healthwatch Brighton and Hove

Personal Independence Payments and Employment Support Allowance

Examining the impact of PIP and ESA assessments on vulnerable people in Brighton and Hove.

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1. Executive summary

During the second half of 2017, Healthwatch Brighton and Hove ("Healthwatch") collated evidence from a number of local organisations about their experiences of supporting people through Personal Independence Payments (PIP) and Employment Support Allowance assessment (ESA) interviews. This report provides a sample of the individual case studies (see Annex C) and supporting organisational data that Healthwatch was provided with. It highlights the general issues that emerged from this research, and provides recommendations to the assessing organisations (ATOS and Maximus).

Healthwatch provided this evidence firstly to the local organisations providing PIP and ESA and asked them to respond. We received no response. Healthwatch will now publish our findings and bring them to the attention of the Brighton and Hove Health and Wellbeing Board. Healthwatch has shared the report's outcomes with the reporting organisations and individuals concerned and we will continue to keep them abreast of our continued efforts and any impact/changes associated with our work.

Table A (below) details the commonly reported concerns raised with Healthwatch, and a number of proposed recommendations which are designed to address these. Some of the recommendations apply to more than one of the identified issues. The research clearly showed that a number of issues had been experienced separately by several local organisations whilst supporting their clients (at this stage we would encourage you to read the individual case studies contained in Annex C).

The most widely reported concerns included:

- Whether all assessors had requisite knowledge of and/or specialist training in 'hidden' medical conditions (mental health conditions, or of those with multiple complex needs).
- Assessors sometimes displaying a lack empathy towards applicants and the impacts of their conditions, which on occasion led to overly intrusive lines of questioning.
- Some assessors being dismissive of advocates and their role in supporting applicants.
- A failure to provide reasonable adjustments where these were warranted i.e. reports of home visit requests being routinely turned down and applicants being notified of last minute cancellations of their appointments.
- Reports which contained factual inaccuracies, and/or which bore little semblance to the applicant's or their advocate's own experience of the interview. We were also told that evidence appeared to be wrongly applied by some assessors.
- Whether the mandatory reconsideration stage serves a valid purpose? We heard a number of examples where decisions to refuse an award of PIP or ESA (or award a higher rate of payment) were upheld at this stage, but then went on to overturned at appeal.

Healthwatch believes that a number of the above concerns could be addressed through the provision of better, ongoing, and more comprehensive training of assessors. In this regard, a number of local organisations expressly stated that they would be happy to help deliver some focussed training to ATOS and Maximus. Training should provide a good knowledge of so-called

'hidden' or non-physical conditions and their impacts; as well as training in specialist areas such as: mental health conditions; suicide awareness; visual impairment; complex needs, as well as LGBTQ affirmative practice. Improved training could also help to improve the quality and content of reports.

Healthwatch would encourage ATOS and Maximum to undertake immediate reviews in the following areas and publish any outcomes:

- how requests for home visits are actioned. It is of paramount importance that reasonable adjustments are always made were these are justified.
- how cases are reviewed at Mandatory Reconsideration. It is important that a separate, review is undertaken by a different assessor and that the outcome clearly demonstrates how any additional evidence has been considered.

2. Introduction

In 2017, Healthwatch received information from a number of local sources about the manner in which Personal Independence (PIP) and ESA Employment Support Allowance (ESA) assessments were being conducted, and the negative impacts this was having on some claimants. Healthwatch were concerned that if these reports were accurate that some individuals might not be able to properly access benefits and advice, and that this could damage their wellbeing and perhaps emotional and mental health. This may particularly be the case for people who were vulnerable, living with enduring mental ill health or who had multiple protected characteristics. Indeed, it was claimants of this nature which local organisations reported being most concerned about.

During the summer and autumn Healthwatch approached local organisations that provide support to individuals going through these assessments. We collated anonymised case study information and asked these organisations to provide us with their experiences (positive and negative); and prompted them to provide suggestions for how the current system might be adapted or improved to ensure it remained robust; but was proportionate and fair.

Aims of the project

Healthwatch Brighton and Hove has a brief to improve the access of people to health, social and care services. As an independent organisation we are able to provide a unique perspective and judgement about where improvements might be made to existing services using the experiences of patients and their carers to do this. The aims of this project were:

- To gather personal case studies from those with direct experience of these assessments.
- To collect additional information about any impacts for individuals.
- To gain an insight into how well these services were meeting the needs of individuals.
- Using the quantitative and qualitative data to identify ways in which these services could be improved to better serve the needs of service users.
- To report our findings to the assessment providers responsible for delivering these services, and to the Brighton and Hove Health and Wellbeing Board.

Methodology
Healthwatch has a network of community and voluntary organisations who work with us and help us gather grassroots information. We approached this network and asked if they could provide us with suitable direct evidence and/or to put out a 'call for evidence' amongst their own groups. We targeted local organisations who we believed may provide support to suitable individuals. We asked them to either reply with their experiences, or arranged to go and meet with them to discuss the issues. A letter from our Chief Executive Officer, David Liley, was issued to encourage organisations to respond.

Through these contacts, this project was brought to the attention of 29 local organisations and 4 individuals. Some organisations existed as part of a wider partnership and in some cases a joint or shared response was issued; in other cases only some organisations within these partnerships responded to our request for information. 4 individuals were asked by supporting organisations if they would be happy to speak directly to us; however only one individual agreed to do this. **Annex A** provides a table which indicates which organisations, partnerships and individuals were reached, and their response to our request.

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TABLE A: A summary of the main concerns reported to Healthwatch and recommended actions which could be taken to address these

CONCERNS	RECOMMENDATIONS
A. ASSESSORS (employees of the assessment providers who carry out assessment interviews) (i) ***Questioning style*** We received reports that the questioning style of some assessors suggested that they did not have specialist knowledge of mental health conditions or of those with multiple complex needs. We also heard examples of intrusive and impersonal lines of questioning. We were told that some applicants felt as if their assessor did not believe they were suffering from a physical/mental condition. (ii) ***Interpersonal skills*** We received reports that some assessors lacked empathy of claimants' needs; whilst others came across as intimidating. (iii) ***Approach to advocates*** We heard stories that some assessors were abrupt and disrespectful of advocates and their role in supporting claimants during assessment interviews.	**The system needs to be resourced to enable it to work in a timely and more flexible manner. It requires fully trained assessors who are competent in responding in an appropriate manner to applicants with complex needs and other vulnerable people.** **The above is especially important given that the main disabling condition for people in receipt of PIP, both nationally and locally, are 'psychiatric disorders' (which includes 'mixed anxiety and depressive disorders' and 'mood disorders')** **A number of local organisations told Healthwatch that they would be happy to assist in providing specialist training for assessors e.g. in autism (especially high functioning autism), mental health conditions and LGBTQ affirmative practice.**
B. ASSESSMENTS (face-to-face interviews with applicants) (iv) ***Adequacy of current face-to-face assessments*** We heard how the current format of face-to-face assessments could cause emotional and physical distress to applicants; especially for those suffering from conditions which made social interaction more challenging. We were also advised that these assessments did not	**Improved assessor training, as highlighted above, could substantially improve the experience of face-to-face assessments.** **Organisations providing assessments should ensure that reasonable adjustments (as required by law from Public Bodies) are made in relation to all aspects of the process e.g. fully accessible assessment centres, audio documents and timely notifications of any changes to**

always provide adequate opportunity for applicants to expand on the points raised, with the line of questioning regarded by some as being a 'tick-box' exercise. *(v) **Cancellation of assessments*** We were told of short-notice cancellations of appointments by the PIP and ESA assessment providers and the distress this caused to applicants, especially those who struggled to leave their homes in order to attend assessments. *(vi) **Cost implications for applicants*** We were told about the increasing cost to applicants of having to provide supporting medical evidence. A specific concern was raised concerning the inappropriateness, and potential cost, to applicants of providing only 'approved' audio recording equipment for ESA assessments.	**assessment times and dates. Centres should avoid over-booking appointments to limit the number of last-minute cancellations.** **The process by which evidence is gathered from other health professionals could be simplified. Healthwatch was told this would make a genuine difference for many applicants. Currently, assessors have the option of asking GPs for medical evidence using a 'factual report form' (and compensate them for filling it out) but this option does not exist for other kinds of healthcare professional. While we strongly believe that the responsibility for gathering medical evidence should rest with the assessment provider, there should be more guidance for individuals who choose to gather their own evidence.** **The rules governing recording equipment should be mirrored across both PIP and ESA assessments, following the PIP model where the assessing organisation provides this.**
C. ACCESSIBILITY *(vii) **Organisations failing to offer home visits*** Organisations reported to us that home visit requests (where assessments are carried out in applicants' homes) were being routinely rejected, even where medical evidence warranted these (especially for applicants with mental health conditions). We were told that ATOS (who carry out ESA assessments) often failed to apply reasonable adjustments even though they already knew that someone was in receipt of Disability Living Allowance and was therefore registered disabled.	**Healthwatch acknowledges that it may not be practicable to change the location of centres. It may however be worth exploring the idea of co-locating some centres, or opening smaller satellite centres in additional locations. These changes would improve access for those with mobility issues and mental health conditions and anxiety disorders, and reduce some of the additional stress caused to applicants.** **Healthwatch would also encourage ATOS and Maximum to undertake an immediate review into how requests for home visits are actioned, and publish any findings. Assessment providers should ensure they offer home visits where medical evidence clearly warrants these.**

