PIP Info - Natalya's Criptivist Info series

This page is not official advice, this is a summary of info and resources I share as a grassroots disability activist.

There is a lot of information on this page under headings. I recommend you select the appropriate area from the Table of Contents rather than trying to read everything.

I sometimes link to 2 or 3 options for external advice. You do not need to read them all, just pick the one which seems most helpful to you. I have listed several options as different formats work for different people. I have labelled everything that has BSL info with "BSL" so search for that for quick access.

Disability News Service has an excellent page of advice, activism, campaigns on PIP and more.

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Overall PIP process explained

Disability Rights UK has one of the best explainers of the whole PIP process.

If you are low on energy/spoons

The best simple but comprehensive resource on PIP is www.pipinfo.net.

There is a step-by-step explainer and wellbeing support with text, videos (including BSL) to complete PIP at Turn2Us.

Pipinfo.net covers each of the PIP activities and explains some really important legal concepts.

Safely, repeatedly, acceptably and timely

When PIP forms or assessors ask if you can do a task, you and they need to consider if you can do the task:

- 1. **Safely** (without pain, nausea, dizziness, risk of harm to yourself or others)
- 2. **Repeatedly** (as often as is reasonably needed without being left unable to do other things)
- 3. to an acceptable standard (reliably) e.g. make a drink without spilling it.

4. In a **timely manner** (no more than 2x normal time)

These four standards are specified in the <u>Regulation 4 of the Welfare Reform Act 2012</u> which is part of the PIP law.

If you cannot do activities to all of the 4 standards above, by PIP terms you cannot do it at all.

There are also legal meanings of words like "*supervision*" "*prompting*" "" etc. You may not HAVE those support things in place, but may be '*deemed to need them*' in PIP terms.

Frequency of ability to do a task

You also have to be able to do PIP activities to standards like *more than 50% of the time*, or be affected at least some time every day.

Honesty in PIP application

You should be truthful (as lying is legally fraud), but understanding the 4 standards and other key PIP rules helps you to understand what information the DWP need to be accurate in the context of "being able to do a task" for PIP purposes.

Do not use "your worst day" as that is not how PIP works and is lying.

PIP Renewal

The DWP sometimes uses a Light Touch Renewal Form AR2 for people with:

- very stable needs which are unlikely to change over time
- high level needs which will either stay the same or get worse
- a planned award review date due on or at State Pension age

Information about AR2 forms

- AR2 form (plain) to be typed into by Natalya
- Sample AR2 form via Benefits and Work (DWP PDF not for claimant use)

I recommend you refer to the PDF or print AR2 while using the plain template I have provided to check you understand all the instructions and declaration contents.

If the DWP has not been helpful and refused you a digital claim or renewal form. You can submit their original form with your typed form in any clear format. I do recommend (if possible) signing the declaration on the DWP's original form and writing "SEE TYPED SHEETS" at least once on the original form so the person receiving the form can understand.

Sources of advice or support

Form completion

<u>Citizens Advice PIP form filling webpages</u> <u>Turn2Us PIP form pages</u> Mental Health and Money Advice org guide to PIP forms (has Scottish, Northern Irish and Welsh specific info)

Sample PIP forms

The DWP publishes <u>sample PIP1 (initial claim)</u> which is the bit usually done by phone and <u>sample PIP2 (How your disability affects you)</u> which is the form you usually complete.

If you need forms you can type into, see the Alternative Formats Team section below.

Do not use these sample forms or any other copies, you are supposed to use the copy of the forms the DWP sends to you. If you have to produce your form in another format for access reasons, send a covering letter explaining this.

Assessment guidance

The <u>DWP themselves publish guidance for assessors</u> covering the whole process and how things should be interpreted. The document has a long table of contents including each activity. This covers things like lipreading not counted as being able to hear in Activity 8 (Communication Verbally), or that SatNavs are not counted as a navigation tool for Activity 13 (Planning and Following a Journey)

If you can afford some money

Benefits and Work is a website subscription that costs £20 a year for individuals. It has comprehensive member-only guides about PIP and many other benefits.

<u>FightBack4Justice</u> is a small charity that can provide some assistance with PIP forms (and other benefits or issues) for about £50-100 per activity which is much lower than commercial rates.

Evidence for your PIP application

You will **need** to provide evidence about your impairments or health conditions for your PIP application. Always send copies, keep your originals.

Getting evidence can be tricky if your condition is quite new, or you haven't received relevant healthcare for a long time but I hope some of the advice below might help.

