition or the medication that they take:

Daily living activities

1. Preparing food
2. Taking nutrition
3. Managing therapy or monitoring a health condition

4. Washing and bathing
5. Managing toilet needs or incontinence
6. Dressing and undressing
7. Communicating verbally
8. Reading and understanding signs, symbols and words
9. Engaging with other people face to face
10. Making budgeting decisions

Mobility activities

1. Planning and following journeys
2. Moving around

For each activity there are a set of descriptors (or statements) which relate to varying degrees of ability. Each descriptor attracts a point, ranging from 0 to 12, and the highest point from each of the descriptors that applies to the claimant's circumstances are added together to give the claimant an overall score. The standard rate of either component is awarded if a claimant is awarded a minimum of 8 points and the enhanced rate is awarded if the claimant is awarded over 12 points.

A full list of the current PIP descriptors and the points that they attract is at Appendix 1.

Appendix 2 details the 2018/19 payment rates for both components of PIP.

Methods

Aims

The main aim of this study was to examine the impact of the transition from DLA to PIP on claimants with mental health problems. The research aimed to explore participants' views on the respective merits of DLA and PIP, the effectiveness of the migration process (including communication from the DWP) and the appropriateness of the PIP medical. The research also focused on the extent to which people with mental health problems benefit from receiving financial help from the social security system through the payment of a disability benefit. Analysis of Disability Solutions West Midlands client feedback shows that service users with mental health problems experience significant difficulty and challenges with coping with benefit changes introduced as a result of welfare reform.

Data collection

This research project adopted a qualitative methodology. Semi-structured, in-depth interviews were conducted with thirteen service users from Disability Solutions. Marshall and Rossman (2006) highlight that a key feature of qualitative interviews is to explore participant's views on an issue and to place significance of their viewpoint. This was an important element of this study as a significant amount of quantitative data is available on the current changes to the disability benefits system, but the focus of this research was on the experience of claimants themselves. Taylor and Bogdan (1998) believe that qualitative interviews can lead to an understanding of events that cannot be directly observed and semi-structured interviews allowed for some flexibility during interviews with participants while still identifying meaningful and comparable themes.

Information packs containing an information sheet in plain English and consent form were posted to service users who met the inclusion criteria for the study (outlined below). Service users who returned the consent form to the lead researcher were contacted to explain more about the research, answer any questions they had and to arrange a date for the interview if they were happy to proceed.

The inclusion criteria for this study was for participants to be aged between 16-65 (the age criteria for PIP), self-identifying as having mental health problems, and having experience of being migrated from DLA to PIP.

Interviews lasted between 25 and 70 minutes. Interviews took place either in participants' own home or in the offices of Disability Solutions. All interviews were recorded with the consent of participants. The interview questions were separated into four main topics:

- Previous experiences of claiming DLA: questions focused on what participants used the DLA payment for and the impact on mental health and well-being of being in receipt of a disability benefit. Some of the main themes that were explored were the extent to which payment of DLA helped with the affordability of care and support services, ability to interact with family and friends, increased mobility options and allowed for greater choices in relation to diet and maintenance and appropriate standards in accommodation.
- Experiences of the impact of transferring to PIP: questions focused on the timescales associated with moving from DLA to PIP, experiences of completing benefit claims forms and communicating with the DWP, quality and availability of advice and support (formal and informal) to assist with the process and the impact of the transition on mental health.
- Experiences of the medical assessment: questions focused on access and quality of advice and support about the medical, the impact of the medical on mental and physical health, the interaction/dynamics of the medical assessment itself and feelings before and after the assessment.
- Experiences of the PIP decision-making and administrative processes: questions focused on the length of time it took to make a decision on entitlement to PIP, understanding of the decision, advice/support with understanding the decision, the need/ability to challenge a negative or inappropriate decision, and the impact that payment of PIP has on mental health/wellbeing and ability to manage a household budget while experiencing a mental health issue.

Data analysis

The data analysis stage of this research project was informed by the principles of thematic analysis as defined by Braun and Clarke (2006). The recorded interviews

were transcribed, and two researchers undertook the analysis to cross check themes and to reduce potential bias. The researchers familiarised themselves with the data, searched for themes, reviewed and named the themes and produced the final project report.