*(viii) **Accessibility of assessment centres*** We were told that the location and required travel to assessment centres caused emotional and physical distress to some applicants, as well as having financial impacts.	**ESA centres could benefit from physical improvements to the environment. At present these are regarded as offering poor place-based setting environments that do not encourage people to recover: the current accommodation has only one room suitable for disabled applicants on the ground floor and the site employs a large number of security personnel which creates an intimidating and uncomfortable feel. It is recommended that ESA centres are improved to make these less intimidating (the PIP environment was reported to be better).**
D. PIP and ESA REPORTS (prepared following face-to-face assessments) *(ix) **Accuracy of content*** We were advised that assessment reports did not always reflect the applicant's/advocate's own assessment experience; and that they sometimes indicated the wrong / objective application of the correct rules. In some cases there was a reported sense of crudeness attached to the way in which an individual's ability to undertake physical tasks had been assessed and reported upon. There were also concerns expressed that DWP decisions were being made on factually inaccurate assessment reports. (x) ***Refusal bias*** It was suggested to us that reports were written with a bias towards refusal (i.e. that assessment providers were working to negative targets). To illustrate this point, we received a number of examples of cases which had been refused outright, and/or where an award had been made only at a lower rate or tier, and that few decisions were changed at the mandatory reconsideration stage (see below). Yet,	**Improved assessor training, as highlighted above, could substantially improve report outcomes and quality.** **Any changes in training should ensure that assessors abide by case law, and that all evidence is presented factually.** **Healthwatch would urge ATOS and Maximum to undertake an immediate review into how cases are reviewed at mandatory reconsideration, and publish their findings. It is important that a separate review is undertaken by a different assessor and that the outcome clearly demonstrates how any additional evidence has been considered.** **We recommend the introduction of a legal or KPI timeframe for when mandatory reconsiderations must be dealt with, and the issuance of public facing guidance about what this phase is intended to achieve. At present, there is no such timeframe and very few decisions are changed at this stage which has called into question its purpose.**

where decisions were challenged at Tribunal stage there were high success rates. (x) ***Report quality*** The written quality of some reports was felt to be poor suggesting that these may be rushed and/or not properly quality assured (i.e. reports which contained factual errors, typos and wording which had been repeatedly ‘cut and pasted’).	

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3. Background to PIP and ESA

Personal Independence Payment and Employment Support Allowance
The following section provides a brief overview of Personal Independence Payment (PIP) and Employment Support Allowance (ESA). A substantial amount of information is available online and some further detail is given in **Annex B** including the current eligibility criteria.

Personal Independence Payment (PIP)
From April 2013, the Department for Work and Pensions (DWP) began to replace Disability Living Allowance (DLA) for working age people with PIP. PIP is designed to provide support to individuals who have a long-term disability, ill-health or terminal ill-health. PIP is paid directly to the individual and is not means tested. PIP is made up of 2 parts: (i) the daily living component, and (ii) the mobility component. Each component can be paid at one of 2 rates, either the standard rate or the enhanced rate. Assessments for PIP in the London and Southern England region are conducted by ATOS healthcare[1]. In most cases (estimated to be 75%) a face-to-face meeting with the claimant is required to determine eligibility, and claims are estimated to take around 74 days to decide.

When an individual is assessed for PIP, a health professional will look at their ability to carry out a range of daily living activities and mobility activities. A successful award of PIP is based on the extent to which a disability or health condition affects that person and the extra help they may need to carry out certain activities (not whether they actually get that help). This is measured against a list of descriptors, which describe varying levels of ability under each activity. The activities and the descriptors are known as the assessment criteria and are set out in regulations.[2] The health professional will write a report for the DWP, and the DWP decision maker will then decide whether an individual is entitled to PIP, at what rate and for how long (all PIP awards are subject to periodic review). It is possible to appeal against a decision to refuse PIP altogether, and/or against the rate that has been awarded.

Employment and Support Allowance (ESA)
ESA is a benefit paid if an individual who has an illness or disability that affects their ability to work. As with PIP, an award of ESA is not based on the disability or illness, rather it is the effects of the condition which matter. There are 2 main types of ESA:

1. contribution-based ESA which is available if the person has paid enough National Insurance contributions
2. income-related ESA which is paid if an individual is on a low income.

All individuals, when they apply for ESA, enter an assessment phase where they will have their ability to work assessed to determine their entitlement, this is called the Work Capability Assessment (WCA). The possible outcomes of the WCA are that claimants can be assessed as:

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[1] https://www.mypipassessment.co.uk/your-assessment/overview/

[2] Download: Table of activities, descriptors and points
Download: Guide to the language used in the activities and descriptors [34 kb]

a. Suitable for the ESA Work Related Activity Group where claimants are able to undertake and participate in work-related activity to help them move towards the labour market,
b. Suitable for the ESA Support Group where claimants are not required to undertake any interviews or work related activity, or
c. Fit for work and therefore not entitled to ESA, although there is a right of appeal.

All individuals are required to complete a capability for work questionnaire (ESA50) about how their condition affects their ability to complete everyday tasks. Their doctor may be asked to provide a medical report, and the individual may be asked to attend a face-to-face medical assessment either at home or a centre (which should be no more than a 90 minute journey away). Individuals can be accompanied at these assessments.

The Health Assessment Advisory Service arranges and carries out ESA assessments for DWP. The purpose of the assessment is to understand how an illness or disability affects a person's daily life. After the assessment, DWP makes the decision as to whether the individual will receive any benefits. The Health Assessment Advisory Service is delivered on behalf of DWP by the Centre for Health and Disability Assessments, operated by MAXIMUS. As with PIP it is possible to appeal against a decision to refuse ESA.

4. Concerns raised with Healthwatch Brighton and Hove

The following section expands on the key areas for concern with PIP and ESA assessments highlighted at the start of this report. Each section includes themes associated with each concern, and are supported by evidence supplied by local organisations and quotes taken from individual case studies. Healthwatch acknowledges that a number of the concerns raised with us in 2017 by local organisations and individuals are not necessarily new or specific to Brighton and Hove, and many existing concerns have been raised at Parliamentary level for example[3] (see Annex B for a summary so far as these relate to PIP):

A. ASSESSORS

The most frequent concern raised with Healthwatch by almost all of the organisations we heard from related to assessors, and the manner in which assessments were conducted. Healthwatch wishes to stress that it was provided with anecdotal evidence of both good and bad assessors, but that the quality of service offered appeared to vary dramatically, and in the main local organisations and individuals were critical of the approach adopted by assessors.

Separate guidance for both PIP and ESA assessors is issued by the DWP[4]. The guidance requires that assessors must be registered practitioners who have met requirements around training,

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[3] researchbriefings.files.parliament.uk/documents/SN06861/SN06861.pdf
[4] PIP https://www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers
ESA https://www.gov.uk/government/publications/work-capability-assessment-handbook-for-healthcare-professionals

experience and competence. They should be experienced practitioners and trained disability analysts. Training (which lasts approximately a week) should provide assessors with the ability to assess claimants with health conditions or disabilities affecting either physical or mental function, and an understanding of the needs of and challenges faced by disabled people.