NHS App

The NHS app is increasingly useful as many hospital appointment, hospital clinic, test results and GP consultation notes are increasingly uploaded in there.

You should be able to access the NHS app on a web browser as well via an app on your smartphone or tablet. https://www.nhs.uk/nhs-app/nhs-app-help-and-support/getting-started-with-the-nhs-app/

I recommend looking in the NHS app/website once logged in to find if there's anything that supports your PIP claim that you can screenshot and print out.

GPs and PIP evidence

Some GPs are not keen on writing letters because it is not an NHS-funded service, takes a lot of time, makes them liable under their medical licence and they are already overwhelmed (worse since Covid).

A GP surgery may also be able to print out your summary record or give you more access in the NHS app if you ask at reception.

Hospital or other clinicians

Hospital clinicians (doctors, nurses, physios etc) may be more helpful in writing a custom letter, or including some specific information in letters they are already sending to you and your GP.

This can be especially useful if you receive very specialist or ongoing support from a clinician who knows you. If you can get something like this, I recommend identifying key PIP areas you would like them to cover so they can write something that is helpful for this purpose.

Requesting copies of your medical records using data protection

You can <u>request copies of your medical records using the Data Protection Act 2018 (and GDPR)</u> but you should do this well in advance of applying for PIP as it can take 1-2 months for that information to arrive.

You can speed up a data protection request by asking for specific and small amounts of information. It is worth checking the NHS app doesn't already give you access.

Advice about PIP evidence

Search online for your condition name + PIP. Many organisations now do PIP guidance about how you may be affected which could help someone writing any custom evidence.

There are condition specific PIP resources that I created.

ALWAYS keep medical letters (if you can) in case they are useful in future. Some won't be helpful but it never hurts to have them.

Turn2Us guide on useful evidence documents for PIP

Mental Health and Money Advice PIP evidence webpage including a sample letter usable for any condition that a clinical practitioner could complete for you.

Citizens Advice PIP evidence page (includes a sample disability affecting you diary)

Deafness specific PIP information

Government BSL and ISL videos about PIP

<u>DWP 'dswpsign' playlist - YouTube PIP videos in BSL</u> (with English closed captions and voice over)

NI Direct BSL PIP information playlist (with English closed captions and voice over)

NI Direct Irish Sign Language (ISL) PIP Information playlist (with English closed captions and voice over)

Other BSL PIP information

<u>DeafPlus Series of PIP webpages with BSL translations</u> on each page <u>DeafLink English and BSL information about PIP</u> Bradford Talking Media BSL PIP tips

Application (deafness)

<u>I have created a Google Doc with information for deaf and hard of hearing people</u> including questions specific to deaf people which might help you think of things to write in your PIP form

Quote the Law for deafness

October 2020 <u>Upper Tier Tribunal (UTT) judgment about washing and bathing in PIP</u> - if you cannot hear fire alarms without hearing aids, you may be able to get 4 daily living points (which combined with communication <u>may help get PIP points</u>). The <u>DWP has now reviewed existing claims</u> (March 2023) - if you are deaf and think this should apply to you, and do not already have enhanced daily living PIP, contact the DWP and ask about it.

In 2016 a <u>Upper Tribunal found that deaf people may be able to get points on Activity 9 "mixing with others"</u> if they find they cannot engage socially with others without assistance. This is likely to be hard to prove and facts-specific to each person's case but may be worth exploring. You could use family members' evidence of difficulties in social situations to support this.

Telephones and PIP

If you put your landline or mobile phone number on your PIP form (or give it to the DWP in another way) expect to get voice calls and voicemails on it - even if you say "SMS only" - this is because the DWP are rubbish.

Below are two template letters for:

- 1) Getting the DWP to stop calling you and remove your numbers.
- 2) Complaining to the DWP if they refuse TextRelay, interpreter assisted or sign relay calls.

To get the DWP or assessment agencies to delete your phone number, you can tell them that they are required to do this under Article 17 of the GDPR, 'Right to Erasure'. If the number is not deleted, you can report them to the Information Commissioner's Office (ICO).

Email communication for PIP

For email or other access issues, see the <u>Alternative Formats Team</u> section below.

Video Relay Services (UK-wide info)

<u>DWP Sign Video</u> (**England and Wales** only) (you have to scroll down to below phone stuff for SignVideo information)

Social Security Scotland (video relay) app for Scotland only.

BSL and ISL video relay for Northern Ireland only (scroll down to 'If you use Sign Language' heading for links)

SignVideo for Independent Assessment Services (IAS), formerly ATOS

SignVideo for Capita (look under BSL translation heading)

Face to Face PIP Assessment - Communication Support

If you are deaf and struggle to hear unfamiliar speakers you are legally entitled to communication support for any PIP assessment. <u>Suzy has explained some types of communication support for deaf and deafblind people</u>.