Findings

This section of the report presents the main findings from the thematic analysis which are grouped into the following three themes:

1. Overall process led to increased anxiety and uncertainty
2. Problems with the PIP claims process
3. Positive experiences/elements

1. Overall process led to increased anxiety and uncertainty

'Because we had been changed, and changed, and changed. When you get a brown envelope and you know what's coming, you think 'now what's this one about?'

'I was worried sick. My nerves, I suffer with my nerves anyway and I shake like anything, so yeah it has caused a lot of anxiety.'

'When it arrived, the brown envelope, I was shaking. Absolutely shaking and in fear it was going say no.'

'The whole experience it was really, really, bad, considering what I have over the previous years of DLA.'

Each of the participants in this research had important and unique experiences of the transition from Disability Living Allowance to Personal Independence Payment. However, a very clear and strong theme that was common to all the interviews was the extent to which the process has led to increased anxiety and uncertainty. The anxiety was often related to specific issues that are described below but as an overall summary, participants expressed concern about a process without clearly described timescales, confusion over revised eligibility criteria, worry about maintenance of essential social security income and uncertainty over future entitlement. Of the 13 participants, two had their allowance increased, six remained the same and five had their allowance decreased. However, overall anxiety and uncertainty applied to everyone.

a. Poor communication with the DWP

'Yeah, I didn't understand that, points. You lose points for this, you lose points for that, you gain points for this, you gain points I don't know.'

'But it was terrible the communication it really was yeah.'

'and I also think that if they are going to send it to me, they could say in the next ... such and such a date, time, you will be getting your forms, so you would expect them to be dropping. But now it is like this thing, hanging over your head, you know it is going to come, but you don't know when it is going to come, and you have got a fair idea it will probably go wrong, so when you are living like this anyway, that's like a big worry.'

All participants indicated dissatisfaction with the communication with the DWP. This was often initially connected to a lack of clear and accurate information about the timescales and process of moving from DLA to PIP. Six participants said that they felt that they relied either on other people they knew or reports in the media to try and understand the reasons for the move to PIP and how they may be affected in financial and practical terms. All participants reported that they did not feel fully informed about how the points system operates under PIP and that it would have been helpful if they had received clear information about this. Some participants felt that when they telephoned the DWP staff were not helpful and failed to provide the information that they needed. Of particular concern to five participants was the lack of clear information about the medical assessment and difficulties in obtaining clear information about when and where these would take place.

b. Issues created by time-limited awards

'Well I feel worried that that's only a time. I mean my condition isn't going to change, so why put me on ten years.'

'I don't agree with them putting a time-limit on it. I mean with what I have got, I am not going to get any better.'

'I am going to be jittery at the end of 2019, also towards 2020, because I know that that is the year that they will start doing the process again into 2021.'

Only one participant indicated that they have an indefinite award of PIP. This means that all other participants in this study have a time-limited PIP award. For claimants with mental health problems this creates real anxieties. Participants expressed concerns that the anxieties associated with the experience of claiming PIP will be repeated in the short-term future. All the participants with a fixed-term award stated that a decision of this nature increases their anxiety, as they are unsure when they will be sent a new form to complete or when they will have to attend a medical assessment. This often leads to a generalised anxiety about future communications with the DWP and receiving letters to the home address. An unanimous opinion was expressed that a future review would in itself cause anxiety and any reduction in income would also impact negatively on mental health.

c. Reluctance to appeal negative decisions

'I don't know, I don't know whether I could have coped with it, I really don't know.

I don't know whether I could go Court.'

Eleven of the thirteen research participants were awarded either a reduced rate of PIP as compared to DLA (five in total) or a comparable amount of PIP as compared to DLA (six in total). However, none of the participants in this study pursued an appeal to a tribunal.

There are two stages to challenge a social security decision: firstly a mandatory reconsideration where a claimant asks the DWP to reconsider the initial decision, and secondly an appeal to a tribunal consisting of a judge, a medical professional, and an expert layperson. The mandatory reconsideration stage is a paper-based exercise and does not require the claimant to attend a hearing. At the tribunal stage a claimant can request a hearing on the basis of the papers without the need to attend in person but is commonly advised to opt for an oral hearing. At an oral hearing evidence can be presented in person to the legally constituted tribunal by both the claimant and their representative. All participants in this research expressed reluctance to pursue an appeal to the tribunal stage. Primarily this was because of anxiety about the formal nature of the hearing itself and the requirement to be questioned by a legally constituted panel. While a social security appeal tribunal is inquisitorial in nature and should not be adversarial, participants associated attending a social security appeal with 'going to court'. Given participants anxiety about the process of moving from DLA

to PIP there was a strong resistance to engaging with another formal stage which would scrutinise the claimant's condition and resulting needs. Furthermore, there is no protection of a current award when an appeal is pursued, meaning a tribunal can reduce benefit entitlement or remove it altogether, and this also strongly influenced decisions not to take cases to the appeal stage.