Lack of consistency

The view reported by the majority of organisations Healthwatch heard from was that the assessing organisations were not good at recognising hidden attributes and were not supportive of individuals' need's. Another organisation reflected back to us that assessors were under a lot of pressure to complete online reports and appeared rushed which unfortunately meant that they came across as "*disengaged, disinterested and judgemental, which is very intimidating to vulnerable people*".

Training and specialist knowledge

There was a sense from some of the organisations who responded to us that assessors were not adequately trained to understand mental health conditions and lacked suitable knowledge around suicide awareness, visual impairment and other conditions; as well as LGBTQ affirmative practice. This has undoubtedly led to doubts amongst some local organisations around the quality and depth of training that assessors receive, but also how they implement their learning into their practice. One organisation told us that "*there appears to be a tendency to focus on physical conditions rather than mental health conditions*". Healthwatch was told that a large number of health professionals carrying out PIP medicals are physiotherapists who, it was felt, may not possess sufficient knowledge of mental health issues, learning difficulties or more complex physical conditions. There are also some occupational therapists, nurses and, very occasionally, doctors doing assessments.

Another organisation told us that assessors do not always ask people how their mental or physical health conditions fluctuate over time, despite this being a requirement of the PIP process; and that this was a frequent omission from many reports. In fact, it seems that even when applicants explained in detail how their condition varied over time, this information did not always make it into their report to the DWP. The following is a quote from an individual which reflects this point "*I do not recall being asked anything directly about my mental health even though I have a bipolar diagnosis and a history of suicide attempts*".

Several organisations raised concerns about how some assessors gathered and used evidence and whether this was always a transparent process. For example, an organisation stated:

> *"Assessments begin as soon as individuals arrive at the centre and observed actions are subsequently included within final assessment reports: e.g. if the person can walk from the lift to the assessment room then they are able to walk a certain distance (ignoring how slowly or painfully this occurred); or if a person is seen raising their hand to their hair, or holding their handbag, or sipping water from a glass then that person can raise their arm implying they can carry out physical activity unaided."*

In another case an assessor described an applicant as being "*happy and chatty*", yet this ignored the fact that the person's mental health led them to become over accommodating to others.

Interaction with applicants

Healthwatch received a number of comments about some assessors failing to show empathy to the applicant's condition(s), with some being described as unfriendly, defensive and combative. In a few cases applicants stated that assessors came across as friendly and supportive but that reports failed to reflect what had been said, leading one individual to say they felt "*duped*".

Advocates

It is possible for individuals who are applying for PIP and ESA to be accompanied at their assessment. DWP guidance of the PIP process[5] in respect of a face-to-face consultation indicates that *"The claimant will be encouraged to take someone along to the consultation to support them if they would find this useful. The person can participate in the discussion. The person chosen is at the discretion of the claimant and might be, but is not limited to, a parent, family member, friend, carer or advocate*"

Local organisations told Healthwatch that the PIP/ESA systems do not always appear to understand the role of advocates/representatives and the crucial role they play in supporting applicants through the process and at face-to-face assessments. For some applicants, their advocate was described as being a life-line. For example one organisation told us that whilst the system did not seem to mind the presence of advocates, it does not necessarily understand how crucial that role is to the service-user.

We were told that some assessors were reported to act in an unfriendly, defensive and combative manner towards advocates. In one instance an advocate felt as if they were being "told off". In a number of examples advocates were told they could not take written notes, which Healthwatch understands is incorrect. When advocates are seen by their clients to be under verbal attack (real or not), organisations reported that this can cause their clients to feel anxiety and distress which can affect the way they then engage with the assessor. In another case it was reported:

> *"At the start of the appointment my client introduced me and explained that I was her mental health advocate. The assessor didn't respond to the introduction, nor did she look at me…. The assessor leant forward and moved a monitor on the desk in front of me…"*

Healthwatch were also told that the system does not empower advocates to act on their clients' behalves, even where this would be beneficial. For example several organisations indicated that their advocates were unable to change appointment times by phone. In one case *"To change the appointment she [the client] had to travel 11 miles into Brighton to make the call with me to rearrange the appointment*…"

[5] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519119/personal-independence-payment-handbook.pdf

B. ASSESSMENTS

Impacts on applicants

We received a large number of concerns and complaints about the manner in which assessments were conducted and the emotional distress this caused for some applicants. In a number of the cases that we heard about, it was reported that applicants had experienced a range of negative effects following their attendance at an assessment centre including collapsing; suffering seizures; being hospitalised; suffering panic attacks; paranoid thoughts; self-harming and feeling suicidal. All of these feelings were attributed to the stress caused by having to attend an assessment and answer very personal questions about their condition.

Healthwatch were told by local organisations that many of their applicants found it difficult and distressing to talk to someone unfamiliar about their mental or physical health condition because of embarrassment, worries about being perceived as weak or unable to cope, and stigma. We were also told that applicants reported feeling invalidated by the process and disbelieved by assessors. The following quotes highlight some of the perceived issues:

> *"I've had at least 3 of these [assessments] and each time I end up feeling worthless afterwards because they do not look at/acknowledge me as a person, just firing off questions… and cutting me off when I have tried to qualify or elaborate… Also because I have a fluctuating condition, which they …ignore …making all their assessments absolutes, on a day that I can do something that most of the time I cannot."*

> *"My client found the [2 hour] wait intolerable and caused a heightened sense of anxiety and distress. During the assessment, they disassociated 4 times, and then regressed to an early childlike state."*

> *"I cannot engage and maintain concentration for long periods of time and when I force myself to do it, it is very detrimental for my health. An example of this was the day I went for the PIP assessment, it was so intense and not suitable for someone suffering with ME. At some point during the interview I had to be excused and go to the toilet as I was feeling really bad. After that interview, I was really poorly with extreme exhaustion for three days unable to leave my bed."*

> *"…for a client who had applied for ESA which identified 23 touch points over a 7 month period (i.e. contacts between the DWP and the client). The client felt a massive sense of relief at the end of the process stating that "I really am ill, aren't I?", but they then felt suicidal several days afterwards. This battle to have their condition acknowledged had a negative impact on their well-being.*

> *"Some clients with mental health problems and other conditions that effective cognitive function experience problems with their memory, thinking and orientation, making it difficult to understand and talk about how their condition affects them on a daily basis."*

Cancellations

A number of local organisations reported to Healthwatch that face-to-face assessments were cancelled by assessment providers on the day, and sometimes just 20-40 minutes before the scheduled appointment time. In some ESA cases cancellations occurred only after the applicant had arrived at the centre in Lewes. This late cancellation process left a number of applicants stranded *en route* which could be incredibly distressing for applicants suffering with anxiety disorders. There was clearly also a knock-on impact for advocates and representatives whose time may be wasted.

Local organisations reported a sense that applicants were afforded limited opportunity to change to their assessment date whereas ATOS and Maximus could apparently do this with impunity. In one case Healthwatch was told about, an applicant suffering with uncontrollable epilepsy exacerbated by stress had his ESA appointment cancelled on three separate occasions just 40 minutes before the allotted time. This was due to staff shortages. On the forth rescheduled date, the advocate advised he was unable to attend to support his client however ATOS advised they would need to cancel the applicant's existing ESA benefit if he did not attend.

In another case, an applicant experienced 3 cancellations for their ESA assessment, each time waiting 2 hours at the assessment centre before being told that their scheduled appointment would not take place.

Evidence

Applicants are asked to complete a DS1500 medical report to support a PIP claim or an ESA50 for ESA. Both forms request information about the individual's medical condition, and can be obtained from their GP, consultant or certain other professionals. The forms can also be accompanied by supporting medical evidence that explains how their condition affects them such as reports from specialist nurses, social workers, occupational therapists and GPs.

The onus of gathering evidence is put on the applicants, sometimes reportedly at cost. One local organisation informed us that some GP's are under strain to provide supporting information, and some charge up to £35 per letter, or are refusing to provide information at all. Healthwatch was advised that while assessors have the option of asking GPs for medical evidence using a 'factual report form' (and compensate them for filling it out) this option does not exist for other kinds of healthcare professional. Understandably, we were advised that making it easier to gather evidence from health professionals could make a significant difference for many PIP/ESA applicants.

Healthwatch was advised that information submitted to support claims was sometimes ignored or not given due credence. One organisation told us:

> *"It seems that evidence provided by support workers or carers isn't always taken into account during the assessment process, despite the fact that they will often be in a better position than other professionals to talk about the day-to-day impact someone's condition has on them. Omitting evidence from their reports to the DWP increases the*

risk of poor and inaccurate decision-making, and denies people the chance to make sure that those who know them well are able to inform their claim."