Natalya has created a <u>template letter to request communication support from the PIP assessment organisation and the DWP</u>. Be aware that if you choose lipspeaking, the PIP assessor may decide because you can lipread the lipspeaker, you can lipread anyone. It may be better (*pragmatic*) to request Lipspeaking with Additional Sign, BSL/English or STTR instead.

If you have requested communication support, this may not show up on your assessment appointment letters which are automatically generated. You may have to phone or email to check communication support has been booked. I complained about this but in my caseCapita refused to change their letters.

I have written a document to help you prepare in advance of your assessment date for what you will do if you arrive for your assessment and there is no communication support.

Phone assessments - beware!

Since 2020 (Covid), most PIP assessments have been by phone. If you are hard of hearing or deaf (or have any other disability that makes using phones hard), I **strongly recommend** you refuse a phone assessment, or you will get no communication points because the assessor will say you can hear and manage a phonecall. Any struggle or stress will not be recognised. I also think text-relay is too unreliable and slow for PIP assessment.

Insist on a video call with captions or face to face assessment 'as a reasonable adjustment for deafness' AND if needed, appropriate communication support.

Impairment/condition specific PIP info

I have found some organisations with condition specific PIP info on another page

Health Assessment Providers

As of 2024, the DWP has 4 different assessment providers depending where you live:

- <u>Maximus</u> + <u>Maximus contact webpage</u> for Northern England
- Capita + Capita Contact page for Midlands, Wales and Northern Ireland
- <u>Serco</u> + <u>Serco Contact page</u> for South West and South
 - Serco seem to have no email or BSL I have emailed to request these.
- Ingeus + Ingeus Contact page for London, East Anglia and South East.

There is a <u>GOV.UK webpage to tell you which provider</u> will provide your assessment based on your location and postcode.

Alternative Formats Team

If you need adjustments to any part of the PIP process, I strongly recommend the DWP PIP Alternative Formats Team.

Sadly from July 2024 I'm hearing that the Alternative Formats team are telling people who email "phone us" and generally not being helpful. I recommend emailing them some of the wording in the <u>Using The</u> <u>Law</u> section of this document and keep arguing back till you get email communications.

Contacting the Alternative Formats Team

You can contact the Alternative Formats Team by email.

You may need to set up email communication by completing some consent forms so the DWP can use email with you. It can take 10+ days for an initial reply, so contact them as early as possible.

DWP keeps making up new email addresses and silently killing others, so here's a list of ones to try:

- format.pip@dwp.gov.uk (as of July 2024)
- PIP@dwp.gov.uk
- <u>SalfordQuays.AlternativeFormatSPOC@dwp.gov.uk</u>

The following addresses are reported not to work

- <u>DCPUALTERNATIVE.FORMATTEAM@DWP.GOV.UK</u> (Reports this is closing as of July 2024)
- WALESSC.PIPALTERNATIVEFORMAT@DWP.GOV.UK doesn't work and suggests resending to PIP@dwp.gov.uk

The DWP has a habit of quietly breaking email addresses, so if any of these addresses do not work, please leave a comment for me or contact me to review this info and I'll "what we know".

Requesting adjustments from the Alternative Formats Team

When requesting adjustments it can be useful to remind the DWP that you are a disabled person requesting a 'reasonable adjustment under Section 20 of the Equality Act 2010' (or Reasonable Adjustment under the Disability Discrimination Acts if you are in Northern Ireland).

I also recommend that you provide brief information about your disability e.g. that you are deaf/HOH, are autistic or have mental health difficulties (which could include anxiety, depression or episodes of depersonalisation, dissociation or similar) + the for your access requests. The <u>Using the Law</u> section of this document has template wording you can try using.

ESA Alternative Formats Team

There is an ESA alternative formats team, contactable at: NEWPORT.ALTERNATIVEFORMATSESACHANGES@dwp.gov.uk

This page is about PIP only, but I know many people also get ESA and ask me about this, so I'm shoving this ESA info in to be helpful.

I haven't been able to find anything 'alternative' for Universal Credit, which may be because the journal is digital by default. If anyone knows differently, please leave a comment.

Types of adjustments you might ask Alternative Formats Teams for

Email communication.

- Larger print or specific format communication.
- Digital PIP forms

Digital PIP forms - to type into

The <u>Alternative Formats Team</u> can provide you with 'digital' completable PDFs of the PIP1 and PIP2 forms (so you should be able to avoid having to phone to start your application). You may have to provide brief information about your disability-need for them.