2. Problems with the PIP claims process

a. Problems recording complex mental health needs on the Personal Independence claim form

'The forms you can't put as much on them, so there wasn't room for me to put what I needed to put on.'

'So where now you are very limited on what you can say on the forms.'

Ten of the research participants expressed concern about the ability to accurately record complex mental health issues on the PIP claim form. Of these ten people, six had received professional help from an adviser in completing the forms. Of particular concern were the brevity of the forms and a lack of ability to convey the complexity of need which can result in periods of heightened vulnerability for claimants. It was often felt that the format of the forms does not allow for a full explanation of needs and that there is an over reliance on a 'tick-box' approach.

b. Issues with the Personal Independence Payment medical assessment

'I had already had these medicals and with my condition (depression and anxiety), I am not going to get any better.'

'She just seemed interested in this script, She was on her computer all the time, then she would look up and ask me a question and then type away.'

'Yeah, I had four appointments and all four were cancelled. And one actually on the morning of the appointment, and yet they phoned me the next day and asked me why I hadn't been for the appointment.'

'All you can hear is her click, click, clicking away and that's it. She doesn't ask you anything properly.'

A striking theme that emerged from the interviews was dissatisfaction with the medical assessment process. This can be split into two main areas: problems with communication about the scheduling of the medical and issues with the medical examination itself. Four participants stated that they had arrived at a medical and were told that it had been cancelled. This provided not only a practical inconvenience and cost but also an associated, and unnecessary anxiety. The participants who experienced a medical cancellation said that they felt that Capita were very defensive about the postponement and could not provide any meaningful or helpful information about rescheduling. One participant attended a medical in a neighbouring city that was cancelled on the day and one participant was contacted by the DWP the day after Capita cancelled an appointment to ask why she did not attend.

Eleven of the thirteen participants were asked to attend a medical. All of these participants expressed some level of dissatisfaction with the medical process. This mainly focused on feeling that the medical assessment was conducted in a very formulaic 'tick-box' way and that it did not allow for a full and accurate picture of mental health to be recorded. Not all of the participants felt that they were treated inappropriately by the medical assessor themselves but even in these circumstances they felt that there was an over-reliance on completing a pro-forma and that the assessor focused on data entry onto a laptop rather than focusing on them as an individual. Two of the participants felt that the medical assessor was 'judging them' and one participant felt that, although the assessor treated them with respect, they were asked to perform a range of physical tasks which were inappropriate and left them in pain.

c. Feeling judged

'That was another thing that it did to me, and I don't know if it has done it... but I started feeling like 'well why did I always have it then, so I have robbed them of all that'

'It is really is, you know you go with the full intention of telling them how you are as an individual, but I really got the feeling that they thought I was lying.'

A recurrent opinion was that the process of claiming PIP left participants feeling judged in a wholly negative way. Participants often felt that their own account of mental health problems was not accepted or was disputed by a process characterised by scrutiny

and lacking a personalised approach. This was most keenly felt when participants attended the medical with the approved healthcare practitioner but was also evident in communication with the DWP.

3. Positive experiences/elements

a. Importance of additional income from disability benefits

All of the research participants indicated that income from disability benefits formed a significant part of their overall income and was important in trying to maintain a reasonable standard of living. For those people who were in receipt of the mobility component of either DLA or PIP it was clear that this is significant in terms of maintaining some level of independence and connection with the outside world. All of the participants in receipt of the mobility component stated that either taxis or a mobility care were crucial for attending medical appointments and maintaining contact with family and friends. It was clear that income from both DLA and PIP is often used to supplement other income and is spend on essential items such as food and utility bills.

b. Positive overall outcomes for some participants

The above themes have been associated with challenges that the migration from DLA to PIP has created for claimants. However, this research project did identify positive outcomes for some participants. Two participants saw an increase in the amount of PIP awarded in comparison to the DLA that they were previously in receipt of and six received a comparable award. As stated above all participants valued the professional support received from Disability Solutions and feel reassured that they will be able to rely on this when they require future support with benefit issues. For some participants the review of their disability benefits has been accompanied by a consideration of the medical and personal support that they need and in some cases has led to the establishment of new networks of support and social capital. The research participants emphasised the importance of the income that PIP provides not only to support them with the extra costs associated with their mental health problems but also with general day to day living expenses such as food and utility bills.