Local organisations also told Healthwatch that some applicants who are already in receipt of Disability Living allowance are receiving letters advising them they need to apply for PIP 'out of the blue'. Healthwatch was advised that the time limits to then apply are too short to enable applicant's to gather supporting medical information i.e. it can however take several months to arrange and receive the results from occupational therapy assessments.

Recording equipment

Several organisations challenged the appropriateness of guidelines[6] concerning the recording of assessment interviews. One organisation told us that whilst recordings are allowed, applicants have to sign to say they will not seek to use these at tribunal or for anything other than personal use, calling into question their usefulness. Healthwatch were told that applicants have to provide recording equipment in the form of a double CD recorder, which were described to us as being expensive and impractical for those living off benefits.

C. ACCESSIBILITY

Healthwatch could not locate any official DWP figures to show the proportion of face-to-face assessments taking place in people's homes rather than in assessment centres. Previously the Government had stated that they expected around 75% of PIP claimants to require a face-to-face assessment, rather than DWP relying on "paper" assessments. It has not been possible to find a similar estimate for ESA face-to-face assessments, although the figure is thought to be high as applicants for ESA have to undergo a work capability assessment to find out if they are eligible, and they are re-tested to ensure their condition has not changed. Where an individual is so required, they must attend their assessment otherwise they risk their PIP or ESA claim being rejected and the application process being re-started.

Healthwatch has learnt that assessment providers are required to ensure that claimants travel no more than 90 minutes (single journey) by public transport to their assessments[7]. This figure is specified as being an absolute maximum. Home consultations can take place either: at the claimant's request if supported by an appropriate health condition or disability and as determined by the assessor; or when the claimant provides confirmation through their health professional that the claimant is unable to travel on health grounds; or at the assessment provider's discretion for a business reason.

Local organisations told Healthwatch however that some people are being unfairly discriminated against in terms of having to travel to assessment centres. For example one individual is reported to have travelled 20 miles to Lewes for their ESA assessment despite suffering from body pain, dissociation and detachment disorders.

[6] https://www.mypipassessment.co.uk/faqs/#during-your-consultation-1096
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/418925/wca-audio-recording-policy-march_2015.pdf

[7] Personal Independence Payment handbook Department for Work and Pensions Page 26 of 40

We were also told that the location of assessment centres, and requirement to attend these, disproportionately affects individuals with certain mental conditions such as agoraphobia; and for those with mobility issues and anxiety disorders. It can also be the case that some individuals who are unable to use public transport risk losing out financially if they are unable to claim back all travel costs. For example, we were told of one individual who paid £50 in taxi fares in order to attend their assessment. (NB public transport costs to and from centres can be reimbursed, but where people use a taxi then prior agreement must be sought and a doctors letter must confirm that the individual is unable to use public transport).

We were given examples involving assessors using the fact that applicants had travelled in to their assessment (as well as the mode of transport taken) against them in final reports. That is, some assessors are reported to use this information to form judgements about the applicant's ability to plan and make journeys (this is one of the PIP descriptors used to assess mobility). The danger of doing this is that it ignores any potential impact upon the applicant, or whether such a journey goes beyond their usual ability. For example, in one case the fact that a person had travelled to the assessment centre was used to indicate they did not have any mobility needs, even though the individual had to be accompanied on all such journeys.

A number of local organisations told us that home visit requests had to be made over 8 weeks in advance, but were being routinely rejected even when medical evidence was provided to support the request. It was reported to us in one case (Case study 7 in Annex C) that an applicant with significant behavioural problems which were well-documented by psychiatric services was required to attend face-to-face PIP assessments on 3 separate occasions. A request for a home visit was declined and the applicant attended another face-to-face assessment having taken large amounts of prescription medication, plus having self-harmed. Despite this, the assessment was carried out and completed. The application for PIP was subsequently turned down but following an appeal, the Tribunal found in their favour and reinstated the benefit.

Another organisation advised us that a larger number of young people were being asked to attend face-to-face assessments, although it was unclear why this was the case. The organisation reported that cases such as these commonly had a lot of supporting evidence e.g. an Education Health and Care Plan, up to date advices from Educational Psychology, Occupational Therapy, Speech and Language therapy assessments, medical, clinical or psychiatric reports.

D. REPORTS

Quality and accuracy of reports

In a number of instances local organisations expressed concern about the quality and accuracy of reports produced by assessors.

We received comments that post assessment reports contained typos, inaccuracies and omissions, and examples of the same paragraph being used several times. For example in one report it wrongly indicated that a physical examination had taken place. In another example a

"… client's report … had the phrase 'Reported difficulties consistent with his condition and medication' used repeatedly throughout his report. This client had a complex range of both physical and mental health conditions so which specific condition or medication was the report referring to?"

Questions were also raised about how assessors used evidence to assess a person's mental or physical health, and how it affected them on a daily basis. The following examples highlight the issue:

> *"An applicant scored no points in relation to the mobility component of her PIP as the report stated that she was 'seen to role a cigarette'. The question is what does this have to do with their ability to walk any distance or not?"*
>
> *"Another client was told he could dress himself as he wore a suit and tie to the assessment but there was no mention of the fact that his son spent well over an hour helping his father to dress as his father wanted to 'look smart'; even though this information was passed onto the assessor*."
>
> *"A post assessment report stated that an individual had come to the centre alone but this ignored the fact that the person's father was in the waiting room and had brought them in. The same report stated that the person was able to get about unaided again ignoring the fact that the father had accompanied them in. The report stated that the person could prepare meals for themselves, yet this was not true as the individual was at risk of self-harming and kitchen knives posed a danger to them."*
>
> *"The original decision letter stated that X was well presented with make-up and looked slim but healthy, and made good eye contact. These observations were stated in their report as reasons to determine that she was capable of carrying out daily living activities and leaving the house with no problems. Had they done a physical examination they would have observed X was severely underweight and malnourishment (but they didn't and she just remained seated with a bag on her lap). After submitting the mandatory reconsideration, X was awarded enhanced rate for daily"*

Application of policy, rules and law

We received a smaller number of comments about assessors applying rules and/or case law incorrectly, or that a subjective interpretation had sometimes seemingly been applied. For example, we were told that whilst PIP is not a job related benefit, some applicants have had the fact that they were working used against them in the post assessment decision. In another example we were told that case law states that an assessment of a person's condition is not solely related to their ability to carry out a task, but whether they can do it without pain and in a timely manner etc., whereas several organisations reported that some assessors seemed to treat the assessment as a tick box exercise. One organisation advised us that the role of the DWP is not to disprove the evidence presented, but rather to accept what the applicant says, but their experience was that the opposite was true in some instances.

Award rates and appeals

A concern which Healthwatch heard time and again throughout this project related to the accuracy of decisions made by DWP; and the impact which poor assessment reports were potentially having in this regard. Several organisations also questioned the purpose of the mandatory reconsideration stage of the PIP / ESA process, advising that few decisions were reversed or amended by the assessing provider; forcing organisations to lodge appeals with the tribunal. This led several local organisations to describe the assessment process as a lottery with there being little clear logic as to which applicants would be successful or not. There was also a sense of frustration reported on the part of applicants who feel that they must repeat their story over and over again before they are finally believed.

> **Mandatory reconsiderations (PIP and ESA)**
> Before an appeal against a negative decision can be made, an applicant must ask for a mandatory reconsideration of their case within once calendar month of the date of the decision. An applicant can appeal to the tribunal if they remain dissatisfied with the outcome of the reconsideration. There is no official time limit controlling when reconsiderations must be completed by DWP.
>
> **Tribunal appeals (PIP)**
> An appeal must be made within one calendar month of the date of the mandatory reconsideration notice, and be lodged with the Social Security and Child Support Tribunal. The DWP has indicated that appeals should be heard within 16 weeks of the appeal being received.

Healthwatch has been unable to locate any official statistics to show how many people have had to rely on appeals to secure either PIP or ESA. Non-DWP data[8] suggests that the number of appeals against decisions made by the DWP is increasing. They show that there were 60,600 Social Security & Child Support appeals between October and December 2016, a reported increase of 47%. Some 85% of those appeals were accounted for by PIP and ESA. The rate at which the decisions made by the DWP on the basis of information supplied by the ATOS and Maximus are overturned is also reported to be increasing.