The DWP goes to great lengths to lie about the existence of digital PIP forms. They refuse to mention that they exist and I have had welfare rights organisations express surprise that I had managed to get one for myself and several friends.

Beware that sometimes the DWP will send out broken PDFs for the PIP forms which have no form fields, can't save or otherwise don't work properly.

Test any forms straight away by trying to type and save a small piece of information. If they do not work, contact the Alternative Formats Team immediately and explain what is wrong with the form, insist on a completable form that can be saved and ask for an appropriate extension of time to complete the form if there is a delay in them providing it.

Mandatory Reconsideration and Appeals

If you are not successful at getting PIP or feel the level is too low (especially if you were mistreated during any assessments, or there are lies all over your report) you need to go through a Mandatory Reconsideration (MR) period before you can formally Appeal.

Both processes have strict timescales unless you have good reasons such as being too ill e.g. in hospital and can prove it, so you should act quickly if you are unsuccessful or unhappy with the levels awarded. You can do a Mandatory Reconsideration for up to 13 months after the letter the DWP send about your PIP award.

Appeal success rates are over 70% for PIP and that does not include the cases that the DWP changes a decision on before the tribunal. So in short, it is definitely worth trying an appeal if you need it.

Mandatory Reconsideration

- AdviceNow PIP Mandatory Reconsideration Request Letter Tool
- Citizens Advice Challenging a PIP decision Mandatory Reconsideration

Appeals

- Citizens Advice Appeals Challenging a PIP decision
- AdviceNow How to Win a PIP appeal guide (free to download)

Sources of assistance with MR and Appeals

A <u>local Citizens Advice</u> may support or refer you.

A law centre may be able to help with appeals.

<u>FightBack4Justice has a range of appeals (and other benefits) services</u> that they charge under £100 to provide.

Using the Law

The DWP is bound by various laws such as the Equality Act 2010 and using this legislation can sometimes be more effective than asking the DWP to follow its own procedures or social security law.

This is not legal advice and I am not legally trained.

I have personally achieved:

- Getting email communication and not having to use a phone.
- Home assessment for PIP without a GP letter specifically requesting it (I used my PIP evidence and demanded it as a Reasonable Adjustment under Section 20 of the Equality Act 2010). I did have to complain to Crapita and I threatened Crapita and the DWP with being sued which did scare them.
- Paper based assessment for an autistic friend using the DWP's own rules for PIP and the Equality Act.
- Gender neutral pronouns "they/them" for a nonbinary friend. It may have helped that Friend had a
 psychiatrist and mental health nurse being very clear in evidence letters that incorrect pronoun
 use caused Friend to experience severe mental distress. The Alternative Formats Team were
 consistently good at correct pronoun use and seemed decent about it.

I will try and break legalling into steps below.

Disclosing and declaring your disability status

First disclose your disability in legalese

"I am a disabled person under the ambit of Section 6 of the Equality Act 2010. I have ***XYZ impairments - list all that is relevant***. I will need the following reasonable adjustments provided under Section 20 of the Act.

- List adjustment + brief reason
- List adjustment + brief reason"

Finishing your adjustment request

Once you have added wording for your request from the sections below. You need to finish your request and remind the DWP of the consequences of not following the law.

You shouldn't have to disclose twice, but in practice you will need to tell the DWP and then again tell the assessment organisation as they don't seem to pass access information between one another.

"It is the DWP's responsibility to ensure that the organisation handling assessments is aware of these adjustment requests and complies with them fully. I believe the assessment organisations are acting as DWP's agents under Sections 109 and 110 of the Equality Act.

If my access needs and adjustments are not properly met by the DWP or associated agents, I will not hesitate to complain to the independent case examiner (ICE) and make a formal complaint against both organisations (as jointly and severally liable respondents) for failure to make reasonable adjustments under section 21 of the Equality Act."

Paper Based Assessment request

The DWP has been forced to recognise that some people would find a face to face assessment excessively stressful, especially if there is strong evidence of autism, learning disabilities or severe mental illness/distress.

Option 1 - Paper based assessment

"I would like to request a Paper Based Assessment as a reasonable adjustment because attending a face to face at a centre or in my home would cause me undue distress because of ***insert reason***. (If you have evidence which supports this, mention it here). I refer to the DWP's "PIP Assessment Guide, Part One - The Assessment Process" paragraph 1.5.5"

Option 2 - Paper based assessment

"The DWP and agents 'healthcare assessment providers Maximus/Capita/Serco/Ingeus **should not** invite me for a face to face assessment at a centre or my home as this is likely to cause me very high levels of stress and distress due to my ***INSERT medical conditions***.