c. Importance of professional support

'If I not had the help of Disability Solutions I don't think I would have got it'

All thirteen of the research participants stated that the professional support of an expert adviser was important both in terms of understanding the migration process and being able to navigate their way through it. Professional support included assistance with completing the PIP claim form, advice on timescales for completing the form, help to collate supporting evidence, and advice on the appeals process. Given the poor communication from the DWP and Capita participants placed importance on being able to rely on a professional who could explain the PIP eligibility criteria in a meaningful way, ensure that deadlines were met and that the full impact of mental health problems was clearly articulated on the claim form and during the medical. Seven participants stated that they were unclear about the points system for PIP and that an adviser from Disability Solutions was the only person who had clearly explained this. All participants stated that a professional welfare rights adviser provided both technical and practical support.

Discussion

The in-depth qualitative interviews that were conducted for this research project provided rich and meaningful data on the experiences of people moving from DLA to PIP in North Staffordshire. This discussion section draws out the main themes from the interviews and places them in a broader context.

The clearest overall finding from this research was the significant extent to which the migration process caused additional anxiety to claimants with existing mental health problems. Crucially, this applied to all participants - including those whose allowance increased as a result of the process. This research demonstrated a clear link between anxiety and the loss/potential loss of benefit income. Participants stated that PIP was often used not only for care and mobility needs but also for general household expenditure (e.g. food and utilities) and there were clearly anxieties about being able to cope without an income viewed as essential.

Participants in this research stated that their mental health problems are exacerbated by uncertainty and changes from well-established norms. The PIP claims process has, therefore, increased anxiety as a result of frequently changing timescales and ambiguity around when a claim for PIP should be submitted, when DLA will stop and how long an award of PIP will last. The DWP states that PIP is 'designed to be a more sustainable benefit and make sure support continues to reach those who face the greatest challenges to taking part in everyday life.' Ironically the High Court decision of December 2017, referred to in the background section to this report, is a positive legal decision for claimants with mental health problems, but does nothing to alleviate the stress associated with the PIP process. The trawl that the DWP is now making through existing PIP claims will have the end result of increasing entitlement for many claimants but is likely to come at a high price for those experiencing mental health problems who will feel their claim and disability is being scrutinised again only a short period after their previous decision.

Dissatisfaction with the communication from the DWP was a consistent theme in this research. Earlier Sections of this report have outlined the ideological and practical changes that have been associated with the rollout of PIP. Clearly the migration to PIP has brought about fundamental changes to the administration of the key non-means

tested benefit currently available in the UK benefit system. This research has strongly indicated that a lack of clear communication about the new points system for PIP has led to claimant uncertainty and anxiety. In introducing PIP the government stated that DLA needed to be replaced as 'There was confusion about the purpose of the benefit, it was complex to claim and there was no systematic way of checking that awards remain correct.' (DWP, 2015) It can be strongly argued that the ambiguous and partial information provided to claimants about PIP has led to a similar confusion and inconsistency in adjudication. It is hard to see how accuracy and transparency can be achieved when the people who are potential PIP claimants remain uncertain at best and confused at worst about the claims process and eligibility criteria. This research strongly suggests that the guarded approach taken by the DWP in terms of claimant communication impedes rather than assists the decision-making process.

Different participants identified challenges with different stages of the PIP claimant journey (e.g. completing the claim form, telephone liaison with DWP staff, the medical examination). A significant problem raised that is encountered towards the start of this journey is with completing the PIP claim form. These problems are connected to the themes already discussed in this section around increased anxiety and poor communication. The latter factor has an impact on the ability to complete forms as participants often did not feel clear about the type of information and evidence that they should be putting in the PIP claim pack. Participants stated that they felt that the forms were complex and could often only be completed satisfactorily with the input of professional advisers. Participants felt that the forms were not always clear and straightforward and there was often an anxiety about putting the wrong things on the form or omitting important information. Of particular concern to some claimants was the difficulty in explaining and documenting complex mental health problems on a form with many standard questions. This was particularly felt to be the case with mental health problems which can be difficult to explain in the written form and are often subject to fluctuation. Significantly two claimants felt that there is less scope to explain the impact of mental health problems on the PIP claim form as compared to the previous DLA form. The difficulties that were expressed in relation to completing the forms illustrate the challenges for the DWP in terms of question design. An eligibility criteria has been introduced for PIP which is supposedly more straightforward than DLA. However, a form which encourages claimants to clearly express the impact of

their mental health problems and allows for accurate decision-making remains elusive. If there is an assumption that PIP claim forms are straightforward to complete, this was not shared by the participants in this research.