DWP official statistics on PIP up to April 2017[9] indicate that:

- Award rates for new claims are 45%, and 73% for DLA reassessment claims by the end of April 2017; 558,000 mandatory reconsideration's had been registered, and that there has been a downward trend in the number of mandatory reconsideration registrations and clearances, driven by the downward trend in the number of claim clearances.
- that 84% of new claims reconsiderations and 79% of reassessed DLA reconsiderations for normal rules resulted in no change to the award. In 98,000 cases a new decision resulted in the award being changed.

[8] http://www.independent.co.uk/voices/disability-assessment-pip-esa-appeals-something-is-wrong-a7635221.html
[9] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/618484/pip-statistics-to-april-2017.pdf

Local organisations provided Healthwatch with a number of examples of applicants they had helped to appeal against a decision to refuse or amend an award of PIP or ESA. One organisation reported to us that they had taken 17 cases to appeal all of which had been successful (12 PIP and 5 ESA). In each case the number of points subsequently awarded to their clients entitled them to enhanced rates of benefit. Another organisation reported a 90% success rate with cases they had supported through to Tribunal. The following are examples provided to us:

> *"We supported a client who suffers with both sensory and some mental health issues. The PIP assessor was respectful to their needs, and asked pertinent questions. The DWP's initial decision was that he did not qualify for any level of benefit. A mandatory reconsideration was requested and within 2 weeks the client was awarded PIP at the standard rate. The case went to tribunal (4-5 month wait) where they found in his favour within less than a minute, and awarded him the enhanced rate."*

> *"A young person, who is deaf, has learning difficulties and who experiences barriers with language in general. As a result she also feels anxiety about going outside her home and is usually accompanied by her support worker or a family member. Her learning difficulties mean that she was awarded the enhanced rate for the care component of PIP. However, she was refused any PIP payment for mobility and the justification given was that she did not have a learning difficulty. Despite the obvious contradiction, her request to have this decision overturned at mandatory reconsideration was rejected. This case went to Tribunal who awarded her the enhanced rate for both the care and mobility components of PIP. This was a waste of the Tribunals time and this case should never have got this far."*

Organisations also highlighted to us the negative impacts on an individual of an outright refusal or reduced award which is subsequently overturned at appeal. For example:

> *"A client with major physical and mobility impairments was refused PIP outright following being "migrated" to PIP from DLA. She lost her benefits and her motability car. Eventually, she won at appeal, but was 6-8 months without benefits or transportation and she had to then reapply for a motability car*."

In another case, we were told how the impacts of an initial refusal could have wide reaching impacts. In the case in question the refusal had resulted in the applicant's mother also losing her carer's allowance. Once again, the decision was overturned at tribunal.

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Annex A: organisations, groups, partnership or individuals contacted

Key:

- 'email response' indicates that we received an acknowledgement from the organisation in response to our call for evidence (NB they may have forwarded the request on; indicated that they did not support individuals with PIP/ESA assessments; provided other potential contacts; provided us with evidence, or any combination of these).
- 'meeting/call' indicates that one-to-one level engagement took place with the organisation either in person or over the phone.
- 'case studies' indicates that the organisation provided Healthwatch with person specific (though anonymised) case studies.
- 'experiences' indicates that the organisation provided us with their experiences of supporting individuals through these assessments.

Organisation / Group	**Response**					
	Email response	**Meeting/ telephone call**	**Case studies**	**Experiences**	**Nil response**	**Other**
AMAZE Supporting parents & carers of children & young people with special educational needs and disabilities	✓	✓	✓	✓		
ASSERT Supporting Adults with Asperger Syndrome or High Functioning Autism	✓	✓	✓	✓		
Brighton and Hove City Council	✓	✓		✓		
Brighton & Hove Food Partnership Non-profit organisation helping people learn to cook, eat a healthy diet, grow their own food and waste less			✓			**See Whitehawk food Bank**
Brighton and Hove Speak Out Offering a range of services to people with learning disabilities	✓			✓		

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Organisation / Group	Response					
	Email response	Meeting/ telephone call	Case studies	Experiences	Nil response	Other
BHT (Brighton Housing Trust) Combating Homelessness, Creating Opportunities, Promoting Change.						**See Moneyworks Partnership below**
Citizens Advice Brighton & Hove (see Moneyworks Partnership)**	✓	✓	✓	✓		**See Moneyworks Partnership below**
Community Support Services, West Sussex Support for adults with learning disabilities in West Sussex	✓					**Provided individual contacts**
Friends, Families and Travellers Working on behalf of all Gypsies, Travellers and Roma	✓	✓	✓	✓		
Hangleton and Knoll project A Community Development charity based in the Hangleton and Knoll	✓					**Provided other contacts. See Moneyworks Partnership below**
Impetus (Interact service) Connecting people to reduce isolation & improve wellbeing	✓		✓			**Provided other contacts**
Individual	✓	✓	✓	✓		
Just Life Works with single homeless people who are living in vulnerable situations	✓		✓	✓		

Organisation / Group	Response					
	Email response	Meeting/ telephone call	Case studies	Experiences	Nil response	Other
LGBT Switchboard Providing support services run for and by LGBT people					✓	
Macmillan Horizon Centre Providing support and services for people affected by cancer					✓	
MIND Mental health charity	✓					**Local office does not provide benefits advice**
MindOut Lesbian, Gay, Bisexual, Trans & Queer Mental Health Service	✓	✓	✓	✓		
Money Advice Plus Provides specialist welfare benefits and debt advice	✓					**See Moneyworks Partnership below**
Moneyworks Partnership* Provides free, independent advice on a range of money issues. Led by Citizens Advice Bureau	✓		✓	✓		**Provided a response on behalf of partnership organisations, unless any partner replied to Healthwatch individually**
Parent and Carers Council A forum for parent carers of children with additional needs					✓	
Possibility People Support for disabled, older people and young people, or anyone with an impairment or long-term condition	✓	✓	✓	✓		

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Organisation / Group	Response					
	Email response	Meeting/ telephone call	Case studies	Experiences	Nil response	Other
St Luke's Advice Service Providing practical help, advice and guidance to people in need.					✓	**See Moneyworks Partnership above**
Terrence Higgins Trust Sexual health service	✓					**Unable to submit a detailed response**
Trust for Developing Communities Improving lives through community development work					✓	
Whitehawk Food Bank Helping local people in crisis	✓		✓			**Shared experiences with Moneyworks Partnership (see above)**

***Moneyworks Partnership**: Moneyworks is here to help Brighton & Hove residents save money, make money and manage their money better. The services are for anyone who is struggling to make ends meet. Moneyworks is a partnership of advice agencies and community education partners led by the Citizens Advice Brighton & Hove (CAB).
Advice partners: Citizens Advice Brighton & Hove (CAB); BHT Advice Centre; Money Advice Plus (MAP); Possability People and St Luke's Advice Service
Community education partners; Brighton Unemployed Centre Families Project; Hangleton & Knoll Project; The Bridge; the Whitehawk Inn.
Brighton and Hove Food Partnership and East Sussex Credit Union are strategic partners.

** **The Citizens Advice Bureau** also work with four education partners including Whitehawk Inn, Brighton Unemployed Families Project, Hangleton and Knoll Project and The Bridge.

Annex B - PIP and ESA

Personal Independence Payment (PIP)

PIP provides support to individuals who have a long-term disability, ill-health or terminal ill-health. A successful award of PIP is based on the effect that a disability or health condition has on a person and the extra help they may need to carry out certain activities (not whether they actually get that help). PIP is paid directly to the individual i.e. not to their carer, and is not means tested so it is irrelevant whether a person has worked, paid National Insurance or what income or savings a person has.

The eligibility criteria for PIP is that the person:

- is aged 16 to 64 (i.e. of working age)
- needs help with everyday tasks, or getting around
- has needed this help for 3 months and expect it to need it for another 9 months
- has lived in England, Scotland or Wales for at least 2 years (separate rules apply for refugees and family members)

From April 2013, the Department for Work and Pensions (DWP) began to replace Disability Living Allowance (DLA) for working age people with PIP. By October 2018, it is intended that most current DLA claimants will have been assessed for PIP instead (if an individual is 65 or over on 8 April 2013 they will continue to receive DLA). The Government has estimated that by 2018 around 607,000 fewer people will receive PIP than would have got DLA and expenditure will be £2.5 billion a year lower. When PIP was introduced the Government stated that entitlement for PIP would be determined by a “new, fairer, objective assessment of individual need” to ensure support was “targeted on those individuals whose health condition or impairment had the greatest impact on their day-to-day lives”.