This request is supported on ***Page X of my DATE EVIDENCE from NAME + ROLE***

I also direct you to the <u>DWP's "PIP Assessment Guide, Part One - The Assessment Process" paragraph 1.5.5</u>"

Requesting a home assessment

The DWP likes to insist that you get your GP to complete paperwork for you to get a home assessment. You do not have to follow the DWP's process. You are legally allowed to use the Equality Act and you don't need as much evidence.

"A home assessment for any face to face assessment is needed as a reasonable adjustment under the Equality Act 2010, due to ***give a brief disability related explanation here***. See evidence X Y and Z which backs this request up."

Requesting communication support

For deaf or deafblind support see the <u>Face to Face PIP Assessment - Communication Support</u> section elsewhere in this document.

Requesting specific pronouns

"I have the protected characteristic of gender-reassignment under Part 2, Section 7 of the Equality Act.

I require the DWP and Capita/Maximus/Serco/Ingeus to address me by and refer to me with gender neutral pronouns "they" "them" "theirs" and if a title must be used, please use Mx."

This could also be used if your usual paperwork is in one gender but you are transitioning or have transitioned and need the DWP to be updated - edit the pronouns as you need.

Option if misgendering can be linked to a disability

"I also believe complying with this request to use my correct pronouns is a reasonable adjustment for disability as to use incorrect gendered language or pronouns will put me at a substantial disadvantage and cause me undue distress. "

Miscellaneous

Random opinionated Natalya thoughts

- The DWP and assessment companies (Capita/Maximus/Serco/Ingeus) are often dishonest and can twist or omit what you say (which is why in-writing information is best).
- Audio record and keep recordings of all telephone calls you make to DWP or Capita/IAS.
- Disclose any access needs like communication support or wheelchair accessible venue in Section 4 of the PIP2 form. You will probably have to re-disclose them again as soon as the assessment centre contacts you as DWP will not reliably pass this information on.
- Send all letters by recorded delivery (and keep the proof).
- Write down and record the received date on all letters as sometimes they arrive late.
- The assessors can legally watch you as soon as you get to the assessment centre land and while
 you are in the building. These observations are given more weight than your reported experience.
 It will be assumed you walked safely, repeatably, reliably and in a timely manner any distance
 from a carpark or drop off point even if you had to stop and rest and tell them this (I am not sure
 how to counteract this).
- Photograph yourself outside their assessment centres (especially if your assessment is cancelled
 or inaccessible so you have to leave) to prove you attended.
- Take a companion to your assessment so you have a witness (if they can take notes, or look like they're taking notes, all the better). The companion should dress as smartly as possible, this is a psychological power 'game' here.
- If you are caught recording an assessment the assessor is likely to insist you stop recording and
 may report you to the DWP there seem to be mixed views on whether recording is unlawful or
 not. (<u>A judgment supporting covert medical assessment recordings</u>) but there is no guarantee a
 social security tribunal will accept them as evidence).
- If you are mistreated or things go wrong, gather as much evidence as you can (and ask your companion to write you a letter describing what they witnessed). Complain in writing to the

assessment company and copy in the DWP as soon as you can afterwards. If you are unwell, send a very brief holding complaint saying more details will follow as soon as you are well enough.

Psychological impact - looking after yourself

Dealing with PIP or any benefits form is emotionally demanding and makes many people feel really horrible inside because you're being asked to say how you or someone else is 'broken' just to get the help and support that is needed.

Everyone is different, but I recommend seeking support if you can in whatever way works for you whether that's talking to friends or family, or something like going for a run or spending time doing hobbies. Times which are likely to be difficult are during/after form filling, before/after the assessment and if you have to deal with mandatory reconsiderations or appeals.

An idea I've seen people do is that an "alternative form" where instead of all the horrible brokenness, you capture or collect (write, draw, craft, film - be more creative than me!) all the positive and good things about you or the person the form is about. You don't share this with the DWP, but it's a way of reminding yourself that the shittiness is the DWP's forms and *NOT* you or the person your forms are about.

If you like academic or political things I highly recommend Donna Reeve's work on "psychoemotional disablism" which can be found online. I found this very powerful in giving me some language to say why the DWP systems are so rotten.

If you are around someone considering PIP, remember it's a huge step and process and just nagging them to apply won't help, but practical support with the form or something else in their life to free up capacity for them may be genuinely helpful.