The next element of the PIP claimant journey that has been identified as posing significant difficulties for claimants is with the medical assessment. Again, communication about basic details about time, date and location of the medical was often poor and contributed to anxiety. Views on the medical assessor themselves were mixed, with some participants feeling that they were treated with respect and others not. However, a more consistent finding was that participants very much felt like they were being 'processed' and that the focus of the medical was on completing a pro-forma form rather than in obtaining a full and accurate picture of mental health problems and needs. As with the completion of forms it should be acknowledged that assessing hundreds of thousands of people for a disability benefit is a challenge, and to ensure accurate and robust decisions a level of consistency is required. However, this research strongly indicates that the balance is too strongly towards a formulaic approach and too far from a tailored and personalised approach and that this is problematic for claimants with mental health problems during the medical. Additionally, there is little evidence to suggest that this approach is necessarily assisting the decision-making process. The findings of the two independent reviews of PIP completed by Paul Gray, the former chair of the Social Security Advisory Committee, indicate that the issues with the medical identified in this local study are evident on a nationwide basis (Gray, 2014, 2017). As with the completion of forms many participants stated that they needed someone to accompany them to the medical. This was always as a support and often to provide a level of advocacy. As the medical assessment is such a key element of the PIP claimant journey (and the findings of medicals are often preferred to the evidence of claimants themselves) improvements to this stage of the process are critical.

A theme evident from this research was the importance of professional support from staff at Disability Solutions (with all stages of the PIP journey). The key learning that can be taken from this is that the PIP claims process is a complex one and that for claimants with mental health problems it is difficult to 'self-manage'. It was perhaps not surprising that support was sought in relation to challenging decisions, but professional

advice was also pursued, and viewed as important, in relation to the supposedly more straightforward tasks of form-filling and comprehending the PIP points system.

A very clear finding from this research was the anxiety caused by the default position of time-limiting the award length of PIP claims. The mental-health problems experienced by participants varied considerably but all the people questioned did experience long-term mental-health problems. The balance between an accountable system with appropriate review mechanisms and the recognition of the long-term needs of claimants needs to be addressed. For many research participants the process of successfully securing an award of PIP has been a long drawn out process, and one which will begin again within the next two or three years. From the evidence of this research this does not appear to be a reasonable use of public resources or appropriate for many claimants experiencing mental health problems.

The findings on a local level can be read together with information produced on a national level. Official government statistics are openly available which indicate the national picture in terms of the numbers of people moving from DLA to PIP and the outcome of decisions (DWP, 2018). As mentioned previously there have also been two independent reviews of the assessment of Personal Independence Payment completed by Gray and published in 2014 and 2017. These reviews were mandated by the Welfare Reform Act 2012 and interestingly a significant number of the issues that were raised in both of Gray's reports were evident in this research. Notably the first review recommended an improvement in communication around the PIP assessment, a move away from a 'one size fits all' claims process towards a more tailored model based on the needs of claimants, improve the collection of further evidence to support a claim, the delivery of a robust quantitative and qualitative evaluation strategy to explore the effectiveness of the PIP assessment process for people with mental health problems and learning disabilities (Gray, 2017). The second reviews key recommendations included the roll-out of better communication products (utilising digital technology), placing greater emphasis on the evidence that carers can provide, transparency of decision making to be improved with claimants being given a copy of the assessment report with a decision letter and health professionals being given more time to consider evidence before an assessment begins, the DWP should undertake reviews into the effectiveness of award reviews and mandatory reconsiderations (Gray, 2017).

The concerns raised by the participants in this research align closely with the findings of these two official reviews of PIP and the above recommendations made by Gray (2014, 2017) would certainly improve the experience of the PIP assessment process for claimants in North Staffordshire if the DWP make appropriate responses to the recommendations.