PIP assessment

When an individual is assessed for PIP, a health professional will look at their ability to carry out a range of daily living activities and mobility activities. The health professional will consider whether a health condition or disability limits an individual’s ability to carry out certain activities and how much help they need with them. The health professional will write a report for the DWP, and the DWP decision maker will then decide whether an individual is entitled to PIP, at what rate and for how long i.e.

- Shorter term awards of up to two years will be given where changes in an individual’s needs could be expected in that period.
- Longer term awards, of five or ten years, will be given where significant changes are less likely. The award will still be reviewed over this time.
- Ongoing awards will be given in the minority of cases where needs are stable and changes are unlikely.

PIP is made up of 2 parts (i) the daily living component and (ii) the mobility component. Each component can be paid at one of 2 rates, either the standard rate or the enhanced rate. In general, if the DWP decision maker decides that that an individual’s ability to carry out a component is limited, they will get the standard rate; if it is severely limited they will get the

enhanced rate. It is possible to appeal against a decision to refuse PIP altogether, and/or against which rate has been awarded.

Support levels

If an individual has a terminal illness they will automatically receive the daily living enhanced rate. The mobility rate will depend on the level of help the person needs with their mobility. The award will last for 3 years.

<table>
<tr><td colspan="3">The daily living rate is for the extra help an individual needs with everyday tasks e.g. preparing food, washing or getting dressed.</td><td colspan="3">The mobility rate is for the extra help an individual needs getting around e.g. moving, planning a journey or following a route.</td></tr>
<tr><th>Component</th><th>Weekly rate</th><th>Points needed</th><th>Component</th><th>Weekly rate</th><th>Points needed</th></tr>
<tr><td>Daily living - standard rate</td><td>£55.65</td><td>8 points under the ten daily living activity headings.</td><td>Mobility - standard rate</td><td>£22</td><td>8 points under the two mobility activity headings.</td></tr>
<tr><td>Daily living - enhanced rate</td><td>£83.10</td><td>12 points</td><td>Mobility - enhanced rate</td><td>£58</td><td>12 points</td></tr>
<tr><td colspan="3">To get the daily living component of PIP, you must have a physical or mental condition that limits your ability to carry out some or all of these 10 activities:
1. preparing food
2. eating and drinking
3. managing your treatments
4. washing and bathing
5. managing toilet needs or incontinence
6. dressing and undressing
7. communicating verbally
8. reading and understanding written information
9. mixing with others
10. making decisions about money</td><td colspan="3">To get the mobility component of PIP, you must have a physical or mental condition that limits your ability to carry out some or all of these two activities:
1. planning and following journeys. This activity assesses an ability to work out and follow a route safely and reliably. Two types of route are considered: familiar and unfamiliar
2. moving around. This activity focuses on physical ability to 'stand' 'and then move'</td></tr>
<tr><td colspan="6">Scoring points ("descriptors")
An individual's ability to carry out each activity is measured against a list of standard statements describing what they can or cannot do; known as the descriptors. The health professional will advise the DWP which descriptor applies to an individual for each activity. PIP assessments do not separate an individual's needs into day-time and night-time needs. Instead, a descriptor can apply if a condition affects an individual's ability to complete a task, at some stage of the day, on over half the days of the period.
- A descriptor applies if it affects an individual's ability for the majority of days (>50%). This is considered over a 12-month period; looking back 3 months; forward 9 months.
- Each descriptor carries a points score ranging from 0 up to 12. E.g there are 6 descriptors for 'Dressing and undressing', ranging from: 'Can dress and undress unaided' (zero points), to 'Cannot dress or undress at all' (eight points).</td></tr>
</table>

- An individual will score points when they are not able to complete a task (i) safely in a way that is unlikely to cause harm either to you or anyone else, either during the activity or afterwards; (ii) to an acceptable standard; (iii) repeatedly as often as is reasonably required and (iv) in a reasonable time period (it should take an individual no more than twice as long someone without that condition). Where two or more descriptors are satisfied on over half the days, the descriptor which scores the highest number of points will apply.

Motability vehicles

All individuals will have their need for a mobility vehicle reassessed as part of the PIP assessment. It is only possible to qualify for the Motability Scheme if an individual is awarded the enhanced rate for mobility. It is therefore possible that an individual may not be able to keep their vehicle.

Previous public scrutiny of PIP[10] (2015)

Parliamentary scrutiny of PIP has shown the following.

Whilst DWP had expected 75% of assessments would require face-to-face consultations rather than being decided on paper, and that they would take 75 minutes on average to conduct, in practice over 97% of assessments had involved face-to-face consultations and they were taking around 120 minutes.

The process for claiming PIP had proved “inaccessible and cumbersome” for claimants. Assessment providers had also encountered difficulties obtaining evidence to support claims from third parties such as GPs, physiotherapists and social workers.

There had been “unacceptable delays in making benefit decisions, placing unwarranted pressure on claimants, disability organisations, and other services.” Many claimants had had to wait over six months for their claim to be decided.[11]

The Department and its contractors had “failed to provide an acceptable standard of service to claimants.” Claimants had experienced difficulties in arranging appointments, long and difficult journeys to assessment centres, assessment providers had cancelled home visits at the last minute, and assessors had failed to turn up when claimants have travelled to assessment centres.

In the above instance, a Public Accounts Committee inquiry of 2014[12] recommended that DWP;

- should make the process easier for claimants by, for example, ensuring that third parties supply information on claimants where relevant and do this in good time.
- must speed up all stages of the process to ensure benefit decisions are made on a timely basis and tackle the backlog of cases that had arisen.

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[10] https://publications.parliament.uk/pa/cm201415/cmselect/cmpubacc/280/280.pdf

[11] On 5 June the High Court ruled that the delays in determining two Personal Independence Payment claims were unacceptable and unlawful. http://www.bailii.org/ew/cases/EWHC/Admin/2015/1607.html

[12] https://publications.parliament.uk/pa/cm201415/cmselect/cmpubacc/280/28002.htm

- should ensure that it, and its contractors, provide an acceptable level of service to claimants by minimising delays and travel times, making home visits when arranged, improving administrative processes, and providing better information to claimants.

PIP statistics (2017)

DWP official statistics on PIP up to April 2017[13] indicate that

- Award rates for new claims are 45%, and 73% for DLA reassessment claims by the end of April 2017, 558,000 mandatory reconsideration's had been registered, and that there has been a downward trend in the number of mandatory reconsideration registrations and clearances, driven by the downward trend in the number of claim clearances.
- That 84% of new claims reconsiderations and 79% of reassessed DLA reconsiderations for normal rules resulted in no change to the award. In 98,000 cases a new decision resulted in the award being changed.
- For normal rules (non-terminally ill) claims:
  - 32% received the Daily Living Award only,
  - 4% received the Mobility Award only, and
  - 64% received both awards.
  - 58% received a component at the enhanced rate, with 27% of these receiving the highest level of awards ('enhanced/enhanced' rates) for both Mobility and Daily Living components.
  - 47% of these have been in payment for less than one year.
- The main disabling condition for people in receipt of PIP:
  - 476,000 (36%) were recorded with 'Psychiatric disorders' (which includes 'Mixed anxiety and depressive disorders' and 'Mood disorders').
  - 283,000 (21%) were recorded with 'Musculoskeletal disease (general)' (which includes 'Osteoarthritis')

Statistics for Brighton and Hove are as follows[14]:

Registrations	11,884
Clearances	10,510
Proportion of clearances awarded	0.54
Total caseload (April 2017)	5,837
New PIP claims	3,367
Reassessment claims (DLA recipients))	2,472
Special rules for terminally ill	81
Normal rules	5,756
Enhanced	1,471
Proportion enhanced	0.26

Medical condition	Number
Psychological	2508
Musculoskeletal	1810
Neurological	536
Respiratory	232
Malignant	195
Cardiovascular	104
Other	457

[13] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/618484/pip-statistics-to-april-2017.pdf

[14] http://dwp-stats.maps.arcgis.com/apps/Viewer/index.html?appid=4f2f5d71f682401b9b78ee5c6ea7887e

Employment and Support Allowance (ESA)

ESA is a benefit paid if an individual has an illness or disability that affects their ability to work. As with PIP, an award of ESA is not based on the disability or illness rather it is the effects of the condition which matter.