Limitations

It should be acknowledged that this is a small-scale research project and there is the potential for 'bias' in the findings. Participants were all known to an advice service and may have contacted Disability Solutions because they required assistance with a PIP claim, and potentially because of dissatisfaction with the claims, assessment or appeals process. However, this should not detract from the clear evidence provided in the interviews that the process led to increased anxiety. In addition, all interviews were conducted in the West Midlands and therefore the findings may not all be generalisable. However, as previously discussed, some of the issues identified in this local study (e.g., around the medical assessment) echo the findings of the two independent, national reviews of PIP (Gray, 2014, 2017). Therefore, these findings to draw out some recommendations at a national level, as well as the local level.

Recommendations

National level

- A large-scale national review of the impact of the migration from DLA to PIP on claimants with mental health problems be conducted. It is recommended that an All-Party Parliamentary Group (such as the group constituted to examine disability or health policy issues) conduct this review, ensuring an inquiry considers evidence from a wide range of stakeholders (including the advice agencies and the DWP) and claimants.
- Currently PIP claimants with the most severe, life-long conditions who receive the highest level of PIP, and are assessed as having needs that are likely to stay the same or increase receive ongoing payment of PIP (being subject to a 'light-touch' review every ten years). It is recommended that Department for Work and Pensions guidance is reviewed so that claimants with severe and enduring mental health problems are included in this category of claimant.
- The Department of Work and Pensions should undertake an extensive review of PIP decisions which have been challenged through the mandatory reconsideration and appeal process to identify areas of the decision-making and evidence gathering process which can be improved.
- The Department for Work and Pensions to develop comprehensive guidance to be issued to claimants on the purpose and role of the PIP medical assessment. This will include guidance on taking a companion to the medical, the type of evidence which can be submitted and how this will be considered as part of the process, and the range of questions typically asked at a medical. A greater emphasis should be placed on evidence provided by health professionals with a good working knowledge of a claimant.
- The Department for Work and Pensions develop accessible guidance documents providing information on how to complete PIP claim forms. The DWP should work with claimant and stakeholder groups to develop this guidance and seek to gain insight on where improvements can be made to the PIP claim form.
- Improvements should be made to both written and verbal communications between the Department for Work and Pensions and claimants/potential

claimants. In particular clarity should be provided on the decision-making timescales and the length of time claimants will have to wait for a PIP medical.

Local level in North Staffordshire

- Advice and advocacy agencies should consider taking a joined-up and co-ordinated approach to supporting claimants at PIP medicals. This would utilise the professional resources available to attend PIP medicals, reduce claimant anxiety, monitor the appropriateness of medicals and ultimately lead to more accurate evidence being provided.
- Advice and advocacy agencies should also consider taking a joined-up and co-ordinated approach to supporting claimants at PIP social security appeal tribunals. This would improve the coverage available to support appellants with PIP medicals and encourage more claimants to pursue appeals to the appeal stage (where appropriate).
- Wider Welfare Reform Group Stoke-on-Trent to consider how to produce a range of guidance materials/training sessions for medical professionals and health and social care staff on providing quality and timely evidence to support PIP claims for people with mental health problems.
- Further longitudinal research should be conducted to assess the long-term impact of the migration from DLA to PIP on people with mental health problems.
- North Staffordshire Advice Partnership to create/have responsibility for the management of a database which records the impact of the migration from DLA to PIP on claimants with mental health problems in North Staffordshire.

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Appendices

Appendix 1: Personal Independence Payment Daily Living and Mobility Activities

Daily Living Activities

1. Preparing food

- a. Can prepare and cook a simple meal unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal. **2 points.**
- c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave **2 points**
- d. Needs prompting to be able to either prepare or cook a simple meal. **2 points.**
- e. Needs supervision or assistance to either prepare or cook a simple meal. **4 points.**
- f. Cannot prepare and cook food. **8 points.**

2. Taking nutrition

- a. Can take nutrition unaided. **0 points.**
- b. Needs:
 - (i) to use an aid or appliance to be able to take nutrition; or
 - (ii) supervision to be able to take nutrition; or
 - (iii) assistance to be able to cut up food. **2 points.**
- c. Needs a therapeutic source to be able to take nutrition. **2 points.**
- d. Needs prompting to be able to take nutrition. **4 points.**
- e. Needs assistance to be able to manage a therapeutic source to take nutrition. **6 points.**
- f. Cannot convey food and drink to their mouth and needs another person to do so. **10 points.**

3. Managing therapy or monitoring a health condition

- a. Either:
 - (i) does not receive medication or therapy or need to monitor a health condition; or
 - (ii) can manage medication or therapy or monitor a health condition unaided. **0 points.**
- b. Needs any one or more of the following:
 - (i) to use an aid or appliance to be able to manage medication;
 - (ii) supervision, prompting or assistance to be able to manage medication.
 - (iii) supervision, prompting or assistance to be able to monitor a health condition. **1 point.**
- c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. **2 points.**
- d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week. **4 points.**
- e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week. **6 points.**
- f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. **8 points.**

4. Washing and bathing

- a. Can wash and bathe unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to wash or bathe. **2 points.**
- c. Needs supervision or prompting to be able to wash or bathe. **2 points.**
- d. Needs assistance to be able to wash either their hair or body below the waist. **2 points.**
- e. Needs assistance to be able to get in or out of a bath or shower. **3 points.**
- f. Needs assistance to be able to wash their body between the shoulders and waist. **4 points.**
- g. Cannot wash and bathe at all and needs another person to wash their entire body. **8 points.**

5. Managing toilet needs or incontinence

- a. Can manage toilet needs or incontinence unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence. **2 points.**

- c. Needs supervision or prompting to be able to manage toilet needs. **2 points.**
- d. Needs assistance to be able to manage toilet needs. **4 points.**
- e. Needs assistance to be able to manage incontinence of either bladder or bowel. **6 points.**
- f. Needs assistance to be able to manage incontinence of both bladder and bowel. **8 points.**

6. Dressing and undressing

- a. Can dress and undress unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to dress or undress. **2 points.**
- c. Needs either:
 - (i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or
 - (ii) prompting or assistance to be able to select appropriate clothing. **2 points.**
- d. Needs assistance to be able to dress or undress their lower body. **2 points.**
- e. Needs assistance to be able to dress or undress their upper body. **4 points.**
- f. Cannot dress or undress at all. **8 points.**

7. Communicating verbally

- a. Can express and understand verbal information unaided. **0 points.**
- b. Needs to use an aid or appliance to be able to speak or hear. **2 points.**
- c. Needs communication support to be able to express or understand complex verbal information. **4 points.**
- d. Needs communication support to be able to express or understand basic verbal information. **8 points.**
- e. Cannot express or understand verbal information at all even with communication support. **12 points.**

8. Reading and understanding signs, symbols and words

- a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses. **0 points.**
- b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information. **2 points.**
- c. Needs prompting to be able to read or understand complex written information. **2 points.**
- d. Needs prompting to be able to read or understand basic written information. **4 points.**
- e. Cannot read or understand signs, symbols or words at all. **8 points.**

9. Engaging with other people face to face

- a. Can engage with other people unaided. **0 points.**
- b. Needs prompting to be able to engage with other people. **2 points.**
- c. Needs social support to be able to engage with other people. **4 points.**
- d. Cannot engage with other people due to such engagement causing either:
 - (i) overwhelming psychological distress to the claimant; or
 - (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person. **8 points.**

10. Making budgeting decisions

- a. Can manage complex budgeting decisions unaided. **0 points.**
- b. Needs prompting or assistance to be able to make complex budgeting decisions. **2 points.**
- c. Needs prompting or assistance to be able to make simple budgeting decisions. **4 points.**
- d. Cannot make any budgeting decisions at all. **6 points.**

Mobility Activities

1. Planning and following journeys

- a. Can plan and follow the route of a journey unaided. **0 points.**
- b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. **4 points.**
- c. For reasons other than psychological distress cannot plan the route of a journey **8 points.**
- d. For reasons other than psychological distress cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. **10 points.**

- e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. **10 points.**
- f. For reasons other than psychological distress cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. **12 points.**

NB – Following the High Court decision of December 2017 the words 'for reasons other than psychological distress' have been held to be unlawful. Until the regulations are amended descriptors c, d and f should be read as though these words are not part of them.

2. Moving around

- a. Can stand and then move more than 200 metres, either aided or unaided. **0 points.**
- b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. **4 points.**
- c. Can stand and then move unaided more than 20 metres but no more than 50 metres. **8 points.**
- d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. **10 points.**
- e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. **12 points.**
- f. Cannot, either aided or unaided:
 - (i) stand; or
 - (ii) move more than 1 metre. **12 points.**

Appendix 2: Personal Independence Payment rates of payment 2018/19

Daily Living Component, standard rate: £57.30

Daily Living component, enhanced rate: £85.60

Mobility, standard rate: £22.65

Mobility, enhanced rate: £59.75