There are 3 types of ESA:

- contribution-based ESA which is available if the person has paid enough National Insurance contributions (this benefit is taxable)
- income-related ESA which is paid if an individual is on a low income (Universal Credit is being introduced on a phased basis to replace income-related ESA).
- new style ESA is available if an individual is eligible to get Universal Credit. New style ESA works in the same way as contribution-based ESA.

The eligibility criteria for ESA is that the person:

- can no longer access Statutory Sick Pay, or was not entitled to this
- is employed, self-employed, unemployed or a student on DLA
- is under State Pension age
- is not getting Jobseeker's Allowance
- has had an illness or disability which affected their ability to work, or
- was unable to work for two or more days out of seven consecutive days, or
- is getting special medical treatment.

To be eligible to claim income-related ESA, the person also needs:

- to have no income or a low income
- to have not paid enough National Insurance contributions, and have savings of less than £16,000 or if they have a partner s/he works for less than 24 hours a week on average.
- to not be claiming Universal Credit.

When ESA was initially introduced, it was announced that existing Incapacity Benefit claimants would be reassessed to see if they were eligible for ESA. Full national implementation began from February 2011 onwards and is on-going. These claimants would then be subject to the standard conditions of an ESA claim, and be required to take part in a WCA**.**

Assessment

When a new customer applies for ESA they enter an assessment phase which normally lasts 13 weeks. While in the assessment phase, for any claim longer than seven days, people are required to supply up-to-date medical evidence. For claims for fewer than seven days, self-certification is accepted. During this phase the individual will have their ability to work assessed to determine their entitlement, this is called the Work Capability Assessment (WCA)[15]. An individual's GP may be asked to provide a medical report, and may be asked to attend a face-to-face medical assessment.

[15] capability for work questionnaire (ESA50)

During the assessment phase the customer will be paid at the 'assessment rate', which is based on the Jobseeker's Allowance personal allowance. ESA claimants' longer term entitlement to claim the benefit is dependent on the outcome of the WCA. The possible outcomes of the WCA are that claimants can be assessed as:

a. Suitable for the ESA Work Related Activity Group (where claimants are able to undertake and participate in work-related activity to help them move towards the labour market),
b. Suitable for the ESA Support Group (where claimants are not required to undertake any interviews or work related activity), or
c. Fit for work and therefore not entitled to ESA, although there is a right of appeal.

As with PIP, it is possible to appeal against a decision to refuse ESA altogether

Support levels

<table>
<tr><td colspan="2">Assessment phase
This lasts for the first 13 weeks of your claim while a decision is made on your capability for work through a Work Capability Assessment.
During this phase, ESA is paid at a basic rate.</td><td colspan="4">Main phase
This phase starts from week 14 of your claim. Your Work Capability Assessment will decide which of the following two groups you are placed in during the main phase of your claim:
• Work Related Activity Group
• Support Group</td></tr>
<tr><td>Person</td><td>Weekly rate</td><td>Group</td><td>Person</td><td>Date of claim</td><td>Weekly rate</td></tr>
<tr><td>A single person aged under 25</td><td>up to £57.90</td><td>Work related activity group</td><td>Single person</td><td>Before 3 April 2017</td><td>Up to £102.15 (award is not time limited)</td></tr>
<tr><td>A single person aged 25 and over</td><td>up to £73.10</td><td>Work related activity group</td><td>Single person</td><td>On or after 3 April 2017</td><td>Up to £73.10 for up to one year</td></tr>
<tr><td colspan="2" rowspan="2">During this stage an individual must complete a questionnaire called an ESA50. They will usually need to attend a medical assessment in person (a face-to-face appointment). The healthcare professional will then report their findings to the DWP who will then decide whether an individual has limited capability for work. If an individual scores less than 15 points, they are deemed fit for work and your ESA will stop.</td><td>Support group</td><td>Single person</td><td>NA</td><td>£109.30</td></tr>
<tr><td colspan="4">Work Related Activity Group
In this group, an individual is expected to take part in work-focused interviews with an Employment Service Adviser. They will be supported to prepare for suitable work. An entitlement to ESA is affected if a person refuses to go to, or fully take part in, the work-focused interviews.
Support Group
In this group, because of an illness or disability which severely affects a person’s ability to work, they will not be expected to take part in any work and will not have to go to work-focused interviews</td></tr>
</table>

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Annex C – case studies

Case study 1 ESA Medical Assessment - concerns with the assessor's engagement - emotional and financial impact on client Client X lives with borderline personality disorder and managed this with support from mental health services. Client X was reportedly very nervous about the assessment. They were unable to use public transport (due to their condition) and had travelled to and from the assessment centre by taxi at a cost of £50. Client X had requested that their advocate keep a list of what they wanted to mention during the assessment. The assessor was reported to have abruptly responded as follows *"I see your advocate is making notes – any notes taken cannot be used in a tribunal, is that clear? If you want the session recorded I can arrange that for tribunal. Do you want the session recorded?"* The assessor's tone was considered to be unfriendly and defensive and they came across as angry. The advocate felt they and their client had done something wrong and were being felt "*told off*". The assessor addressed the above question to Client X who did not know how to answer, and later advised their advocate that the only word they had heard was *"Tribunal",* which felt scary to them. In response to the question, Client X went very red, and then burst into tears. Client X needed some time to compose themselves as they were feeling very upset and scared. Their reaction was put down to the feeling of being under pressure to answer the above question. The advocate felt that the assessor's combative and defensive approach was totally unnecessary, and in their opinion caused emotional harm to Client X.
Case study 2 ESA Medical Assessment - physical & emotional distress on client - limitation of advocate's role in being able to fully support their client - case where a home visit may have avoided distress Client X had experienced early childhood trauma and had been diagnosed with a somatic disorder. This meant that any mental distress/anxiety was expressed physically with symptoms of bodily pain, dissociation and detachment. Client X had needed to travel 20 miles to the assessment centre in Lewes. Client X felt very stressed and collapsed on approaching the ESA assessment centre and again in reception; with the latter incident leading to a seizure and requiring their admission into hospital. Client X then had to make their own way home from hospital by train, despite feeling vulnerable, physically unstable and distressed.

As the assessment did not take place, Client X was sent another appointment, again in Lewes but on a weekend which meant that their advocate could not also attend. The advocate was unable to change the appointment by phone and was told that Client X would need to make the call, which they were unable to do due to anxiety and distress they experienced when using the phone and talking to strangers. To change the appointment Client X had to travel into Brighton to make the call with her advocate supporting her.

Case study 3
ESA Medical Assessment
- physical & emotional impact on client

Client X suffered from complex trauma and dissociative disorder. Client X was also prone to falling when stressed and collapsed just after arriving at the assessment centre. As a result, adjustments were made so that Client X could be seen on the ground floor. As there was only one suitable room, this led to a 2 hour wait which caused Client X to feel a heightened state of anxiety and distress. During the assessment itself Client X disassociated four times, and then regressed to an early childlike state, making a disclosure about a trauma experienced in childhood. Their overall behaviour changed and was reportedly 'unrecognisable'. The assessor allowed time for this, but continued to ask questions like "why don't you wash yourself" and "how do you get your shopping". After the assessment Client X was shaky, physically unstable and found walking difficult; and on leaving the assessment room they collapsed fell to the floor and fitted for about 20 minutes. Client X was subsequently taken to hospital. Previous ESA appointments are reported to have had a similar impact on Client X.

Case study 4
ESA Medical Assessment
- concerns with the assessor's engagement
- emotional and financial impact on client

Client X was very distressed about the appointment and was shaking and crying whilst waiting to be seen. Client X was concerned that the assessment would involve answering questions childhood trauma.

At the start of the appointment Client X introduced their mental health advocate, but the assessor reportedly did not respond to the introduction, nor acknowledge them. Client X cried and shook as they answered questions; however no comfort break or reassurance was offered by the assessor.

Client X requested their advocate to support them if questioned about their suicidal thoughts/distress, however the assessor stated to Client X "I need you to tell me". This caused Client X distress. The advocate attempted to provide information but was asked not to by the assessor who is reported to have leant forward and moved a monitor on the desk to block them. This angered Client X who asked to terminate the appointment. Afterwards, it took a considerable amount of time for Client X to stop crying and shaking. Client X stated they were feeling suicidal at this time and indicated that this was as a direct result of how the assessor had treated them.

Case study 5
ESA Medical Assessment (March 2017)
- cancelled appointments
- quality of decision, not fully based on medical evidence
- concerns with the assessor's engagement

The time line for this case is as follows;

- a Work Capability Questionnaire was submitted in December 2016.
- a health assessment appointment was booked for 17 January in Lewes. Client X arrived in time, was kept waiting for about 2 hours but then told by the centre that they did not have the right paperwork and they would have to reschedule.
- Rebooked for 25 January. Client X was called by the centre on their mobile whilst en route to Lewes to say there was a delay in seeing people and they wanted to reschedule. Client X refused as they were already on their way in. On arrival they waited for 2 hours before being told the appointment would not go ahead.
- Rescheduled 15 February. Attended in Lewes again, waited 2 hours before being told they still did not have the appropriate paperwork
- 8th March – Client X was finally successfully seen by a nurse who carried out the appointment.

During the appointment the assessor was judged to be distant, formal and rarely made any eye contact. No empathy or compassion was reportedly shown towards Client X's injuries. The decision letter came through a few weeks later and advised that Client X had been placed in the Work Related Activity Group, despite having recently had a finger amputated from a work injury; experiencing nerve damage in their other hand following surgery and suffering from depression and PTSD.

From the initial ESA sign on date (back in September 2016) up to the above decision letter in March/ April 2017, Client X was only receiving £73.10 a week, which they were struggling to live on. After the decision letter it was increased to over £100 a week and they received a back payment of £800. However, Client X's advocate submitted a mandatory reconsideration asking that he be moved to the Support Group and collected medical evidence from Client X's GP, hand surgeon in London and occupational therapist. An outcome is awaited.

Case study 6
PIP Assessment
- concerns with the assessor's engagement
- quality of decision, not fully based on medical evidence

Client X attended a face-to-face assessment having already submitted a completed application form which listed their various illnesses and how these affected both the daily living and mobility elements of PIP. At the appointment the assessor failed to engage with Client X reportedly "writing frantically at her computer, barely making eye contact and asking questions whilst looking at her computer screen, not at Client X". The assessor was judged to be unfriendly, showed little empathy, was clinical and barely interacted. A physical examination was not undertaken and Client X remained seated throughout so that the lower half of their body was not visible.

Client X talked excessively and inappropriately answered questions. It is believed that this should have highlighted her inability to communicate appropriately. For example, when asked how Client X managed to dress, they started talking about when their father died. It is felt that the assessor, if fully trained, would have recognised symptoms of Client X's reported PTSD, depression and anxiety disorder.

The decision letter advised that Client X had scored 0 points for everything. The letter stated that Client X was well presented with make-up and looked slim but healthy, and made good eye contact. These observations were stated in the report as reasons to determine that Client X was capable of carrying out daily living activities and leaving the house with no problems.

Client X's advocate prepared a mandatory reconsideration letter addressing each point for daily living and mobility and challenging it. The advocate also gathered further medical evidence, getting a special letter from the GP, a liver consultant, a homeless nurse and a form confirming Client X's weight and malnutrition diagnosis. It is felt that had the assessor carried out a physical examination they would have observed that Client X was severely underweight and malnourished. Following the submission of the mandatory reconsideration, Client X was awarded the enhanced rate for daily living and mobility at £564.40 a month.

Case study 7
PIP assessment (March, 2017)
- physical & emotional distress on client
- case where a home visit may have avoided distress

Client X suffered with significant behavioural problems which were well-documented by psychiatric services. Client X was required to attend face-to- face PIP assessments on 3 separate occasions but on each occasion the assessment could not be completed and the police attended. As a result of the distress caused to Client X a home assessment was requested. Client X's problems were exacerbated by authority figures which were again documented and evidenced. This request was declined due to a perceived danger which may be posed to the visiting assessor. Client X attended another face-to-face assessment which they attended having taken large amounts of prescription medication; plus having self-harmed. Despite this, the assessment was carried out and completed. Client X's application for PIP was subsequently turned down but following an appeal, the Tribunal found in their favour and reinstated the benefit.

In this case, a complaint was made against ATOS. Following the receipt of two responses from two different people in the same department that contradicted each other, the complaint was raised with the Independent Case Examiner.

Case study 8
PIP assessment (Dec, 2016)
- physical & emotional distress on client
- concerns with the assessor's engagement
- factual inaccuracy of report
- case where a home visit may have avoided distress

Client X suffered from a number of mental health conditions and often felt over whelmed by normal activities (their conditions included anxiety, depression, borderline personality order and PTS). Client X attended the ATOS centre in Brighton. Client X was always accompanied when she went out and relied on parental support to use public transport. A home visit request had been refused despite the client suffering from agoraphobia. Client X was given just a weeks' notice of the assessment and so was not able to attend with an advocate. An advocate needed to support Client X whose medical condition caused them to suppress things and limited their ability to recall events.

During the appointment Client X was in a manic episode; was not fully aware of their actions; they broke down several times and could not answer questions easily (leading them to feel disbelieved).

During the assessment the assessor is reported to have displayed no warmth, or empathy or obvious knowledge of mental health conditions. The assessor's report included various inaccuracies:

- it stated that whilst Client X had said they could not leave the house. unaccompanied, they had nevertheless attended the assessment centre alone. This ignored the fact that Client X's father was in the waiting room and had brought them in.
- It stated that Client X was fine with money, yet they were in debt.
- it stated that Client X could prepare meals, yet this was not true as Client X was at risk of self-harming and kitchen knives posed a danger to them.
- it described Client X as being happy and chatty, yet this ignored the fact that their mental health condition led them to become over accommodating.
- Overall, the report was poorly drafted. The same paragraph had been cut and pasted several times. The report also inaccurately described Client X's medical condition. The report did not provide any guidance for lodging a request to have their case mandatorily reconsidered.

Client X reports that the assessment made them feel like a liar. It caused Client X to doubt themselves and pushed them into a psychotic episode for 3 weeks.

Client X also applied for ESA in September 2016 but is still waiting to have an initial assessment.

Case study 9
PIP assessment (Dec, 2016)
- quality of decision, not fully based on medical evidence
- factual inaccuracy of report

Following an assessment, Client X was awarded 9 points for the daily living element of PIP. The assessor is reported to have mainly concentrated on how a long-term condition affected their daily living, but did not take into account the impacts of injuries to both of Client X's hands. Client X was already in receipt of PIP for their long-term condition, but had wanted to report the injuries to their hands for the first time at an appointment in December.

Client X reports that the physical examination used during the PIP assessment, including putting on his jacket with no difficulty, were used as justifications that Client X was able to carry out all personal care, washing and cooking without any problems or assistance.

Client X's advocate submitted a mandatory reconsideration challenging each of the refusals under both daily living and mobility criteria, which took over 2 weeks to do. Despite Client X having a formal package of care in place, provided by Adult Social Care, to help them with their daily living activities, their PIP claim rejected by the DWP. This case is now pending an appeal hearing.

Case study 10
PIP assessment (2017)
- quality of decision, not fully based on medical evidence
- factual inaccuracy of report
- physical & emotional distress on client

Client X was reassessed for PIP having been in receipt of DLA for a number of years. At the time, they were paid at the higher-level mobility rate, and the middle rate for daily care/living. At the assessment Client X reported that they felt intimidated.

Despite having submitting a substantial amount of medical evidence, Client X's award was decreased to the standard mobility level, and they were awarded nothing for daily care/living.

Client X's advocate applied for a mandatory reconsideration on their behalf challenging the report findings which in part stated that 'Client X is on low levels of medication for anxiety and depression'. Client X's advocate highlighted that the medication being taken was the highest level possible without being supervised in a hospital environment. The mandatory reconsideration moved Client X onto the standard care/living rate but kept them on standard mobility rate which meant Client X had to return their mobility car.

Client X's advocate supported them through to appeal where the judge awarded the applicant the higher rate for both mobility and care/living. Although the process was successful, it is reported to have taken its toll on the applicant who reported that their wellbeing had suffered as a result of the onerous process.

healthwatch
Brighton and Hove

Healthwatch would like to thank all of those organisations and individuals who provided such valuable insights and helped deliver this report.

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